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Religious Coping, Hopelessness and Quality of Life in Mothers of Children in Pediatric Cardiac Surgery Intensive Care Unit

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ABSTRACT

Introduction: Congenital heart diseases are among the leading causes of infant mortality.
Objective: This research investigated the religious coping, hopelessness and quality of life in mothers of children who underwent open heart surgery and were hospitalized in the Pediatric Cardiac Surgery Intensive Care Unit.
Methods: In the study, data were collected from 225 mothers whose children underwent open-heart surgery using a Demographic Form, Religious and Spiritual Coping Scale, Beck Hopelessness Scale, and Quality of Life Scale.
Results: It was found that while the hopelessness sub-dimension and total score and the negative religious coping scale sub-dimension mean scores were low, the positive religious coping scale sub-dimension mean scores were high and the quality of life scale mean scores were moderate. It was determined that there was a negative relationship between the negative religious coping sub-dimension and the quality of life scale's general health status, social relations, and environment sub-dimensions, and between the quality of life scale and the hopelessness scale.
Conclusion: It can be said that more studies are needed to understand the relationship between the religious coping styles of mothers with children with congenital heart disease and their levels of hope and quality of life, and to eliminate the contradictions in the literature.

Keywords: Pediatric, Cardiac Surgery, Hopelessness, Religious Coping, Quality of Life.

INTRODUCTION

Congenital heart disease (CHD) is responsible for a large proportion of infant mortality (1). The child's disease negatively affects all family members (2). In particular, the parent who assumes the responsibility of caregiving may experience problems such as social isolation such as not being able to spare time for himself/herself and his/her environment, financial and psychological problems, and difficulty in choosing between his/her own needs and the needs of other family members and the needs of the child with CHD. Parents, particularly mothers of children with CHD, often struggle to manage health issues effectively while worrying about their child's future. Research indicates that they experience significant psychological stress and feelings of hopelessness related to accepting the diagnosis, navigating the treatment process, caring for their child, and facing mortality risks, all of which adversely affect their quality of life (3-5).

Coping with the difficulties experienced by parents of children with CHD is very important in terms of disease management of the child with CHD, continuity of family processes, and self-actualization of the caregiver parent. For many people, religious beliefs, a source of refuge and comfort after sudden changes in the natural course of life or traumatic events6; can also help parents of children with CHD cope with the difficulties they experience.7 Religious coping is the individual's attempt to relax and find peace by using religious feelings, thoughts, and behaviors within the religious system/belief integrity in situations that they cannot control or overcome.8 Studies have reported that parents of children with CHD turn to spirituality, see the child's heart disease as a divine test, and trust God to heal the child (4,9,10).

Health professionals need to consider the culture, religion, and spirituality of the sick child and caregiver parents during the intensive care process of children with CHD, which is a long and critical process after open heart surgery. Understanding how parents handle and use coping strategies can help to manage

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when caregiving becomes difficult effectively (7). This research investigated the religious coping, hopelessness and quality of life in mothers of children who underwent open heart surgery and were hospitalized in the Pediatric Cardiac Surgery Intensive Care Unit (PCSICU).

Research Questions

-What are the religious coping styles, hopelessness levels, and quality of life of mothers of children undergoing open heart surgery and hospitalized in the PCSICU?

-What factors influence the religious coping styles, hopelessness, and quality of life of mothers of children undergoing open heart surgery and hospitalized in the PCSICU?

-Is there a relationship between the religious coping styles, hopelessness, and quality of life of mothers of children undergoing open heart surgery and hospitalized in the PCSICU?

METHODS

Design and Purpose of the Study

This descriptive study was conducted with mothers whose children were hospitalized in the PCSICU between January 2018 and February 2019 hospital in Turkey. The aim of the study was to determine the religious coping style, hopelessness, and quality of life levels of mothers whose children underwent open heart surgery.

Participants

Mothers whose children had open heart surgery and were hospitalized in the PCSICU, who could speak Turkish, were literate, had a religious belief, and agreed to participate in the study were included in the study.

Population and Sample of the Study

The study's sample size was determined as 222 by setting the effect size as 0.3, power as 99%, and α as 0.01. Mothers of children who have undergone open-heart surgery, have a religious belief, and agree to participate were included in the study.

Data Collection

After explaining the purpose of the study to mothers who met the inclusion criteria, they were asked to complete the Demographic Form, the Religious and Spiritual Coping Scale (RSCS), the Beck Hopelessness Scale (BHS) and the WHOQOL-BREF Quality of Life Scale-Brief Version. Completing the forms takes approximately 20-25 minutes.

Data Collection Tools

Demographic Form

It is a form consisting of questions about the mother and the child receiving treatment and care in the PCSICU, including the mother's age, education level, employment status, family type, the child's age, gender, diagnosis, previous surgery, duration of stay in intensive care, previous stay in intensive care, whether the mother received information about the disease and whether she found the information received sufficient.

The Religious and Spiritual Coping Scale (RSCS)

It is a Likert-type scale developed by Pargament et al. (1998) and validated and validated for Turkish by Eksi in 2001. The scale has two subscales: seven items related to the Positive Religious Coping Style (items 1, 2, 6, 8, 9, 11, and 13) and seven items related to the Negative Religious Coping Style (items 3, 4, 5, 7, 10, 12, and 14), for a total of 14 items. Higher scores on the scale indicate higher levels of positive or negative religious coping styles (11,12).

The Beck Hopelessness Scale (BHS)

Developed by Beck et al. (1974), its Turkish validity and reliability studies were conducted by Seber et al. (1993) and Durak & Palabıyıkoglu (1994). The scale consists of 20 statements; congruent answers are scored as 1 and incongruent answers are scored as 0, with the total score ranging from 0 to 20. Items 1, 3, 7, 11, and 18 of the BHS constitute the "Feelings and Expectations About the Future" sub-dimension; items 2, 4, 9, 12, 14, 16, 17, and 20 constitute the "Loss of Motivation" sub-dimension; and items 5, 6, 8, 10, 13, 15, and 19 constitute the "Hope" sub-dimension. High scores on the scale indicate a high level of hopelessness (13,14).

The WHOQOL-BREF Quality of Life Scale-Brief Version

The WHOQOL-BREF short form, developed by the World Health Organization (WHO), is a valid, reliable, and practical alternative to the WHOQOL-100 and consists of 26 questions. The Turkish validity and reliability study of the scale was conducted by Eser and colleagues. Questions include general health status (1st and 2nd), physical health (3rd, 4th, 10th, 15th, 16th, 17th, and 18th), psychological status (5th, 6th, 7th, 11th, 19th, and 26th), social relationships (20th, 21st, and 22nd), and environmental status (8th, 9th, 12th, 13th, 14th, 23rd, 24th, 25th, and 27th). Domain scores are obtained by multiplying the mean of the items comprising the domain by 4. Domain scores range from 4 to 20. As the total score increases, the quality of life increases proportionally (15).

Data Analysis

Data were analyzed using the IBM SPSS Statistics Standard Concurrent User V 26 (IBM Corp., Armonk, New York, USA) statistical package program. Percentages, arithmetic mean, standard deviation, median, minimum, and maximum values were presented as descriptive statistics, and distribution of data was assessed using the Shapiro-Wilk normality test and Q-Q plots. Independent t or Mann-Whitney U tests were used for comparisons of two independent groups according to data distribution, and ANOVA or Kruskal-Wallis tests were used for comparisons of more than two independent groups. Spearman correlation analysis was used to assess the relationship between scale scores.

Ethical Approval

Before beginning the study, ethics committee approval (No. 46) and institutional permission from the hospital were obtained. The mothers were informed about the study beforehand, and their informed consent was obtained through an "informed consent form." The study was conducted in accordance with the principles of the Declaration of Helsinki. Permission for the use of the scales used in the study was obtained electronically via email from the scale authors.

RESULTS

The mothers' mean age was 30.71±6.25 years, 34.2% were primary school graduates, 83.1% did not work, and 82.2% lived in nuclear families. The mean age of the children was 24.98±41.89 months, 41.3% were male, 54.3% had cyanotic heart disease, 68.4% had not undergone surgery previously, 56.0% stayed in the PCSICU for 1-3 days, and there was a history of previous intensive care hospitalization in 49.3%. It was determined that 96.4% of the mothers received information about their child's disease and 59.5% found the information they received sufficient (Table 1).

It was found that the mothers' BHS sub-dimension and average total scores were generally low, negative RSCS sub-dimension averages were low, positive RSCS sub-dimension averages were high, and average WHOQOL BREF-TR scores were moderate (Table 2).

It was found that mothers who graduated from primary school had higher BHS scores than mothers who graduated from university ($p \leq 0.001$). It was determined that mothers who did not work, whose child had not undergone surgery previously, whose child had not been hospitalized in the PCSICU before, and who did not find the information they received sufficient had higher BHS scores ($p<0.05$). The negative RSCS scores of mothers who worked, whose child had undergone previous surgery, and whose child

was hospitalized in the PCSICU before were lower, and mothers who were primary school graduates and did not work had higher positive RSCS scores ($p<0.05$, Table 3).

Table 1. Characteristics of Children and Their Mothers in PCSICU

	n	%
Age (Mean±Sd: 30.71±6.25)		
Education status		
Primary school	77	34.2
Middle school	51	22.7
High school	48	21.3
University	49	21.8
Working status		
Working	38	16.9
Not working	187	83.1
Family type		
Extended family	40	17.8
Nuclear family	185	82.2
Age/month (Mean±Sd: 24.98±41.89)		
Gender		
Female	93	41.3
Male	132	58.7
Diagnosis		
Acyanotic	103	45.7
Cyanotic	122	54.3
Prior surgery status		
Undergoing surgery	71	31.6
Not undergoing surgery	154	68.4
Length of stay in intensive care		
1-3 days	126	56.0
Over 4 days	99	44.0
Prior hospitalization in intensive care		
Yes	111	49.3
No	114	50.7
Getting information about the disease		
Yes	217	96.4
No	8	3.6
Finding the information received sufficient (n=217)		
Yes	129	59.5
No	21	9.6
Partially	67	30.9

Table 2. Religious Coping Style Scale, Beck Hopelessness Scale, and WHOQOL BREF-TR Quality of Life Scale scores of mothers with children in PCSICU

Scales	Mean±*Sd*
Beck Hopelessness Scale (BHS)	
Emotions and expectations about the future sub-dimension	0.80±1.15
Motivation loss sub-dimension	2.57±1.85
Hope sub-dimension	1.61±1.40
BHS total	4.98±3.35
Religious Coping Style Scale (RCSS)	
Negative Religious Coping sub-dimension	8.96±2.96
Positive Religious Coping sub-dimension	24.72±4.05
WHOQOL BREF-TR Quality of Life Scale	
General health sub-dimension	56.22±22.23
Physical health sub-dimension	49.52±13.69
Psychological sub-dimension	60.26±13.26
Social relations sub-dimension	63.67±19.90
Environment sub-dimension	53.83±15.52

Table 3. Beck Hopelessness Scale (BDS) and Religious Coping Style Scale scores of mothers who had children in PCSICU, according to some variables

Scales	BHS	Negative RCSS	Positive RCSS
	Mean ±*Sd*	Mean ±*Sd*	Mean ±*Sd*
Education status			
Primary school	5.94±3.62[a]	9.22±3.12	25.97±2.85[a]
Middle school	5.10±2.64[ab]	8.82±2.64	24.33±4.64[ab]
High school	4.88±3.64[ab]	9.69±3.80	24.15±3.95[ab]
University	3.47±2.77[b]	8.00±1.54	23.73±4.70[b]
Test*	**19.366; ≤.001**	6.783; .079	**10.643; .014**
Working status			
Working	3.58±3.45	8.03±1.65	22.95±5.02
Not working	5.27±3.27	9.16±3.13	25.09±3.74
Test	**-3.608; ≤.001**	**-2.115; .034**	**-2.929; .003**
Prior surgery status			
Undergoing surgery	4.71±3.44	8.65±2.74	24.68±4.15
Not undergoing surgery	5.56±3.10	9.65±3.30	24.82±3.86
Test	**-2.596; .009**	**-2.372; .018**	-.123; .902
Prior hospitalization in intensive care			
Yes	4.64±3.40	8.74±3.10	25.00±3.75
No	5.33±3.28	9.20±2.80	24.44±4.34
Test	**-2.128; .033**	**-2.131; .033**	-.688; .491
Finding the information received sufficient (n=217)			
Yes	4.60±3.18[a]	8.94±2.84	24.85±4.00
No	7.00±4.31[b]	9.29±2.88	24.57±3.82
Partially	4.85±2.93[a]	8.66±2.53	24.48±4.33
Test*	**6.792; .034**	1.448; .485	.487; .784

* Kruskal Wallis test, ** Mann-Whitney U test was used, chi-square/z;p values were given. The superscripts a, b show within-group differences in each group, and measurements with the same letters are similar.

It was found that the general health sub-dimension scores of the mothers whose children were aged 13 months and over and the social relations sub-dimension scores of the mothers whose children had acyanotic heart disease were lower ($p<0.05$). It was determined that the general health status and psychological and environment sub-dimensions scores of the mothers whose children had not had surgery before were lower and the difference was statistically significant ($p<0.05$, Table 4).

Table 4. WHOQOL BREF-TR Quality of Life Scale scores of mothers who had children in PCSICU according to some variables

Scales	1	2	3	4	5
	Mean ±*Sd*	Mean ±*Sd*	Mean ±*Sd*	Mean ±*Sd*	Mean ±*Sd*
Age/month					
Under 3 months	61.17±22.94[a]	49.52±12.83	61.78±11.83	64.11±16.32	55.88±13.79
4-12 months	57.57±23.19[ab]	49.90±13.06	60.74±14.03	63.73±20.80	54.18±17.37
Over 13 months	50.32±19.40[b]	49.19±15.12	58.39±13.78	63.19±22.27	51.58±15.19
Test*	**11.665; .003**	.050; .975	2.196; .333	.051; .975	3.233; .199
Diagnosis					
Acyanotic	54.61±22.95	49.79±13.50	59.51±13.85	60.28±20.15	52.67±16.06
Cyanotic	57.58±21.59	49.30±13.89	60.89±12.77	66.53±19.31	54.82±15.04
Test*	-1.039; .299	-.396; .692	-.949, .343	**-2.578; .010**	-1.373; .170
The child's previous surgery					
Undergoing surgery	58.04±23.29	49.68±13.11	61.58±13.29	65.31±19.04	55.56±15.20
Not undergoing surgery	52.29±19.29	49.20±14.96	57.39±12.84	60.09±21.36	50.09±15.64
Test*	**-2.283; .022**	-.114; .909	**-2.103; .035**	-1.568; .117	**-2.509; .012**

* Kruskal Wallis test, ** Mann-Whitney U test was used, chi-square/z;p values were given. The superscripts a, b show within-group differences in each group, and measurements with the same letters are similar.
1. General health sub-dimension
2. Physical health sub-dimension
3. Psychological sub-dimension
4. Social relations sub-dimension
5. Environment sub-dimension

It was determined that there was a weak and negative correlation between the RSCS negative religious coping sub-dimension and the general health status, social relations, and environment sub-dimensions of the quality of life scale (r=-0.136, r=-0.143, r=-0.133 and p<0.05, respectively). It was determined that there was a moderate negative correlation between the quality of life scale and the hopelessness scale (r=-0.252, p≤0.001) (Table 5).

Table 5. Correlation between the Religious Coping Style Scale, Beck Hopelessness Scale (BHS), and WHOQOL BREF-TR Quality of Life Scale scores of mothers who had children in PCSICU

Scales	1	2	3	4	5
Beck Hopelessness Scale (BHS) total	**-.252****	-.124	**-.317****	**-.142***	**-.370****
	.000	.063	**.000**	**.033**	**.000**
RCSS Negative Religious Coping sub-dimension	**-.136***	.086	-.063	**-.143***	**-.133***
	.041	.201	.350	**.032**	**.046**
RCSS Positive Religious Coping sub-dimension	-.066	-.083	-.063	-.126	-.080
	.322	.213	.349	.059	.230
1. General health sub-dimension 2. Physical health sub-dimension 3. Psychological sub-dimension 4. Social relations sub-dimension 5. Environment sub-dimension					

DISCUSSION

Caring for a child with CHD affects parents in many ways, physically, psychologically, socially, and financially. It is argued that religious beliefs have a role in facilitating coping with the disease process of parents who have children with chronic diseases such as CHD (7). Although it is known that mothers seek faith and turn to spirituality during the acceptance phase of their children's diagnosis and treatment process, very few studies have examined the religious coping styles of mothers of children with CHD (16). The strengths of this study were that the literature on the subject was very limited and that the hopelessness and quality of life levels of mothers of children with CHD were examined in addition to their religious coping styles.

It has been reported in the literature that mothers of children with CHD experience anxiety, hopelessness, and depression (2,17). Contrary to the literature, in our study, it was noteworthy that although mothers of children undergoing open heart surgery and hospitalization in the PCSICU had a high level of positive religious coping, they had low levels of hopelessness and negative religious coping. Similarly, Liu et al. reported in a study that parents had high levels of positive religious coping and moderate levels of negative religious coping, and there was a negative correlation between the level of depression in parents and their positive religious coping styles (18). In another study, no relationship was found between the religious beliefs of parents of children with CHD and depressive symptoms (16). In our study, it was observed that the majority of children with CHD had complex cyanotic heart disease, almost half of them had previously been hospitalized in PCSICUs, and 31.6% had previously undergone open heart surgery. The low hopelessness levels of mothers may be due to their use of coping mechanisms that they developed based on their past surgery and intensive care experience. Another study reported that as the optimism of mothers of children with coronary heart disease increased, their resilience also increased (19). Another notable finding is that mothers who found the information they received from healthcare professionals sufficient were less hopeless. Receiving information about the process can help mothers reduce their hopelessness by mitigating uncertainty. In our study, it was determined that negative religious coping was lower in mothers whose children had undergone previous surgery and were hospitalized in the PCSICU. On the contrary, in a study conducted with mothers of children with CHD in Korea, it was found that the stress of mothers whose children had undergone previous surgery was higher than that of mothers whose children did not undergo surgery (3). Repetitive surgeries and intensive care hospitalizations may increase the stress in parents of children with CHD, and experiencing this process may strengthen mothers' effective coping mechanisms.

In a study was found that parents of children with CHD had a lower quality of life, and the quality of life was determined by the child's age, the type and severity of the disease and the presence of other comorbidities (20). In our study, it was determined that the scores of the general health status, and

psychological and environmental sub-dimensions of quality of life scale of mothers whose children had undergone previous surgery were higher. In addition, as the child's age became younger, the score of the general health status sub-dimension of the quality of life scale was higher, and the score of the social relations sub-dimension of the quality of life scale was higher in mothers whose children's diagnosis was cyanotic CHD. Bektaş et al. found that the quality of life for parents decreased as care burden and symptom count increased in their study of parents of children with CHD (21). Our study determined that the quality of life of mothers whose children had undergone previous surgery was better. This result may be due to decreased symptoms in children due to the surgeries and their experience in this process.

Religious beliefs can affect many aspects of a person's life, including health-related issues. There is growing evidence of a link between religion and health, mostly positive but sometimes negative (22). Our study found a weak negative correlation between the RSCS negative religious coping sub-dimension and the general health, social relations, and environment sub-dimensions of the quality of life scale, as well as a moderate negative correlation between the quality of life and hopelessness scales. In line with this result, it can be concluded that supporting the positive religious coping of mothers of children who have undergone open heart surgery and hospitalization in PCSICU may reduce hopelessness levels and increase their quality of life. However, it may also be concluded that a better understanding of the mechanisms underlying this relationship and accompanying faith-based intervention studies is needed.

Study Limitations

The fact that the scales used in the study were based on mothers' self-reporting and the sample size of the study are among the limitations.

CONCLUSION

The mothers of children with CHD have serious concerns about their child's future, which goes beyond their typical caregiver role. This situation peaks, especially when the child with CHD is admitted to the intensive care unit. The hopelessness of mothers negatively affects their quality of life, which prevents mothers from participating in child care and complicates family processes. As a result of this research, it can be said that supporting positive religious coping of mothers of children who have undergone open heart surgery and hospitalized in PCSICU can reduce their hopelessness levels and increase their quality of life. In addition, the high level of hopelessness of mothers who cannot receive sufficient information about the disease process shows how important it is for nurses, who are the primary caregivers in intensive care, to include the family in the care process. The studies conducted with mothers who have children with CHD can raise awareness and guide health professionals in meeting the needs of mothers and families. Therefore, it is recommended to strengthen communication processes with mothers of children with CHD and to provide effective information.

DESCRIPTIONS

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