

The relationship between hopelessness and perceived social support levels of parents with children with congenital heart disease

Tugba Nur Oden^{1*}, Rahsan Cam²

1 Ege University, University Hospital, Organ Transplantation Center, Izmir, TR

2 Adnan Menderes University, Faculty of Nursing, Surgical Nursing Department, Aydin, TR

* Corresponding Author: Tugba Nur Oden E-mail: tugba.nur.ozturk@ege.edu.tr

ABSTRACT

Objective: This study was conducted to evaluate the relationship between hopelessness and perceived social support levels of parents with children with congenital heart disease (CHD).

Material and Methods: This cross-sectional study was conducted with parents of children who underwent surgery for CHD, and data were collected from 100 parents who agreed to participate in the study. A descriptive information form for the sociodemographic characteristics of the parents, "Beck Hopelessness Scale (BHS)" and "Multidimensional Scale of Perceived Social Support (MSPSS)" were used to collect the data. Data were analysed using descriptive statistics and Spearman's correlation tests.

Results: The mean score of the hopelessness level of the parents participating in the study was 6.15 ± 4.23 , and the mean perceived general social support score was 69.55 ± 15.47 . There was a significant negative correlation between the hopelessness levels of mothers and social support (SS) received from the family, from significant others, and general SS scores. There was a significant positive correlation between the hopelessness levels of the mothers and the SS level received from the family ($p < 0.05$).

Conclusion: In this study, the parents of children with CHD have low levels of hopelessness and perceived SS levels are high. Moreover, the relationship between hopelessness and perceived SS levels varies according to the sex of the parents. In our study, the SS level of mothers had a higher effect on the hopelessness level. It is recommended that the SS levels of the parents of children with CHD should be increased to help them cope with hopelessness.

Key words: Congenital abnormalities; hope; social support; parents

INTRODUCTION

Congenital heart diseases (CHD) are a common type of congenital anomaly that can be seen in 1–8 out of every 100 live births and is responsible for ~30%–50% of birth defects in infants and early childhood (1-2). Mortality and morbidity rates in CHD are related to the type of disease. Cyanotic CHD has a more critical course (3). Babies with critical health conditions can start medical treatment and undergo surgery within one year after birth (4).

Having a child with CHD can be very stressful for parents (5). When parents learn that they will have a baby, they can have high expectations and hope. Despite technological advances, many families of babies with CHD are unaware of the diagnosis throughout pregnancy. Families can face the fact that their baby is born with a potentially life-threatening situation a few hours, days, or weeks after a baby's birth celebration. The effect of the child's illness on the parent changes as per the life-threatening nature of the disease (6). Parents are faced with short- or long-term psychological mood changes with the start of diagnosis and treatment procedures. Hopelessness is one of them (7). Hopelessness is defined as a set of cognitive schemas that contain negative expectations about the individual and his/her future life (8). Hopelessness experienced by the family negatively affects individuals' compliance with treatment, their efforts, motivation and coping mechanisms (9).

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Social support (SS) those individuals receive from their relatives is important in developing coping mechanisms for hopelessness. Individuals are required to get SS from family, friends, people in similar situations or significant others such that they do not feel lonely. SS can help parents not feel lonely and get emotional support. SS is the sum of the material and spiritual aids that are provided by relatives and friends to increase the resilience of the individual to stress, to protect the mental/physical well-being and to prevent the development of psychopathology against the problem (10). The lack of adequate SS mechanisms in parents with children with CHD may increase the risk of developing psychological disorders (7).

The relationship between the level of hopelessness and perceived SS on different populations has been investigated in the national and international literature (8, 11-13). Generally, studies conducted on parents with children with CHD examine the relationship between SS level and quality of life and stress level (14, 15, 16). There are no published studies examining the relationship between hopelessness and perceived SS level in parents with children with CHD. Therefore, this study was conducted to evaluate the relationship between hopelessness and perceived SS levels of families with children with CHD.

Study Question

1. Is there a relationship between the hopelessness level and the perceived SS level in parents who have a child with CHD?

MATERIAL and METHODS

This study is a cross-sectional research. The study was conducted with families of children aged 0–6 who were admitted to the cardiovascular surgery department (CVD) of a university hospital in Izmir, diagnosed with CHD and underwent surgery. The population of the study comprised parents of children who were admitted to the CVD because of CHD and underwent surgery. The sample of the study comprised 96 parents (mothers or fathers) determined as per a priori power analysis. The sample size was determined to be 100 for convenience in statistical evaluation. Parents who volunteered to participate in the research, over the age of 18, healthy mental status, without vision, hearing or speech problems, speaks Turkish language, with children aged 0–6 years who underwent surgery for congenital heart disease were included in the study.

An introductory information form evaluating the socio-demographic characteristics of the parents and their children, a questionnaire form comprising the MSPSS and the BHS were used to collect the data. Data were collected between August and December 2015.

Descriptive Information Form: The form comprised three closed-ended and two open-ended questions about sociodemographic information of the child with CHD and the parents, prepared by the researchers in line with the literature. The form included the parents' sex, age, educational status, as well as the age, sex and diagnosis of the child.

Beck Hopelessness Scale (BHS): The scale was developed by Beck et al. (17). Turkish validity was made by Seber et al. (18), and the scale was adapted to our country after being

examined with a larger sample by Durak & Palabiyikoglu (19). The scale comprises 20 items. According to the answer key, 11 of the items should be answered 'yes' and 9 should be answered 'no'. Based on the answer key, certain questions get '1 point', certain questions get '0 points' and the mean hopelessness level is calculated with the arithmetic sum. Average score ranges from 0 to 20 points. Higher scores indicate higher level of hopelessness (18).

Multidimensional Scale of Perceived Social Support (MSPSS): The scale was developed by Zimet et al. (20). Turkish validity was made by Eker et al. (21). The scale is a data collection tool used to determine the level of SS. It is a seven-point Likert-type scale and comprises 12 items. The scale has three sub-dimensions: SS from family, friends and significant others (fiancée, partner, and lover). SS from the family is investigated in items '3-4-8-11', SS from friends is investigated in items '6-7-9-12', and SS from significant others is investigated in items '1-2-5-10'. The score range of each subscale is between 4-28 points. The total scale score is in the range of 12-84 points. Higher scores indicate higher level of perceived SS. The Cronbach's alpha coefficient (α) of the scale was determined as 0.86. Cronbach's alpha coefficients for sub-dimensions were determined as $\alpha = 0.83$ for family, $\alpha = 0.84$ for friends, and $\alpha = 0.88$ for significant others (21). In this study, Cronbach's alpha coefficient was reported to be $\alpha = 0.91$.

Data analysis was performed in digital environment using IBM SPSS Version 21.0 package program. Number, percentage, mean and standard deviation were used in the analysis of descriptive data. Normality was evaluated using the Shapiro–Wilk normality test. Mann–Whitney U test, Independent samples t test and Kruskal–Wallis test were used for comparison between groups. Spearman's correlation coefficient was used to examine the relationship between scale scores. Values with p less than 0.05 were considered significant.

The study was conducted according to the guidelines of the Declaration of Helsinki. Written permission was obtained from the Ege University Clinical Research Ethics Committee to conduct the study. Before applying the questionnaire, verbal and written consents were obtained from the parents participating in the study, explaining the purpose of this study.

RESULTS

Table 1 lists the distribution of sociodemographic characteristics of parents and children participating in this study. The average BHS score of the parents was reported to be 6.15 ± 4.23 . Mean MSPSS subscale scores were 25.06 ± 5.33 for family, 22.52 ± 6.50 for friends, and 21.97 ± 7.25 for significant others. Mean MSPSS score of the parents was 69.55 ± 15.47 .

BHS scores as per the age and sex of the parents ($p > 0.05$), a significant difference was reported between the BHS scores according to the education level of parents ($p: 0.023$). While the mean BHS score of the parents who were primary school graduates was high (7.13 ± 3.71), the mean BHS score of parents who were of university graduates was low (4.54 ± 3.37). No significant difference was reported between mean

BHS scores of the parents as per the sociodemographic characteristics of children ($p > 0.05$).

Table 3 lists the comparison of sociodemographic characteristics of the parents and their children with the mean MSPSS scores. According to the results, no significant difference was reported between MSPSS scores of parents according to the sociodemographic characteristics ($p > 0.05$). A statistically significant relationship was reported between mean SS score of the parents obtained from the family and the ages of the children with CHD ($p: 0.008$). A significant difference was reported between the mean SS scores obtained from significant others according to the diagnoses of children with CHD ($p: 0.044$). No significant difference was reported between the mean MSPSS scores of the parents as per the sex of the children ($p > 0.05$).

Table 4 lists the relationship between the MSPSS scores and BHS scores of the mothers participating in this study. A moderate negative correlation was reported between the hopelessness level of the mothers and the perceived SS obtained from the family ($r: -0.492, p: 0.00$). Moreover, a weak negative correlation was reported between the hopelessness level and perceived SS from significant others ($r: -0.349, p: 0.013$) and overall perceived SS ($r: -0.293, p: 0.039$).

Table 5 lists the relationship between the MSPSS scores and BHS scores of the mothers participating in this study. A weak significant correlation was reported between the hopelessness level of the fathers and perceived SS from the family ($r: 0.380, p: 0.06$).

Table 1: Descriptive Characteristics (n = 100)

Sociodemographic Characteristics		Number (n)	Percent (%)
<i>Sociodemographic Characteristics of Parents</i>			
Gender	Female	50	50.0
	Male	50	50.0
Age	25 years and under	16	16.0
	26 years and older	84	84.0
Education Status	Primary school	15	15.0
	Middle School	26	26.0
	High school	35	35.0
	University	24	24.0
<i>Sociodemographic Characteristics of Children</i>			
Gender	Female	53	53.0
	Male	47	47.0
Age	0-1 Years	63	63.0
	2-3 years	31	31.0
	4-6 Years	6	6.0
Diagnosis	Acyanotic Heart Disease	49	49.0
	Cyanotic Heart Disease	51	51.0

Table 2: Comparison of Mean BHS Scores According to Sociodemographic Characteristics of Parents and Children (n = 100)

Variable	N	X ± SD	Test value	p value	
<i>Sociodemographic Characteristics of Parents</i>					
Gender	Female	50	6.44 ± 4.51	U: 1183.500	0.644
	Male	50	5.86 ± 3.95		
Age	25 years and under	16	8.00 ± 4.64	t: 1.934	0.056
	26 years and older	84	5.79 ± 4.08		
Education Status	Primary school	15	7.13 ± 3.71	KW: 9.549	0.023
	Middle School	26	7.07 ± 4.46		
	High school	35	6.14 ± 4.60		
	University	24	4.54 ± 3.37		
<i>Sociodemographic Characteristics of Children</i>					
Gender	Female	53	6.07 ± 4.46	U: 1170.000	0.599
	Male	47	6.23 ± 3.99		
Age	0-1 years	63	5.68 ± 4.03	KW: 4.649	0.098
	2-3 years	31	6.67 ± 4.62		
	4-6 years	6	8.33 ± 3.77		
Diagnosis	Acyanotic	49	5.18 ± 3.31	U: 1029.500	0.126
	Cyanotic	51	7.07 ± 4.80		

BHS: Beck Hopelessness Scale, n: Number, X ± SD: Mean ± Standard Deviation, KW: Kruskal Wallis test, U: Mann Whitney U test, t: t test, $p < 0.05^*$

Table 3. Comparison of Mean MSPSS Scores According to Sociodemographic Characteristics of Parents and Children (n = 100)

Variable		n	SS from Family X ± SD	SS from Friend X ± SD	SS From Significant Other X ± SD	Overall SS Score X ± SD
<i>Sociodemographic Characteristics of Parents</i>						
Gender	Female	50	25.24±5.65	22.84±6.64	22.88±7.10	70.96±15.82
	Male	50	24.88±5.04	22.20±6.41	21.06±7.35	68.14±15.15
			U:1104.00 p:0.262	U:1136.50 p:0.420	U:1013.00 p:0.091	U:1066.50 p:0.200
Age	25 years and under	16	23.18±6.71	21.56±7.36	21.75±7.78	66.50±18.67
	26 years and older	84	25.41±4.99	22.70 ± 6.36	22.01±7.19	70.13±14.85
			t:-1.543 p:0.126	t:-0.641 p:0.523	t:-0.132 p:0.895	t:-0.859 p:0.393
Education Status	Primary school	15	24.33±5.40	21.00±7.65	21.26±7.67	66.60±20.14
	Middle School	26	25.46±4.51	21.84±5.29	22.38±6.26	69.69±12.29
	High school	35	24.08±7.01	22.80±7.01	23.51±6.72	70.40±17.01
	University	24	26.50±2.35	23.79±6.27	19.70±8.45	70.00±13.61
			KW:1.35 p:0.716	KW:3.37 p:0.337	KW:3.33 p:0.343	KW:0.95 p:0.813
<i>Sociodemographic Characteristics of Children</i>						
Gender	Female	53	24.47±6.17	21.84±7.10	21.90±7.50	68.22±17.28
	Male	47	25.72±4.15	23.27±5.73	22.04±7.04	71.04±13.17
			U:1105.00 p:0.281	U:1157.00 p:0.528	U:1217.00 p:0.839	U:1185.00 p:0.672
Age	0-1 Age	63	25.74±4.77	23.01±6.27	22.57±7.07	71.61±14.25
	2-3 years	31	24.45±5.93	22.03 ±6.09	21.67±7.11	68.16±14.88
	4-6 Age	6	21.00±6.41	16.83±8.86	17.16±9.23	55.00±23.97
			KW:9.572 p:0.008 *	KW:5.60 p:0.061	KW:3.36 p:0.186	KW:4.98 p:0.083
Diagnosis	Acyanotic	49	25.12±5.73	22.97±6.35	23.36±6.34	71.46±15.22
	Cyanotic	51	25.00±4.96	22.07±6.68	20.62±7.85	67.70±15.64
			U:1150.00 p:0.444	U:1118.5 p:0.351	U:967.50 p:0.044 *	U:1031.00 p:0.127

MSPSS: Multidimensional Perceived Social Support Scale, SS: Social Support, n: Number, X ± SD: Mean ± Standard Deviation, KW: Kruskal Wallis test, U: Mann Whitney U test, t: t test, p < 0.05*

Table 4: The Relationship Between Mothers' MSPSS and BHS Scores (n = 50)

	r and p	SS from Family	SS from Friend	SS From Significant Other	Overall SS Score	Hopelessness
SS from Family	r	1.000				
	p					
SS from Friend	r	0.499	1.000			
	p	0.000				
SS From Significant Other	r	0.451	0.662	1.000		
	p	0.001	0.000			
Overall SS Score	r	0.622	0.872	0.887	1.000	
	p	0.000	0.000	0.000		
Hopelessness	r	-0.492*	-0.130	-0.349 *	-0.293*	1.000
	p	0.000	0.369	0.013	0.039	

MSPSS: Multidimensional Scale of Perceived Social Support, BHS: Beck Hopelessness Scale, SS: Social Support, r: Spearman Correlation Coefficient, p < 0.05*

Table 5: The Relationship Between Fathers' MSPSS and BHS Scores (n = 50)

	r and p	SS from Family	SS from Friend	SS From Significant Other	Overall SS Score	Hopelessness
SS from Family	r p	1.000				
SS from Friend	r p	0.591 0.000	1.000			
SS From Significant Other	r p	0.445 0.001	0.611 0.000	1.000		
Overall SS Score	r p	0.694 0.000	0.865 0.000	0.880 0.000	1.000	
Hopelessness	r p	0.380* 0.006	-0.241 0.092	-0.073 0.613	-0.156 0.278	1.000

MSPSS: Multidimensional Scale of Perceived Social Support, BHS: Beck Hopelessness Scale, SS: Social Support, r: Spearman Correlation Coefficient, p <0.05*

DISCUSSION

This study was performed to examine the relationship between hopelessness levels and perceived SS levels of parents with children with congenital heart disease who underwent surgery.

In this study, the mean BHS score was reported to be 6.15 ± 4.23 . Lowoko & Soares (15) examined hopelessness in parents with and without children with CHD and reported a mean BHS score as 4.8 ± 0.1 . Similar results were reported in other studies conducted on parents (22, 23). Our results agree with the literature, and parents' perception of hopelessness was reported to be low.

When the differences between mean hopelessness levels according to parental education status were examined, the mean hopelessness level of primary school graduates (7.13 ± 3.71) was higher compared to individuals; however, the mean hopelessness level of university graduates was lower compared to other individuals (4.54 ± 3.37). A significant difference was reported between the mean hopelessness levels according to parental education level ($p < 0.05$). Akandere et al. (25), Durat et al. (26) and Yildirim & Yildirim (27) reported that parents who graduated from primary school had higher levels of hopelessness.

Çatalbaş et al. (28) reported that the hopelessness level of parents who received education was lower. The reason for the low level of hopelessness in parents with a high level of education may be that these parents have more information about their children's disease, treatment and care opportunities, and develop appropriate coping mechanisms and use problem-solving resources well in this process. For individuals with a low level of education, factors such as social status, roles in the society, not getting enough financial or moral support from their relatives, insufficient coping mechanisms, and not being able to benefit from existing resources can cause hopelessness.

In our study, perceived SS scores were reported to be high. MSPSS subscale mean scores were as follows: SS from the family was 25.06 ± 5.3 , SS from friends was 22.52 ± 6.50 , and SS from significant others was 21.97 ± 7.25 . The overall SS score was 69.55 ± 15.47 . Deveci & Ahmetoglu (24)'s results are similar to the results of this study.

When the differences between the MSPSS mean scores of the parents were examined as per the ages of children with CHD, the total scale and general SS scores of individuals with children in the 0–1 age group (71.61 ± 14.25) were reported to be higher than those of parents with children in other age groups. While there was no significant difference between the perceived SS levels received from friends and significant others as per the ages of children with CHD ($p > 0.05$), a significant difference was reported between the perceived SS levels received from the family ($p < 0.05$). Hoekstra-Weber et al. (29) examined perceived SS in parents of cancer patients and concluded that SS decreased over time. Most children with CHD are diagnosed and start treatment within the first year (4). Based on this proposition, the reason for the high levels of SS received from the family in children aged 0–1 years in this study may be attributed to the intensive diagnosis and treatment procedures in the first year.

Parents with a child with acyanotic CHD had higher scores on all subscales and the total scale (71.46 ± 15.22) compared to parents with a child with cyanotic CHD. In both groups, the perceived SS received from the family was reported to be high. No significant difference was reported between the perceived SS of parents received from the family and friends as per the diagnoses of children with CHD ($p > 0.05$); however, a significant difference was reported between the perceived SS received from significant others ($p < 0.05$). In the literature, there are differences in SS levels as per the severity of the disease. Almesned et al. (30) investigated SS in the parents of children with complex and mild congenital heart disease and reported that SS from families was higher in complex heart diseases. In this study, there was a difference between SS levels received from significant others, and families with children with cyanotic CHD had lower levels of SS from significant others (spouse, flirt, physician, and individual with the same experience). Azhar et al. (31) stated that parents with children with CHD require more information than given and that the emotional, moral and educational support physicians provide to parents can affect the quality of life of parents. In their meta-analysis, Lumsten et al. (32) stated that the support that parents with children with CHD give to each other and the support they receive from individuals with the same experience are important factors for coping mechanisms. Parents with a child with

cyanotic CHD may have high levels of anxiety and stress (33). Therefore, they may require more SS from significant others.

There was a significant negative correlation between mothers' hopelessness and SS from family and significant others and overall SS levels ($p < 0.05$). It can be stated that the level of hopelessness decreases as the level of SS from the family and significant others, as well as overall SS, increases. However, no significant relationship was reported between the level of hopelessness of fathers and the level of SS from friends and significant others and the overall SS. A positive and significant relationship was determined between the SS received from the family and the level of hopelessness ($p < 0.05$). As the level of SS received from the family increases, the level of hopelessness increases.

Similar to the results of mothers, there are studies in the literature showing a negative correlation between the level of hopelessness and perceived SS (8,11,12,13,34). Mothers require more SS than fathers to cope with hopelessness (15, 35). In this study, SS received from the family affects the hopelessness level of mothers by 49%. In a qualitative study conducted with parents with CHD, parents stated that their families assumed certain responsibilities during the course of the disease and provided physical support and emotional support. They stated that they received support from other individuals who had the same experience in increasing their hope during the course of the disease (36). In this context, the relationship between mothers' hopelessness and SS levels is consistent with the literature. However, the positive correlation between the hopelessness level of the fathers and SS received from the family is surprising. Generally, studies in the literature report a negative correlation between hopelessness and SS levels. Hoekstra-Weber et al. (29) examined SS and psychological adaptation in parents of pediatric cancer patients, and the fathers participating in the study stated that they received support during the course of the disease, but they cared more about being satisfied with the support rather than the level of SS received. In this context, our results are similar to the results of Hoekstra-Weber et al. (29).

The limitations of the study are that only volunteer patients participated in the study and the data were collected from single hospital.

CONCLUSION

There is a relationship between hopelessness and perceived SS levels in parents of children with CHD. SS received from the family plays a big role in the parents' level of hopelessness. Creating sources of physical, emotional, spiritual, and informational support for parents during treatment of CHD can increase their level of SS and reduce the level of hopelessness. In this context, it is recommended to provide family-centered care for parents, to increase communication with family members, to meet their educational requirements with the help of healthcare professionals, to increase communication with individuals who have had the same experience, and to provide psychosocial support.

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