ORIGINAL ARTICLE

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Anxiety, Coping and Social Support Among Parents Who Have Children with Chronic Kidney Disease

ABSTRACT

Objective: Present study has been conducted to investigate anxiety levels, coping strategies, social support systems among parents who have children with chronic kidney disease and interrelations among the three indicators.

Methods: This study has been planned among parents of 180 children with a chronic kidney disease being admitted to Hacettepe University, Children's Hospital, Nephrology Polyclinic. Sociodemographic information form, state & trait anxiety inventory and short form of the assessment scale for coping strategies have been employed as data gathering tools.

Results: With respect to gender it was detected that mothers resorted to self-distraction coping strategy and with respect to educational level, parents with no formal educational background resorted to denial. Trait anxiety score was the highest among parents whose children were in the second stage of disease. As the coping strategies among parents receiving social support in the treatment process was examined, it surfaced that positive reframing, acceptance, humor and use of emotional support and similar problem-focused coping strategies were more frequently opted for. Contrary to that, it was identified that among parents receiving no social support from their relatives, scores of self-blame, substance use and state anxiety were relatively higher.

Conclusion: At the end of this study it was concluded that parents having children with a chronic kidney disease were more effective in utilizing social support mechanisms as a problem-focused coping strategy when compared to the other group of parents.

Keywords: Parent, Chronic Kidney Disease, Anxiety, Coping, Social Support

Kronik Böbrek Yetmezliği Hastası Çocuğa Sahip Ebeveynlerde Kaygı, Başetme ve Sosyal Destek

ÖZET

Amaç: Araştırma kronik böbrek yetmezliği hastası çocuğa sahip ebeveynlerin kaygı düzeylerini, başetme tutumlarını, sosyal destek sistemlerini ve bunlar arasındaki ilişkiyi incelemek amacıyla gerçekleştirilmiştir.

Gereç ve Yöntem: Çalışma Hacettepe Üniversitesi Çocuk Hastanesi Nefroloji Polikliniğine başvuruda bulunan 180 kronik böbrek yetmezliği hastası çocuğun ebeveynleri ile planlanmıştır. Veri toplama aracı olarak sosyodemografik bilgi formu, sürekli - durumluk kaygı envanteri ile başetme tutumlarını değerlendirme ölçeğinin kısa formu kullanılmıştır.

Bulgular: Cinsiyet açısından annelerin zihni dağıtma, eğitim durumu açısından herhangi bir okul mezunu olmayanların inkâr odaklı başetme yolunu kullandıkları bulunmuştur. Hastalığın ikinci aşamasında olan çocukların ebeveynlerinin sürekli kaygı puanı en yüksektir. Tedavi sürecinde çevresinden sosyal destek alan ebeveynlerin başetme stratejileri incelendiğinde olumlu yeniden yorumlama, kabullenme, mizah ve duygusal destek kullanımı gibi sorun odaklı başetme stillerine daha fazla başvurdukları görülmektedir. Bunun yanında çevrelerinden bu desteği alamayan ebeveynlerin ise kendini suçlama, madde kullanımı ve durumluk kaygı puanları yüksek bulunmuştur.

Sonuç: Sosyal destek mekanizmalarını daha iyi kullanan kronik böbrek yetmezliği hastası çocuğa sahip ebeveynler bu süreçte diğer ebeveynlere göre daha başarılı olarak kabul edilen sorun odaklı başetme stratejilerini kullanmaktadır.

Anahtar Kelimeler: Ebeveyn, Kronik Böbrek Yetmezliği, Kaygı, Anksiyete, Başetme, Sosyal Destek

INTRODUCTION

Chronic Kidney Disease (CKD) is a progressive kidney disease that moves towards a worse state functionally and inevitably (1). CKD does not only damage the physical health of patients although has negative effects on the psychological health, daily functions, general well-being and social functionality of patients (2).

This disease is less prevalent among children (3). Pediatric CKD leads to growth retardation and neuro-cognitive disorder; significantly damages not only physical but also psychological state of well-being (4). Throughout this process quality of life of children degrades, special care needs arise, and finally children must cope with physical, social, and emotional problems during the treatment (5).

In addition to pediatric CKD children, their parents also must cope with financial, biological, psychological and social problems (6). CKD affects parents' daily routines and psychosocial adaptation (7). CKD is generically analyzed within five stages from start stage and final stage kidney disease and in connection with each consecutive stage. Parents of the children experiencing the disease must cope with a long list of psychosocial problems ranging from feeling sorrow due to the growth retardation and worsened wellbeing of the child. There are many variables in this list: hesitation to accept the prognosis, staying fully alert always due to disease symptoms, depression, social exclusion, feel the uneasiness in social and family life due to newly acquired caregiver role (8-10). Also, educational and professional situations, marital harmony, presence of social security, intensity of child's disease, child's age, higher needs for medical assistance and several other factors affect parents' level of accepting and perceiving the disease, and their cooperation with child, stress and anxiety levels (11).

In medical literature there are various approaches to prevent, alleviate and reverse CKD (12). For the recent decades medical literature has concurrently indicated psychosocial factors such as social support, cognitive factors, stress and coping strategies (13-15). However previous studies that examined psychosocial factors were mainly related to children thereby there were a few numbers of studies focusing on family-related dimension of this disease. Because of the lack of psychosocial dimension of children with CKD and their parents in the literature; this study has been conducted to investigate anxiety levels, coping attitudes, social support systems among parents who have children with CKD and interrelations among the three indicators.

MATERIAL AND METHODS

The methodological approach of study has been planned in quantitative style; hence sampling measurement was not selected. Population of current research consisted of parents of 180 children with CKD being admitted to Hacettepe University, Children' Hospital, and Nephrology Polyclinic between 10.10.2015-17.01.2016. This study was done in compliance with the Helsinki Declaration, and was reviewed and approved by the Ethics Committee of Hacettepe University. Socio-demographic information of parents are as displayed in Table 1. As can be monitored in the Table 1, of all the interviewed parents, mothers constitute the larger portion (62,2%) and the respondents vary between ages 31-40 (51,6%); the ratio of married ones with high-school or equivalent level of educational degree was (36,5%), and has income level below middle class (44,8%). Children are generically belonging to 4th or 5th stage of disease (54,7%).

Table 1. Socio-demographic Information

		n	%
Gender	Female	112	62,2
	Male	68	37,8
Age	Age 20 and below	9	5,5
	Between 21-30	32	19,6
	Between 31-40	84	51,6
	Age 41 and above	38	23,3
Educational level	No formal diploma	7	3,9
	Elementary school graduate	28	15,7
	Middle school graduate	41	23,0
	High school or equivalent graduate	65	36,5
	Four-year college and post graduate	37	20,8
Marital status	Married	146	81,1
	Single	34	18,9
Average monthly income level	1000 TL and below	55	33,3
	1001-2000 TL	74	44,8
	2001-3000 TL	21	12,7
	3001 TL and above	15	9,1
Diagnosis stage	1st stage	15	9,4
	2nd stage	17	10,7
	3rd stage	40	25,2
	4th stage or 5th stage	87	54,7

Inclusion criteria of the study were parenting a child diagnosed with CKD at least for six months, no presence of any psychiatric disorder and volunteering to participate in the research. Socio-demographic information form designed by the researchers, state & trait anxiety inventory and short form of the assessment scale for coping strategies have been employed as data gathering tools.

State & Trait Anxiety Inventory: Originally designed by Spielberger et al. (16) this inventory consisting of two separate scales including 20 items to reflect individuals' state and trait anxiety levels were adapted to Turkish culture

by Öner and Le Compte (17). This inventory in the format of self-report and 4 points Likert scale in which items vary in accordance with the frequency or intensity levels of emotions. Total average score received from this inventory fluctuates between 20 to 80. High score indicates higher anxiety level whilst low score indicates lower anxiety level.

Short Form of Coping Strategies Assessment Scale: In our study shortened and readjusted version of Coping Strategies Assessment Scale (COPE) designed in 1989 by Carver, Scheier and Weintraub (18) but shortened and readjusted by Carver as Short Form of Coping Strategies Assessment Scale was utilized (19). The Scale contained 28 questions defining problem and emotion focused coping strategies. In this scale there are 14 subscales (self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, self-blame) each of which integrates two statements. High score in each coping strategy indicates that this strategy is used more intensively. Psychometric assessment of the scale to confirm the validity and reliability for Turkish society was conducted by Tuna (20).

Statistical Methods: In this study, trait variables were represented via mean variable or standard deviation values whilst categorical variables were represented via frequency and percentage values. Shapiro-Wilk Test was employed to analyze whether the data performed or not performed a normal distribution and it was manifested that the data did not perform a normal distribution. Accordingly, Mann Whitney U Test was employed for independent paired samples and Kruskal Wallis tests were harnessed for multiple-group comparisons. Statistical analyses were performed in SPSS v. 21 program and found to be p<,05, which is a statistically significant value.

RESULTS

Obtained findings of this study were structured upon the relationship between socio-demographic variables & coping and anxiety; whether social support was received and if yes, the givers of social support; and the connection between social support & coping and anxiety. As the relationship between socio-demographic variables & coping and anxiety was investigated it was reported that self-distraction score of females (p=,002) was higher than males' score. With respect to denial score however, there was not a statistically significant difference between different groups of educational level. Hence, denial score (p=,012) was highest among those with no formal educational degree. Among those with diagnosis stage; mean rank score of the patients in the first stage was 76,63; mean rank score of the patients in the second stage was 106,35; mean rank score of the patients in the third stage was 69,36; mean rank score of the patients in the fourth or fifth stages was 80,32. As can be inferred from the table below, trait anxiety score (p=,049) was highest among parents whose children were diagnosed with stage-two disease (Table 2).

Table 2. Relationship between Socio-demographic Variables & Coping and Anxiety

Self-distraction	**n**	**Mean rank**	**U**	**p**
Female	112	99,82	2764,5	,002*
Male	68	75,15		
Denial	**n**	**Mean rank**	**X2**	**p**
No formal educational degree	7	134,57	12,844	,012*
Elementary school graduate	28	102,52		
Middle school graduate	41	87,46		
High school or equivalent graduate	65	77,07		
Four-year college and post graduate	37	95,22		
State-trait Anxiety Score	**n**	**Mean rank**	**X2**	**p**
1st stage	15	76,63	7,819	,049*
2nd stage	17	106,35		
3rd stage	40	69,36		
4th or 5th stage	87	80,32		

As can be seen in Table 3, the use of coping strategies such as denial, venting, substance use and use of emotional support that are seen as emotion-focused coping strategies are positively correlated with state anxiety. Also, positive reframing that is seen as problem-focused coping strategy is positively correlated with trait anxiety.

Among the participants the ratio of the ones receiving social support during disease process equated to 81,6%. As the providers of social support were examined; 96,5% of participants received social support from their families; 31,2% of participants received social support from their relatives; 21% of participants received social

support from their friends; 12,9% of participants received social support from their neighbors and 10,8% of participants received social support from relatives of other patients (Table 4).

Table 3. The Relationship Between Coping and Anxiety

	State anxiety score	Trait anxiety score
Active coping	-,056	-,029
Planning	-,099	,026
Religion	-,058	,033
Positive reframing	,047	,233**
Acceptance	-,066	,013
Humor	,093	-,003
Use of emotional support	,203**	,098
Use of instrumental support	,082	,078
Self-distraction	,022	,111
Denial	,230**	,099
Venting	,228**	,155*
Substance use	,240**	-,020
Behavioral disengagement	,137	,070
Self-blame	-,030	,035

Table 4. Receiving Social Support and Providers of Social Support

		n	%
Receiving Social Support	Yes	147	81,6
	No	33	18,4
Receiving Social Support from Family	Yes	142	96,5
	No	5	4,5
Receiving Social Support from Friends	Yes	31	21
	No	116	79
Receiving Social Support from Relatives	Yes	46	31,2
	No	101	68,8
Receiving Social Support from Neighbors	Yes	19	12,9
	No	128	87,1
Receiving Social Support from Relatives of other Patients	Yes	16	10,8
	No	131	89,2

As the coping strategies of the parents having received support during the treatment process is examined it surfaces that parents resorted more frequently to problem-focused coping strategies such as positive reframing (p=,008), acceptance (p=,022), humor (p=,033) and use of emotional support (p=,001). On the other hand, it was also revealed that among those who did not receive social support from their family during treatment process, self-blame score (p=,005) was comparatively higher. Further to that, venting score (p=,005) was comparatively higher among those having received social support from friends during treatment process. Among those who did not receive social support from relatives of other patients, state anxiety score (p=,017) and substance use score (p=,019) were comparatively higher (Table 5).

Table 5. Relationship between Social Support & Coping and Anxiety

Receiving Social Support from the Surrounding		**n**	**Mean rank**	**U**	**p**
Positive reframing	Yes	75	98,41	2819,5	,008*
	No	98	78,27		
Acceptance	Yes	75	96,68	2949,0	,022*
	No	98	79,59		
Humor	Yes	75	95,99	3000,5	,033*
	No	98	80,12		
Use of emotional support	Yes	75	101,23	2608,0	,001*
	No	98	76,11		
Receiving Social Support from Family		**n**	**Mean rank**	**U**	**p**
Self-blame	Yes	142	84,97	1913,0	,005*
	No	38	111,16		
Receiving Social Support from Friends		**n**	**Mean rank**	**U**	**p**
Venting	Yes	31	113,97	1582	,005*
	No	149	85,62		
Receiving Social Support from parents of other patients		**n**	**Mean rank**	**U**	**p**
State anxiety	Yes	16	60,84	837,5	,017*
	No	164	93,39		
Substance use	Yes	16	68,50	960	,019*
	No	164	92,65		

DISCUSSION

CKD is a problem that affects multidimensionally the child and parents who play the role of caregivers. To enhance the quality of treatment once the child grows older and to identify the frequency of preventable diseases it is essential to probe deeper into pediatric CKD because the actual prevalence and frequency of spread of pediatric CKD in Turkey unknown yet (21). On the other hand, experiencing a chronic disease during childhood means the emergence of novel conditions that challenge the lifestyles of families and parents. Adaptation to such novel conditions for the chronic patient places the burden and responsibility of caregiving to parents and mothers most particularly.

Long-term care is a stressful process for caregivers and this state is rather significant to realize the way caregiver related stressors are coped with. The responsibility to take care of a chronic patient is generically placed on the shoulders of partners, parents and siblings (22). Results of international studies conducted to investigate the families of pediatric patients evidenced that a great majority of participants are mothers (23-26). Also, in our study most of our participants were also mothers. The lead role of mothers during caregiving process can be attributed to social gender roles and unfamiliarity of men to the responsibilities of care giving (27). The truth is placing the burden of caregiving to one parent singly may endanger the management of a child's chronic disease, hence it is crucial to build a connection between parents and utilizing accumulated health information as a couple (28).

Hooper et al. (29) delivered critical messages about CKD: (1) Children and adolescents with CKD are prone to developing neuro-developmental risks, (2) Parents are socio-behaviorally prepared, (3) Parents are anxious, but this anxiety level is below clinical level, (4) Social-behavioral anxieties have naturally been internalized. Within the framework of such messages, parents resort to an assortment of approaches to cope with the chronic disease of their children. As manifested in a qualitative study, parents resort to coping strategies such as seeking social support, focusing on their positive aspects, and emotional and religious ways of coping (30). Tong et al. (31) detected the parents use internal and external coping strategies in their study. Internal coping strategies were seeking a psychological & emotional response inherent in parents, accepting the sorrowful condition and adapting to the disease of the child. On the other hand, external coping resources included family, friends and social support from the community. In a different study (32) it was witnessed that males employed problem-focused coping methods more frequently than emotion-focused coping methods whereas mothers also employed passive coping methods during the caregiving process to a pediatric CKD patient (33). Dabrowska and Pisula (24) conducted a research among parents with autistic children detected that compared to fathers, mothers more frequently use emotion focused coping strategies in their study. In our study, with respect to gender variable, self-distraction score which is emotion focused coping method (p=,002) was found to be higher among females.

In order to overcome CKD-induced challenges it is a must to provide a comprehensive social support system for the patients (35). Social support is a complex network that while meeting his/her own emotional needs an individual can also receive information and support. Social support can also be provided by family, friends and relevant social networks. Furthermore, social support helps to adaptation for a better quality of life and treatment process (36-38). Indeed, the findings of our study are also in line with previous studies. Furthermore, when in our study the focus was on the participants who could not receive family social support during treatment process, self-blame score (p=,005) of parents was measured higher. As coping strategies of parents having received social support during treatment process was examined it surfaced that they resorted more frequently to problem-focused coping strategies such as positive reframing (p=,008), acceptance (p=,022), humor (p=,033) and use of emotional support (p=,001). On the other hand, it was also revealed that among those who did not receive social support from their family during treatment process, self-blame score (p=,005) and substance use score (p=,019) were higher.

Another finding in this study was social support of relatives of other patients has a positive effect on the state anxiety level of parents (p=,017). In parallel with this finding of our study, Gray and Holden (39) conducted a research among parents of autistic children and found out that intense use of social support alleviated parental anxiety level. According to the study of Chan et al. (40) social support significantly alleviated the burden and anxiety levels of the caregivers of CKD patients. Also, social support that progressively climbed during the first three months, led to a parallel rise in lower anxiety scores. As reported by Grapsa et al. (41) although social support is the most important assistance, a very limited quantity of caregivers can access medical and social support.

CONCLUSION

To summarize; within the scope of present study most interviewees were mothers who resorted to self-distraction as a coping strategy more frequently than fathers. One of the findings was that with respect to educational level, parents with no formal educational degree resorted to denial-focused coping strategy more frequently than other parents. As the coping strategies of the parents having received support during the treatment

process is examined it surfaces that parents resorted more frequently to problem-focused coping strategies such as positive reframing, acceptance, humor and use of emotional support. On the other hand, it was also revealed that among those who did not receive social support from their family during treatment process, self-blame, substance use and state anxiety scores were comparatively higher. Based on all these findings it can feasibly be claimed that among mothers who have children with CKD, those with lower educational level and inadequate opportunity for social support systems failed to effectively cope with disease condition. Thus, it would be beneficial to render psychosocial support to such parents by mental health professionals. As a concluding remark it can be noted that after this study, conducting a qualitative research among parents who have children with CKD would further illuminate the focal topic.

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