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A Comparison of Caregiving Burden and Social Support Levels of Parents of Children Undergoing Liver Transplant

Emriye Hilal Yayan [a], Mehmet Emin Düken [b,*]

[a] Department of Child Health Nursing, Faculty of Nursing, Inönü University, Turkey
[b] Department of Child Health Nursing, Faculty of Health Sciences, Harran University, Turkey

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ABSTRACT

Purpose: This study was conducted to compare caregiving burden and social support levels of parents of children who have undergone a liver transplant.
Designs and methods: This study utilized a descriptive, cross-sectional research design. Data were collected using a parent information form, the Zarit Burden Interview, and the Multidimensional Scale of Perceived Social Support. Data were collected via face-to-face interview after written consent was obtained from the parents of children who had received a liver transplant.
Results: Parent participants were found to have a high caregiving burden and low levels of social support from their surroundings. Parents who experienced change in their work life, social and family relationships, and had economic problems post-transplant, had a higher caregiving burden and may have lower social support. Parents whose children had a transplant from a cadaveric donor and continued to attend school were found to have a lower caregiving burden. There was a negative correlation between parent caregiving burden and social support scores; that is, caregiving burden ($R^2 = 0.57$, $p < 0.01$) was significantly affected by social support ($B = -0.682$, $\beta = -0.757$).
Conclusions: This study concluded that parents receiving social support may have a lower caregiving burden, and some of their socio-demographic characteristics may have a positive effect on social support and caregiving burden.
Practice implications: Health professionals need to pay special attention to the social support and caregiving burden of parents whose children have had an organ transplant.

Introduction

Organ transplantation is a regular, valid, and advanced treatment method for many chronic organ diseases at the present time. Since there is no other treatment option for chronic solid organ failures such as kidney, lung, liver, heart, and pancreas, organ transplantation continues to be relevant (Kacmaz & Barlas, 2014). Liver transplants are an important treatment method for children with end-stage organ failure (Çetin & Ayşın, 2007). A total of 599 liver transplants were performed on children under the age of 18 in the United States in 2017, and 131 have already been performed in 2018, between January and May. Some 16,577 liver transplants have been performed in the United States since 1988 (OPTN, 2018). Although the age range of patients is not specified, 1446 liver transplants were performed in Turkey in 2017, and 519 were performed between January and May 2018 (T.C.S.B, 2018).

Transplantation is an important treatment method for children with acute and chronic liver failure. Children who have a liver transplant sustain their life like a patient with a chronic disease, constantly visiting hospital for controls, taking medicines and receiving care from their parents, which increases parents' caregiving burden (Williams, Eilers, Heermann, & Smith, 2012). On the other hand, children with chronic disease need care and continuous monitoring and control from caregivers throughout their life (Durualp, Kara, Yılmaz, & Alaybeyoğlu, 2010). A study conducted by Lerret, Johnson, and Haglund (2017) with children who had received an organ transplant and their parents, reported that absence from school, the use of immunosuppressive medicines with lifelong side effects, the risk of infection, the personal care of the child, and the constant control of the child led to an increase in parents' anxiety, fear, and caregiving burden. A study conducted by Fredericks, Lopez, Magee, Shieck, and Opipari-Arrigan (2007) found that the quality of life of children who had undergone a liver transplant was lower than that of children with cancer, diabetes, and healthy children. Moreover, the limitations on school and social life, and frequent hospitalization of children who undergo a liver transplant have an effect on family activities and increase the caregiving burden of the parents (Fredericks et al., 2007). Nicholas et al. (2010) reported that factors such as the regular hospital visits, a lifetime of taking medicine, the risk of infection, and the development of post-transplant complications increased parents' caregiving burden. Denny et al. (2012) reported in

* Corresponding author.
E-mail addresses: emriye.yayan@inonu.edu.tr (E.H. Yayan), eminduken@harran.edu.tr (M.E. Düken).

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their study conducted with the children who had undergone a liver transplant and with their parents that the adaptation of family members and deterioration in their activities, change in family roles as well as financial and economic difficulties increased parents' caregiving burden.

A study conducted by Elcigil and Conk (2010) with mothers of children with cancer reported that care and treatment of the child, care of siblings, continuous hospitalizations, and family members quitting their job increased mothers' caregiving burden. The same study found that mothers did not receive sufficient social support from their family and friends (Elcigil & Conk, 2010). Another study stated that parents of children with chronic diseases are concerned with their continued care and treatment; also, the inability to allocate time to their siblings, and the lack of social support from the community which lead to social isolation (Karakavak & Çırak, 2006). Atagün, Balaban, Atagün, Elagöz, and Özpolat (2011) found that caregivers did not take enough time for themselves, felt tired, had economic problems, and did not receive adequate social support from their community. Recent advances in medical and surgical techniques have increased the survival rate of children who receive a liver transplant to 89.1, 87.5, and 83.8% in the last one, five, and ten years, respectively (Soeda et al., 2017). There is an emergence of literature on the lives of those who have undergone transplants due to the increasing number of such operations. It is important to conduct research to determine the needs of caregivers of children with organ transplants for better holistic care. Therefore, we conducted this study to compare caregiving burden and social support level of parents of children who have undergone a liver transplant.

Method

Study design and sample

This study was designed as a descriptive cross-sectional study. It was conducted in the clinics of Liver Transplantation Institute between April 1, 2017 and April 1, 2018. The population of the study consisted of the parents of children who had undergone a liver transplant and were registered in the hospital patient-tracking system. All children who met the inclusion criteria between these dates were included in the study. All parents of children who had undergone transplant surgery in the six months prior to the study and did not have any secondary chronic disease were included in the study. A total of 165 candidate parents were identified for the study, but three parents refused to participate, and four of the children had other chronic diseases. Thus, the study was completed with 158 parents.

Data collection

After the clinic's agreement and the ethics committee's approval were obtained for the study, a proper place was designated in the polyclinic for the families who agreed to participate, and the measurement scales were explained. Data were collected via face-to-face interview with the parents within 30 min of these explanations being given.

Data collection tools

The data were collected using a parent information form, the Zarit Burden Interview, and the Multidimensional Scale of Perceived Social Support.

Parent information form

The parent information form comprised 15 questions regarding their age, gender, education, occupation, age of child, school attendance.

Zarit Burden Interview (ZBI)

The Zarit Burden Interview is a scale developed by Reever and Bach-Peterson in 1980 to evaluate the stress levels of caregivers (Zarit, Reever, & Bach-Peterson, 1980). The validity and reliability of the Turkish version of the Zarit Burden Interview were tested by İnci and Erdem (2006). The Cronbach's alpha value of the scale varied between 0.87 and 0.99. In this study it was found that the Cronbach's alpha value varied between 0.85 and 0.94. The Zarit Burden Interview is used to determine the difficulties and problems experienced by the caregivers of patients with chronic diseases. The scale, which can be completed by the caregivers themselves or by the researcher, consists of 22 questions that determine the effect of caregiving on the individual's life. In this study, the scale was filled by the parent who cared for the children with liver transplantation. Each question is answered on a 5-point Likert-type scale ranging from 0 to 4. A minimum of 0 (zero) points and a maximum of 88 points can be obtained on the full scale. Scores of 0–20 points indicate "No caregiving burden," 21–40 points indicate "Mild caregiving burden," 41–60 points indicate "Moderate caregiving burden," and 61–88 points indicate "Severe caregiving burden." Questions on the scale are generally related to social and emotional concerns. A higher score on the scale is understood to indicate a higher caregiving burden (İnci & Erdem, 2008).

Multidimensional Scale of Perceived Social Support (MSPSS)

The Multidimensional Scale of Perceived Social Support was developed by Dahlem, Zimet, & Walker (1991) to identify social support elements perceived by individuals (Dahlem et al., 1991). The validity and reliability of the Turkish version of the scale were tested by Eker, Arkar, & Yaldız (2001). The Multidimensional Scale of Perceived Social Support consists of 12 items scored on a 7-point Likert-type scale ranging from 1 ("absolutely not") to 7 ("absolutely"). It consists of three subscales: friends, family, and private person. A minimum of 12 points and a maximum of 84 points can be obtained from the scale. Higher scores indicate that perceived social support is high (Eker et al., 2001). The Cronbach's alpha reliability coefficient of the scale was 0.85 (Eker et al., 2001). In this study, it was found to be 0.83.

Ethical considerations

Ethical approval was obtained from the Non-Invasive Clinical Research and Publication Ethics Committee of Inonu University's Institute of Health Sciences. Written consent was obtained from the families who agreed to participate in the study after they were informed about the purpose of the research and the scales to be administered.

Data analysis

The data were analyzed using the SPSS (Statistical Package for Social Sciences) 22.0 package. Simple linear regression, one-way ANOVA, student-*t*, and Spearman correlation tests were used to perform statistical analysis.

Results

The mean age of the parents participating in the study was 37.5 ± 7.1, while the mean age of the children was 8.1 ± 4.8. This study found that parents had mean scores of 48.3 ± 24.9 and 47.9 ± 27.6 for caregiving burden and social support, respectively.

More than half (55.7%) of participating parents were women, 26.6% had primary school education, 41.8% were housewives, 76.6% reported no health problems, and 44.3% experienced difficulties during the transplant process. Of the children who had undergone liver transplant, 55.7% were male. Of the parents whose children had undergone a liver transplant, 60.8% stated that changes occurred in their social life,

Table 1
Comparisons of some socio-demographic characteristics with the mean scores on Zarit Burden Interview and the Multidimensional Scale of Perceived Social Support.

Socio-demographic characteristics		Zarit Burden Interview	Multidimensional Scale of Perceived Social Support
Gender of child	Female (70)	42.9 ± 24.7	52.2 ± 28.8
	Male (88)	52.7 ± 24.3	44.5 ± 26.3
	Test values	2.502	1.746
	p-Values	**0.013**	0.083
Gender of parent	Female (88)	54.1 ± 23.5	42.4 ± 25.3
	Male (70)	41.1 ± 24.8	54.7 ± 29.0
	Test values	3.393	2.848
	p-Values	**0.001**	**0.005**
Change in work life	Yes (102)	60.9 ± 19.2	33.6 ± 21.3
	No (56)	25.5 ± 16.3	73.9 ± 16.6
	Test values	11.666	12.257
	p-Values	**0.000**	**0.000**
Change in social relations	Yes (96)	61.3 ± 18.1	32.8 ± 20.0
	No (62)	28.2 ± 20.2	71.2 ± 20.8
	Test values	10.741	11.610
	p-Values	**0.000**	**0.000**
Change in family relations	Yes (116)	58.0 ± 20.6	37.8 ± 23.9
	No (42)	21.8 ± 14.2	75.7 ± 15.4
	Test values	10.526	9.555
	p-Values	**0.000**	**0.000**
Economic problems	Yes (113)	56.9 ± 21.4	38.3 ± 24.0
	No (45)	26.9 ± 19.7	72.0 ± 20.6
	Test values	8.116	8.281
	p-Values	**0.000**	**0.000**
Transplant type	Living	53.7 ± 24.0	43.5 ± 26.6
	Cadaveric	33.6 ± 21.2	60.0 ± 27.0
	Test values	4.770	3.446
	p-Values	**0.000**	**0.001**

Sample *t*-test.

64.6% in their working life, and 73.4% in family functioning and family relations, and 71.5% stated that they had economic problems (Table 5).

Results determined that the parents of boys who had undergone liver transplant had a higher mean score on caregiving burden with a significant difference between their mean scores support scales ($p < 0.005$). The parents of girls who had undergone liver transplant were found to score higher on social support, but there was no significant difference between their mean scores. The mothers whose children had undergone a liver transplant were found to have higher caregiving burden, but lower social support scores. There was a statistically significant difference between parents' mean scores on caregiving burden and social support in terms of their gender ($p < 0.005$). Parents who had not encountered these changes in their working life, social relations, family functioning, and encountered economic problems after their children underwent a liver transplant, were found to have higher mean scores on caregiving burden, and there was a statistically significant difference between their mean scores ($p < 0.001$). This study also found that the parents who had no change in working life, social relations, family functioning, and encountered no economic problems had higher mean scores on social support, and there was a statistically significant difference between their mean scores ($p < 0.001$). The parents whose children had a transplant from a cadaveric donor had lower caregiving burden but higher social support scores. There was a statistically significant difference in mean scores on caregiving burden and social support among parents regarding transplant type ($p < 0.001$) (Table 1).

Examination of the parents' mean scores on caregiving burden and social support showed that the parents with the highest caregiving burden had an elementary education only (63.5 ± 18.4) while the parents with the lowest mean score had a university education (28.0 ± 21.6). There was a statistically significant difference between parents' mean

Table 2
Comparisons of some socio-demographic characteristics with the mean scores on Zarit Burden Interview and the Multidimensional Scale of Perceived Social Support.

Socio-demographic characteristics		Zarit Burden Interview	Multidimensional Scale of Perceived Social Support
Educational level of parents	Literate (38)	57.2 ± 19.0	34.2 ± 21.4
	Primary school (42)	63.5 ± 18.4	32.0 ± 20.2
	Secondary school (21)	55.1 ± 21.2	44.9 ± 27.2
	High school (29)	29.4 ± 21.3	69.3 ± 22.7
	University (28)	28.0 ± 21.6	70.4 ± 20.4
	Test values	22.106	23.365
	p-Values	0.000	0.000
Influence of liver transplantation on family	Well (40)	30.9 ± 22.0	66.9 ± 24.3
	Normal (48)	44.7 ± 24.7	54.4 ± 28.6
	Bad (70)	60.8 ± 19.4	32.6 ± 19.1
	Test values	25.020	29.404
	p-Values	0.000	0.000
Child's school attendance	Constant (55)	30.8 ± 17.8	65.9 ± 24.0
	Rare (31)	50.2 ± 26.8	42.5 ± 27.2
	Absent (72)	61.0 ± 20.5	36.4 ± 23.1
	Test values	32.238	24.027
	p-Values	0.000	0.000

One-Way ANOVA.

Table 3
Relationships between Zarit Burden Interview, the Multidimensional Scale of Perceived Social Support, age of the child, and age of parents.

		Multidimensional Scale of Perceived Social Support	Age of parent	Age of child
Zarit Burden Interview	*r*	−0.757**	−0.046	−0.305**
	p	0.000	0.569	0.000
Multidimensional Scale of Perceived Social Support	*r*		0.017	0.217**
	p		0.816	0.000

Bivariate correlate.
** Correlation is significant at the 0.01 level (2-tailed).

scores caregiving burden in terms of their educational level ($p < 0.001$). The parents with a university education had the highest mean scores on social support (70.4 ± 20.4) while those with primary school education level had the lowest mean scores (32.0 ± 20.2). There was a significant difference between parents' mean scores on educational level and social support ($p < 0.001$). Examination of the status of the families affected by liver transplant showed that the parents who were affected positively by the transplant process had higher mean scores on social support, and lower mean scores on caregiving burden ($p < 0.001$). The parents whose children continued to attend school after their liver transplant were found to have the lowest mean scores on caregiving burden and the highest mean score on social support. There was a significant difference between the school attendance of children post-liver transplant and their parents' mean scores on caregiving burden and social support ($p < 0.001$) (Table 2).

There was a negative correlation between the caregiving burden and social support scores ($r = -0.757$, $p = 0.000$). The social support scale positively correlated and increased with the child's age ($r = 0.217$, $p = 0.000$). There was a negative correlation between caregiving burden and the child's age ($r = -0.305$, $p = 0.000$). As the child's age increased, caregiving burden decreased and social support increased (Table 3).

The simple linear regression analysis showed that there was a high, significant correlation between social support and caregiving burden ($R = 0.55$, $R^2 = 0.57$, $p < 0.01$). Accordingly, social support accounted for 57% of the total variance of caregiving burden. The examination of the standardized (β) coefficient and *t*-values suggested that social support was an important predictor of caregiving burden (Table 4).

Discussion

This study found that psychosocial factors such as work life, social life and family relationships had an effect on the parents' caregiving burden and social support levels after the children's liver transplantation. Fredericks et al. (2008) reported that the activities, adaptation, physical, and psychosocial functioning of families whose children had organ transplants were impaired, which resulted in an emotional impact on the family and increased their caregiving burden. A study conducted by Fujita (2016) on adolescents who had undergone a liver transplant reported that the limitations imposed on physical activity, the use of immunosuppressive medicines on a regular basis, and the uncertainty of the child's future caused an increase in parents' caregiving burden. In a qualitative study conducted by Zhang et al. (2014) with children who had undergone liver transplants and their parents, the parents reported that providing physical care for children and protecting them from diseases associated with immunosuppressive use were the major causes of caregiving burden. Zhang et al. (2014) found that providing care for their sick children, and their siblings, and dealing with daily routines at home could lead to an increase in the caregiving burden of parents. The finding reported by the present study, that the parents whose children had received a liver transplant might have high caregiving burden but low social support level, is in line with the literature. The necessity of providing continuous care for their children may have reduced the social support resources of parents because they have less time for social relations (Denny et al., 2012). This study found that social support may be an important determinant of the parents' caregiving burden, which is among its most important contributions to the literature.

This study found that mothers had higher caregiving burden and lower social support levels than fathers. Mothers whose children receive a liver transplant may have higher caregiving burden than fathers because they spend more time caring for their children and stay with their children throughout hospital visits (Posfay-Barbe, Barbe, Wetterwald, Belli, & McLin, 2013). A qualitative study conducted with parents who had children with chronic diseases found that mothers had higher caregiving burden due to the fact that they were constantly taking their children to the hospital, spent time caring for them, and their husbands did not take enough responsibility (Karakavak & Çırak, 2006). A study conducted with mothers who had children with chronic diseases reported that the increased caregiving burden and lack of social support from their community affected the relationships with their spouses, led them to feel anger towards their spouses, and reduced their capacity to provide attention and care to their other children (Karakavak & Çırak, 2006). A study which examined caregiving burden and social support for parents in South Korea showed that as parents received support from their spouses, friends, and people around them, their caregiving burden was reduced (Oh & Lee, 2009). A study which examined the social support and caregiving burdens of parents of children with muscular dystrophy in Italy showed that as the social support of the family and people around them decreased, the psychological burden of the parents increased (Magliano et al., 2015). Our study showed

Table 4
Simple linear regression analysis of caregiving burden.

	B	SE	β	*t*	*p*	*R*	R^2
Constant	–	2.606	–	–	–	0.557	0.573
Social support	−0.682	0.047	−0.757	−14.461	0.000		

SE = 16.315, F = 209.119, $p < 0.001$.

Table 5
Socio-demographic characteristics of children and parents.

		N	%
Parent's gender	Female	88	55.7
	Male	70	44.3
Parent's educational status	Literate	38	24.0
	Primary school	42	26.6
	Secondary school	21	13.3
	High school	29	18.4
	University	28	17.7
Parent's job	Unemployed	15	9.5
	Housewife	66	41.8
	Worker	37	23.4
	Officer	40	25.3
Do you have a health problem?	Yes	37	23.4
	No	121	76.6
How was your experience of the organ transplant?	Good	40	25.3
	Medium	48	30.4
	Bad	70	44.3
Children's gender	Girl	70	44.3
	Boy	88	55.7
Has your social life changed since the transplant?	Yes	96	60.8
	No	62	39.2
Has your working life changed after the transplantation?	Yes	102	64.6
	No	56	35.4
Have there been any changes in family functioning and family relations after the transplantation?	Yes	116	73.4
	No	42	26.6
Have you had any economic problems since the transplantation?	Yes	113	71.5
	No	45	28.5

that mothers of children who underwent a liver transplant reported to have a higher caregiving burden but lower social support than fathers.

We found that parents who experienced change in their working life, social relations, family functioning, and family relations, and who encountered economic problems after their children received a liver transplant had a higher caregiving burden and less social support from their community. Parents of children with chronic diseases were found to have physical, emotional, and economic problems. Moreover, the prolonged hospitalization of children was reported to increase the caregiving burden on parents due to the continuous care needed by the child, and the long working hours of the parents (Taşçıoğlu, Beyazıt, & Ayhan, 2017). A study conducted by Erdem et al. (2013) with parents of children with chronic diseases reported that factors such as giving care to another with the care of the child, economic problems, and having a child with another health problem increase parents' caregiving burden. Parents who had children with chronic diseases were found to have physical, emotional, and economic problems, leading to greater caregiving burden (Tuncay, Mollaoğlu, & Fertelli, 2015). A study conducted by Alahan, Aylaz, and Yetiş (2015) with mothers of children with chronic diseases reported that the mean caregiving burden scores of mothers with stable economic status were lower. Parents whose children had received a transplant experienced stress and anxiety due to the deterioration of family relationships and routines, role changes, and financial burdens, which may lead to an increase in their caregiving burden and a decrease in social support of parents through affecting friendships and family relationships (Williams et al., 2012). Our study found that parents whose children underwent liver transplant displayed similar conditions to parents of children with chronic diseases. It was found that parents could have impaired working, social, and family relations and economic difficulties. This was one of the most important findings of the study.

Our study reported that the parents whose children had a transplant from cadaveric donor had lower caregiving burden and received more social support from their community. This may be due to the fact that in cases of living transplants, the donor can be a family member and the family must therefore care for both donor and recipient. However, this needs to be investigated further due to lack of sufficient data.

A study conducted by Alonso et al. (2008) with children who had received a liver transplant and their parents found that family functions and quality of life could be impaired as the educational level of parents decreased. The educational level of parents has important effects on relations with their children, family harmony, and their roles (Posfay-Barbe et al., 2013). Alahan et al. reported that the caregiving burden of parents of children with chronic diseases decreased as their educational level increased (Alahan et al., 2015). Another study conducted with mothers of children staying in hospital found that as the educational level of mothers increased, the level of social support they received also increased and the level of anxiety and depression decreased (Yüzer, Yiğit, & Taşdelen, 2006). The education levels of the parents of children who have undergone a liver transplantation can affect their caregiving burden and social support levels.

The provision of daily care for children post-transplant, the use of immunosuppressive medication throughout the child's life, the risk of infection due to immunosuppressive use and financial burden can have negative effects on the lives of parents (Kikuchi & Kamibeppu, 2015). It has been stated that parents of children who have undergone a transplant cannot do social activities, neglect housework, feel a sense of hopelessness, and experience constant stress (Yadav et al., 2017). A study found that the quality of life of parents whose children had undergone liver transplant was affected negatively by impairment of their family functions and harmony, and disruption of their activities and roles post-transplant (Alonso et al., 2008). Zhang et al. (2014) reported that parents receiving adequate social support from their community had lower caregiving burden. Our study found that parents who were negatively affected during the transplant period might have a high caregiving burden.

Studies on liver transplants in the literature have reported that most children are absent from school for >20 days post-transplant (Gilmour, Sorensen, Anand, Yin, & Alonso, 2010; Haavisto et al., 2013; Ng et al., 2012; Sudan et al., 2004). However, the effect of this on parents' caregiving burden and social support is not reported. Therefore, this study found that children's school attendance had an important effect on the caregiving burden and social support scores of their parents. Children who attended school had less caregiving needs as they may have received support from their friends and teachers resulting in a positive effect on the parents.

Similar to our study, previous studies have shown that the younger the child with chronic disease, the higher the caregiving burden of parents. There was also a negative relationship between parents' caregiving burden and their social support scores (Alahan et al., 2015; Taşçıoğlu et al., 2017). Our study showed that the older the child, the greater the social support from parents' community, and the lighter their caregiving burden.

Limitations of the study

The research center in this study is an important one which transplants organs from different geographical regions. Both caregiving burden and social support concepts are affected by the cultural characteristics of the societies in question. This is a relevant limitation in our study, because the cultural characteristics of the families were not taken into consideration.

Implications for practice

Health professionals should pay special attention to parents' caregiving burden which may be high after a liver transplant, which is a major surgery. Families can be evaluated to identify the effects of sociodemographic characteristics on social support and caregiving burden. Caregiving burden can be reduced by improving parents' social support resources. Health professionals who give care to children who received an organ transplant should support the parents in terms of their caregiving burden and social support. While giving care to both patients and parents, health professionals should take patients' working life after transplantation, socioeconomic situation, and social and family relations into consideration.

Conclusion

This study found that parents whose children underwent a liver transplant might have high caregiving burden, but low social support level. As the age of the child increased, the social support received by the parents increased and their caregiving burden decreased. This study detected that parents' age did not affect caregiving burden or social support. The parents of the children who had received transplants from cadaveric donors had a less caregiving burden and received better social support. The children's sex did not affect the caregiving burden or social support levels of parents, but parents of male children had greater caregiving burden and received less social support. It was found that parents' educational level, parents' gender, and school attendance of children post-transplant could have an effect on the caregiving burden and social support scores of parents. On the other hand, the present study shows that change in work, social, and family relationships and encountering economic problems post-transplant may affect the caregiving burden and social support scores of parents.

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Conflict of interest

The authors have no relevant conflicts of interest to disclose.

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