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A study on the caregivers' burden and social support among primary caregivers of kidney recipients

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***Abstract*---**Caring for a person who is undergoing a serious health problem or in the state of recovering from a health issue is a tiresome task for any other individual. Most people who take care of such people are close family members. They have to spend a potential proportion of their day/time with the patients by helping them in all aspects, including medication, personal care, and hygiene. The care process brings potential psychological and physical health issues to the caregivers, especially the primary caregiver, who is supposed to spend most of the time with the patients. In the currently available literature, it is evident that primary caregivers undergo severe psychological and psychosocial issues. The case is crucial in the context of the caregivers of organ recipients. In this context, the present study explored the social support and caregiving burden of primary caregivers of kidney recipients. The study was conducted among the primary care givers of kidney recipients from kidney patient associations in northern Kerala. The total sample of the present study was a hundred. The data was collected through interviews using two standardized scales. The result indicates a statistically significant difference in the caregiving burden based on gender and differences in the social support based on employment status. A positive correlation was found between age and social support and between age and caregiving burden. Also, a negative correlation exists between social support and the caregiving burden. This study implies interventions for improving social support and reducing the caregiving burden among the caregivers.

***Keywords*---**Social Support, Caregiving burden, Primary Caregivers, Kidney Recipients, Kerala.

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Introduction

The growth of medical research has positively impacted people's longevity and wellbeing. Organ transplantation is a modern surgical treatment that exemplifies this. Organ failure has become a major public health issue in today's culture. The rise in organ failure is primarily due to lifestyle and epidemiological profile changes. Losing a vital body organ will severely influence a person's quality of life and, more importantly, pose a life-threatening difficulty. According to reports from the world, thousands of people die every year while waiting for organ transplants (Abouna, 2008; Farrel et al., 2011).

The surgical procedure for organ transplantation is complex with physical, psychological, legal, societal, and economic aspects. Surgical procurers' physical and psychological ramifications, for both donors and receivers, are critical to one's future wellbeing. The post-surgery phase necessitates much physical, emotional, and psychological attention. In India, their close family members typically care about organ recipients, such as their husband, wife, father, mother, son, daughter, brother, or sister. For the individual who cares for organ recipients, the care process might be challenging. The care process will profoundly impact the person's social, psychological, and emotional wellbeing (Rodrigue et al., 2010; Paschou et al., 2018; Vovlianou et al., 2021).

The continued care process leads to significant health and psychological problems for the primary caregivers and the person they care for. The major problems that may arise during care include stress, burnout, poor quality of life, caregiving burden, and depression. It is common for primary caregivers to develop psychosomatic symptoms due to the stress of care. The primary caregivers' social and recreational aspects will also be affected due to the spending of long hours on the care of the person (Penkower et al., 2003; Kadioglu et al., 2012). The situation of the primary caregivers of the organ recipients is also not different. The post-surgical period after the organ transplantation requires specialized care in accordance with the type of organ transplanted.

In most cases, the organ recipients are not in a position to take care of themselves and need continuous care from a nearby family member or relative. The need for acute care significantly affects primary caregivers (Avsar et al., 2013; Avsar et al., 2015). The primary caregivers have to compromise their health and other demands, resulting in poor quality of life and a higher caregiving burden. The case is further complex when the donor himself/herself is the primary caregiver.

Caring for a person with organ failure and after an organ transplant places a huge emotional and financial strain on the primary family caregivers and the entire family. People go through a variety of psychological and social issues while in care. The currently available literature has touched on these topics to some extent. The carers' physical health is one of the most important domains of influence. Yiengprugsawan et al. (2012) found that caregivers suffer from physical and emotional health issues. Back discomfort and poor psychological health are two of the most common issues among caretakers. Full-time caretakers have more severe concerns than part-time caregivers, and females have more severe issues than males.

Yalcinkaya et al. (2010) found that caregivers experience physical health problems such as back pain and other symptoms due to the care burden. Schulz & Sherwood (2008) found that family members who care for someone who is critically ill experience a lot of stress. Physical and mental health issues are all too common among family caregivers. People generally develop psychosomatic symptoms as a result of long-term caring for the sick person. Another study by David, Roth, Lisa, and William (2015) found that the practice of caregiving puts caregivers' physical health at risk. In the currently available literature, the issue of caregiving burden and quality of life of the caregivers are well studied in different contexts. Most of the research underlines the caregiving process leads to potential burdens and poor quality of life.

However, there is a lack of evidence from the Indian context on the various aspects of the primary caregivers. The studies focusing on the social support and burden aspects are lacking in the current literature. In this context, the present study explored the perceived social support and caregivers’ burden in detail. The sociodemographic variable and other patient-specific aspects are taken into consideration in this study.

Methods and Materials

The present study employed a rigorous and systematic research method, tools and techniques for the conduct of the study. A descriptive research design guided the study. The study was conducted in the Northern part of Kerala. The potential samples were identified through the kidney patients’ associations in Northern Kerala. The list of people who have undergone organ transplantation in the last two years was accessed from these associations. A purposive sampling technique was adopted for the present study based on inclusion criteria. The primary caregivers of the organ recipients were only selected as the sample of the present study. The primary caregivers of organ recipients who have completed at least three months post-surgery were only considered as the present study's sample. However, the primary caregivers of those organ recipients who are availing of regular nursing services from a professional were excluded from the study. A total sample of a hundred was included for the present study.

The information for the present study was collected through interviews. Interviews were conducted at the hospitals during regular checkups or at the place of residence of the participants. A checklist was developed to explore the sociodemographic profile of the respondents. The checklist is intended to unveil the sociodemographic and economic factor that possibly influences the caregiver's burden and social support. Apart from this, two standardized scales were employed to measure the core variable under study. Firstly, the Burden Scale for Family Caregivers (BSFC) by Elmar Grasel, Teresa Chiu and Rosemary Oliver (2003). The scale is used to assess the subjective experience of the caregivers' burden. The scale has 28 items consisting of positive and negative items. The responses must be recorded on a four-point Likert scale extending from strongly agree to disagree. Secondly, the multidimensional scale of social support was developed by Zimet, Dahlem, Zimet & Farley (1988). The three domains of measurement assessed in the scale include family, friends, and significant others. The scale has a total of 12 items, with four items in each subscale. Both of these scales are statistically reliable and validated. These scales have been widely used to study various populations across the globe, including India.

Information for the present study was collected from the respondents who were voluntarily ready to involve in the study. The aim and objectives of the study were communicated to the respondents to make their participation meaningful and convey to them why the information was being gathered. Information sought from the respondents was kept confidential and personal indications of the people involved in the study were not made public. The same will be communicated to the respondents too. Written informed consent was being taken from the respondents.

Results and Discussion

The study indicates insightful results about the subject matter under study. Table 01 showcases the sociodemographic details of the participants. As evidenced in previous research, this study also shows that most primary caregivers are females (93%). Most of them also constitute donors; hence, the gender disparity is evident (Katz-Greenberg & Shah, 2022; Kaplan et al., 2022). It is evident that 55 percent of the respondents are involved in any of the income-generating status while 45 are not currently involved in any such activities.

Table- 01 – Socio-demographic Features (N=100)

Gender	Frequency	Percent
Male Female	7 93	7 93
Employment Status	Frequency	Percent
Yes No	55 45	45 45
Religion	Frequency	Percent
Hindu Muslim Christian	61 34 5	61 34 5
Relationship with the Patient	Frequency	Percent
Father Husband Mother Wife	5 2 19 74	5 2 19 74
Type of Family	Frequency	Percent
Nuclear Joint	89 11	89 11

Sixty-one percent of the study sample belonged to Hindu religion while 34 percent were Muslims. Five percent of the participants identified themselves belonging to Christianity. Seventy-four percent of the primary caregivers are wives, while 19 percent are mothers. Husband and father constitute only 2 and 5 percent respectively. Eighty-nine percent of the respondents lived in nuclear families while

11 percent lived in joint families. This trend typically represents the modern Kerala family.

Table-02: T-test for Caregiving Burden/Social Support and Gender

Domains	Group	N	Mean	Std. Deviation	Std. Error	Mean Difference	T	Sig
Caregiving Burden	Male	7	41.4286	10.54920	3.98722	-12.30261	-2.869	.005
	Female	93	53.7312	10.96550	1.13707	-12.30261		
Social Support	Male	7	39.5714	6.67975	2.52471	2.70380	1.035	.303
	Female	93	36.7742	6.91270	.71681	2.62449		

An independent sample t-test was carried out to see the difference in the caregiving burden and social support based on gender. The result found that there is a significant difference in the mean score of caregiving burden of male participants (M=41.4286, SD= 10.54920) and females (M=53.7312, SD=1.13707) with t (-2.869) p= .005. However, the mean score of social support is not different for male participants (M=39.5714, SD= 6.67975) and females (M=36.7742, SD=6.91270) with t (.71681) p= .303. This result indicates that the caregiving burden is higher among females than males, which is also evident in available literature (Zwar et al., 2022; Bueno & Chase, 2022). However, a statistically significant difference is not evident in the social support based on gender.

Table-03: T-test for Caregiving Burden/Social Support and Employment Status

Domains	Group	N	Mean	Std. Deviation	Std. Error	Mean Difference	T	Sig
Caregiving Burden	Yes	55	55.0545	10.17881	1.37251	4.85455	2.171	.032
	No	45	50.2000	12.18904	1.81703	4.85455		
Social Support	Yes	55	34.9818	5.28271	.71232	-4.41818	-3.345	.001
	No	45	39.4000	7.86939	1.17310	-4.41818		

An independent sample t-test was carried out to see the difference in the caregiving burden and social support based on the employment status. The result found that there is no significant difference in the mean score of caregiving burden of respondents having employment (M=55.0545, SD= 10.17881) and not having employment (M=50.2000, SD=12.18904) with t (-4.85455) p= .032. However, the mean score of social support is different for participants having employment (M=34.9818, SD= 5.28271) and their counterparts (M=39.4000, SD=7.86939) with t (1.17310) p= .303. This result indicates that social support is better among caregivers with employment compared to those who don't have an occupation. However, a statistically significant difference in the caregiving burden based on employment status is not evident.

Table-04: Correlation between Psychological wellbeing and Perceived Social Support

		Age	Caregiving Burden	Social Support
Age	Pearson Correlation	1	-.672**	.640**
	Sig. (2-tailed)		.000	.000
	N	100	100	100
Caregiving Burden	Pearson Correlation	-.672**	1	-.778**
	Sig. (2-tailed)	.000		.000
	N	100	100	100
Social Support	Pearson Correlation	.640**	-.778**	1
	Sig. (2-tailed)	.000	.000	
	N	100	100	100

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

The Pearson correlation coefficient explored the relationship between age, caregiving burden, and perceived social support. It was hypothesized that age doesn't relate to the perceived social support and caregiving burden. The Pearson correlation result shows a positive correlation between age and social support at < 0.01 level [*r*= .640, *n*=100, *p*=.000]. The result underlines that increased age will increase the perceived social support of primary caregivers. However, the person correlation results shows that there is a negative correlation between age and caregiving burden at < 0.01 level [*r*= -.672, *n*=100, *p*=.000]. This indicates that the increased age results in decreased caregiving burden. This is consistent with the recent evidence (Rahmani et al., 2022).

Similarly, it was evident from the Pearson correlation that a negative correlation exists between social support and caregiving burden at < 0.01 level [*r*= -.778, *n*=100, *p*=.000]. This indicates that the improved perceived social support will decrease the caregiving burden. Recent evidence also suggests that social support is a determining factor in the caregiving burden (Tao et al., 2022; Liu et al., 2022).

Conclusion

This study explored the social support and caregiving burden among the primary caregivers of kidney recipients. Drawing a hundred samples from the northern part of Kerala, this study manifests important indications of the subject matter. As evident in the literature, most of the primary caregivers and donors are women. Mostly, wives play the role of caregivers, followed by mothers. The study also found that the caregiving burden is statistically different based on gender-females have a high burden. Employment status is found to be influencing social support. People who are working reported better social support than their counterparts. Further, this study shows a positive correlation between age and social support and between age and caregiving burden. Also, a negative correlation exists between social support and the caregiving burden. This study implies interventions for improving social support and reducing the caregiving burden among the caregivers.

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