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A Study of Burden and Quality of Life in Caregivers of Person with Severe Mental Illness

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INTRODUCTION

Several decades ago, people suffering from mental illness were admitted and treated in psychiatric institutes only. But recent advancement in medical science and increased awareness about mental illness resulted in decreased institutionalization. Now a day more and more family are directly involved in taking care of mentally ill patient with the help of community services and mental health professionals.This change highlights not only the relevance of emotions and affections within a family, but also the great amount of burden experienced by these relatives while taking care of a psychotic patient as well. Thus, "informal care" is playing a significant role in development and evaluation of health programs and policies (Clark and Drake 1994). The family provides not just practical help and personal care but also gives emotional support to the mentally ill relative.

Caregiver is person who is taking care and responsibility of ill person. This care usually informal and unpaid but sometime caregiver can be paid professional person. Caregiver generally takes responsibility of ill person (physically or mentally ill person)'s treatment, medication, managing patient's need and requirement, handling crisis and looking after patient's overall well being.Generally a family member plays role of caregiver of severely ill person, but on many occasion, professional care taker are hired to for these purpose.

The burden experience by caregiver while taking care of mentally ill patient who is staying at home is first acknowledged by Grad and Sainbury in the early 1960s (Krupnik, Pilling, Killepsy-2005). Severe mental illness like schizophrenia or bipolar affective disorder, depression can have serious impact on the life of sufferer as well as their caregivers.

Caregiver burden has been defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual. Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers (Zarit et al. 1980, Parks &Novielli 2000, Etters et al. 2008, Carretero et al. 2009). In another word, Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness. For example, a person caring for someone with a chronic illness may experience stressors suchas financial strain, managing the patient's symptoms, dealing with crises, the loss of friends, or the loss of intimacy.

In 1993, The WHOQOL (The World Health Organization Quality of Life) Group defined **Quality Of Life** as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a wide concept implying many aspects and many interpretations have come from it.

Quality of life concept comprises different dimensions: individual's physical and emotional health, psychological and social well-being, fulfilment of personal expectations and goals, economic assurance, and finally functional capacity to develop daily routines normally (Garre J, et al. 2007).

In the health field, Quality Of Life (a construct closely related to burden) is one of the most important components associated with delivering an integral service to an ill person and their family, emphasizing the subjective perspective held by the patient and the family. In this context, one of the main objectives is the development of supporting activities rather than reducing symptoms and preventing relapses only. (Alejendra, Jose, Claudia 2009)

It has been seen that caring for patient with chronic mentally illness like schizophrenia can cause emotional distress in caregivers (Yusuf and Nuhu-2011, Sunil Srivastava-2005) Caregivers of schizophrenia experiences increased level of psychological distress.

A study conducted by Charalampos Mitsonis,et al (2012) suggests that clinical features of schizophrenia influence distress levels in caregivers of patients with chronic schizophrenia. The stronger predictors of distress appear to be female caregiver’s gender, duration of illness as well as positive and negative symptomatology. Expressed emotions play significant role in outcome of chronic mental illness.

Study conducted by Muscroft and Bowl (2000) showed that caregivers reported burden in different areas including effects on family functioning, social isolation, financial problems, and health. Most of the notable community-based studies proved that 18-47% of caregivers land in depression.

In indian context the study conducted by Sunil Srivastava (2005) on ‘perception of burden by caregiver of patients of schizophrenia’ found low positive correlation between age <30 years and factor 2, i.e. physical and mental health of the caregiver, and with factor 6, i.e. taking responsibility, may be indicative of a heavy psychological and physical strain on the caregiver and his/her responsibility-taking behaviour of patients with schizophrenia in their formative or early productive period.

In another study by Ampalam P, Gunturu S, Padma V. (2012) compared caregiver burden in caregivers of psychiatric illness and chronic medical illness. Findings in this study show that the caregiver burden scores in the caregivers of psychiatric patients were significantly higher than that of chronic medical illness (P<0.0001). The caregiver burden was found to increase with the duration of illness as well as with the age of caregiver. The caregiver burden in our population was less as the OB and DB did not cross the reference higher value in the given scale, whereas the emotional impact measured by SB was on the higher side.

Dillehay and Sandysdefined caregiver burden as a psychological state that appears as a combination of physical and emotional work, social pressure, and financial restrictions which are consequences of taking care of a patient.

It has been seen that family member or carer of persons with severe mental illness faces many challenges while taking care of ill member of family, e.g. taking care of patient’s symptoms, family and social responsibility, financial matters etc. These various psychological, social, financial etc. issues causes great amount of distress in caregiver and thus in return affect caregiver’s quality of life. Hence present study aimed to assess burden experienced by caregiver and how their quality of life is affected while taking care of mentally ill family member or relative.

METHOD

Aim:

The aim of the study is to understand the relationship between caregiver burden and quality of life in caregivers of person with severe mental illness.

Objective:

- To assess the caregiver burden in caregivers of person with severe mental illness
- To assess the quality of life of caregivers of person with severe mental illness
- To assess the relationship between caregiver burden and quality of life in caregiver's of person with severe mental illness.

Research Design: It is cross-sectional within group design

Sample

Sample of 40 caregivers of person with severe mental illness who attended OPD in Hospital for Mental Health, Ahmedabad were selected.

Tools: Following tools are used in the present study.

I) **Socio-demographic datasheet**

ii) **Caregiver Burden Interview(Zarit, 1980):** It has 22 items and scoring range from 0 to 4. Maximum possible score is 88. It also measures that degree of burden experienced. Score 0 to 20= Little or no burden, 21 to 40= Mild to moderate burden, 41 to 60= Moderate to severe burden and 61 to 88= Severe burden. This tool has good reliability and validity.

iii) WHO-Quality of Life-bref-(26 items,WHOQOL-field trial version, 1996):This tool is developed by World Health Organization in 1996. It comprise 26 items and measures four domain namely, i)Physical domain ii) Psychological domain iii) Social domain iv) Environmental domain.

Operational Definition of Severe Mental Illness: In this study, 'severe mental illness' defined as person having either schizophrenia or bipolar affective disorder (as per ICD-10 diagnostic criteria) and duration of the illness is minimum two years.

Procedure: Initially caregiver was explained about the purpose of the study. After getting consent form from caregiver,
above mentioned tools were administered individually.

Statistics: SPSS is used for data analysis. Mean, frequency, percentage of variables are calculated. Person correlation also used to understand the relationship among variables.

RESULT AND DISCUSSION

Table No.1: Frequency and Percentage of Age, Gender and Domicile

Age	**Frequency**	**Percent**
18 to 30 yrs	3	7.5
31 to 40 yrs	7	17.5
41 to 50 yrs	12	30.0
51 to 60 yrs	6	15.0
61 and above	12	30.0
Total	40	100.0
Gender		
Male	22	55.0
Female	18	45.0
Total	40	100.0
Domicile		
Rural	16	40.0
Urban	24	60.0
Total	40	100.0

Findings (table-1) shows that most of the caregiver were aged between 41 to 50 yrs (30%) and 61 and above years (30%). Findings also show that in the present sample 55% of male and 45% of female are taking care of severely mentally ill person in the family. More caregivers are residing in urban area (60%) then in rural area (40%).

Table No.2: Frequency and Percentage of Education, Occupation and SES

Education in year	**Frequency**	**Percentage**
0 to 5 yrs	14	35
6 to 9 yrs	10	25
10 and above	16	40
Total	40	100
Occupation	**Frequency**	**Percentage**
Farmer	4	10.0
Service/ job	6	15.0
Business/ self employed	3	7.5
Daily wager	12	30.0
Others e.g.home maker, retired, student	15	37.5
Total	40	100.0
Socio-economic strata	**Frequency**	**Percentage**
Low SES	33	82.5
Middle SES	7	17.5
High SES	0	00
Total	40	100.0

Above mentioned table findings show that 35% of caregivers has attended school up to 5 std. 25% studied between 6 to 9std and 40% caregivers has studied 10th or higher than that. Findings also show that majority of caregivers in present study are home maker, house wife, retired person or student. 30% caregivers are working as daily wager and 15% are doing private job or are in service. Very few caregivers are self employed or have their own business(7.5%) and few 10% caregivers are working as farmer(10%) .

Findings also show that majority of caregivers belongs to lower socio-economic strata (82.5%). 17.5% caregivers belongs to middle SES. However there is no caregiver belonging to higher SES reported in present study.

Table No.3: Frequency and percentage of marital status and family type

Marital Status	**Frequency**	**Percentage**
Married	29	72.5
Single	3	7.5
Divorced/ separated	1	2.5
Widow/ widower	7	17.5
Total	40	100.0
Family Type		
Nuclear family	27	67.5
Joint family	11	27.5
Extended family	2	5.0
Total	40	100.0

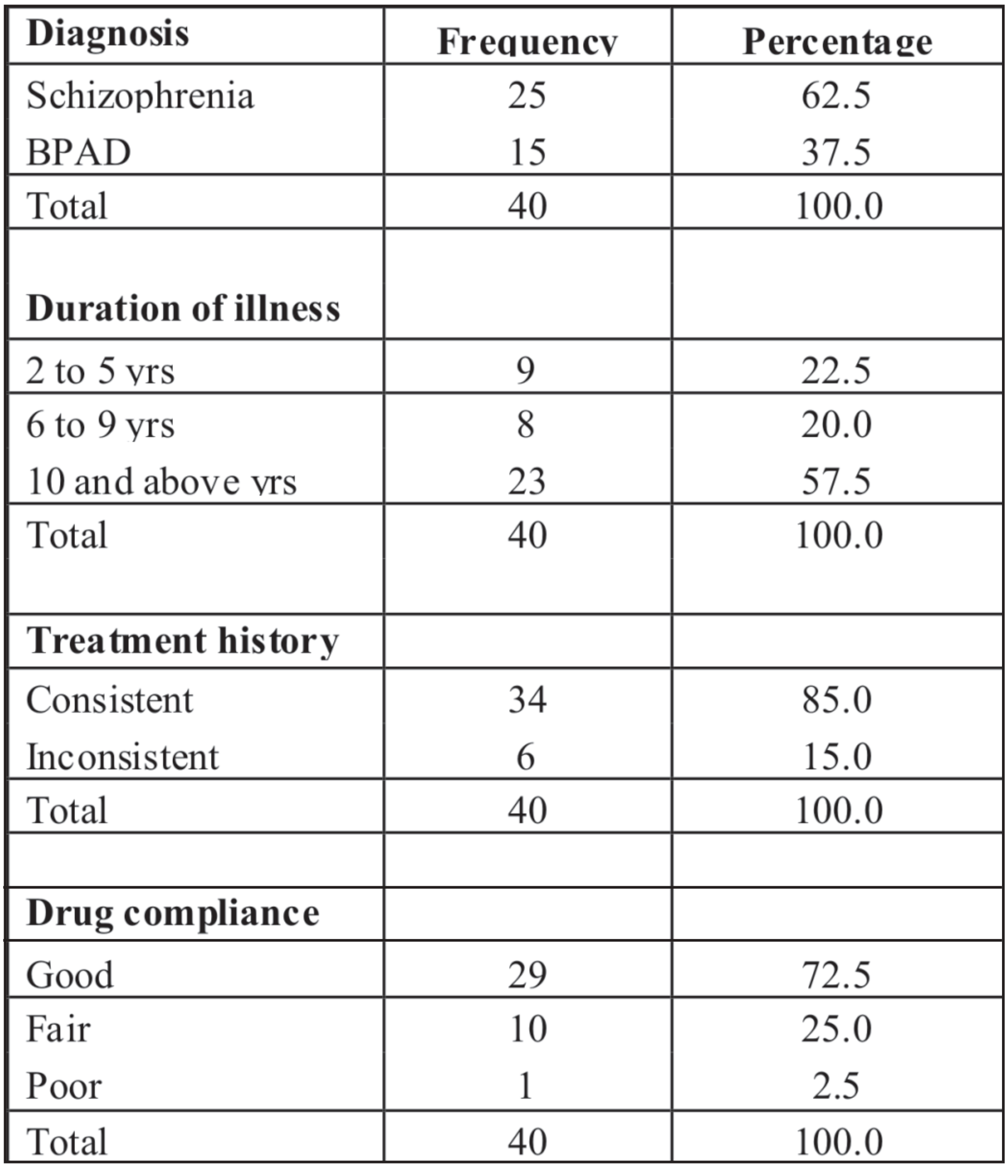
Finding on table-3 shows that majority of caregivers are married (72.5%), and several caregivers are widow/widower (17.5%). More caregivers are staying in nuclear family (67.5%) than joint family (27.5%). However few caregivers are staying with extended family (5%) also.

Table No. 4: Caregiver's relationship with person with severe mental illness

Caregiver's relationship	**Frequency**	**Percentage**
Mother	10	25.0
Father	7	17.5
Husband	6	15.0
Wife	4	10.0
Sister	2	5.0
Brother	4	10.0
Son	4	10.0
Daughter	2	5.0
Others (relative, neighbour, professional care taker	1	2.5
Total	40	100.0

When we look at the caregivers relationship with mentally ill person, findings on table-4 show that majority of caregivers are primary, immediate family members like parents and spouse. In present study also we can see that mother (25%), father (17.5%), Husband (15%) and wife (10%) are main caregiver. Very few caregivers are sibling (brother-10%, sister-5%) or children (son-10%, daughter-5%).

Table No. 5: Frequency and percentage of diagnosis, duration of illness, treatment historyand drug compliance.



Diagnosis	**Frequency**	**Percentage**
Schizophrenia	25	62.5
BPAD	15	37.5
Total	40	100.0
Duration of illness		
2 to 5 yrs	9	22.5
6 to 9 yrs	8	20.0
10 and above yrs	23	57.5
Total	40	100.0
Treatment history		
Consistent	34	85.0
Inconsistent	6	15.0
Total	40	100.0
Drug compliance		
Good	29	72.5
Fair	10	25.0
Poor	1	2.5
Total	40	100.0

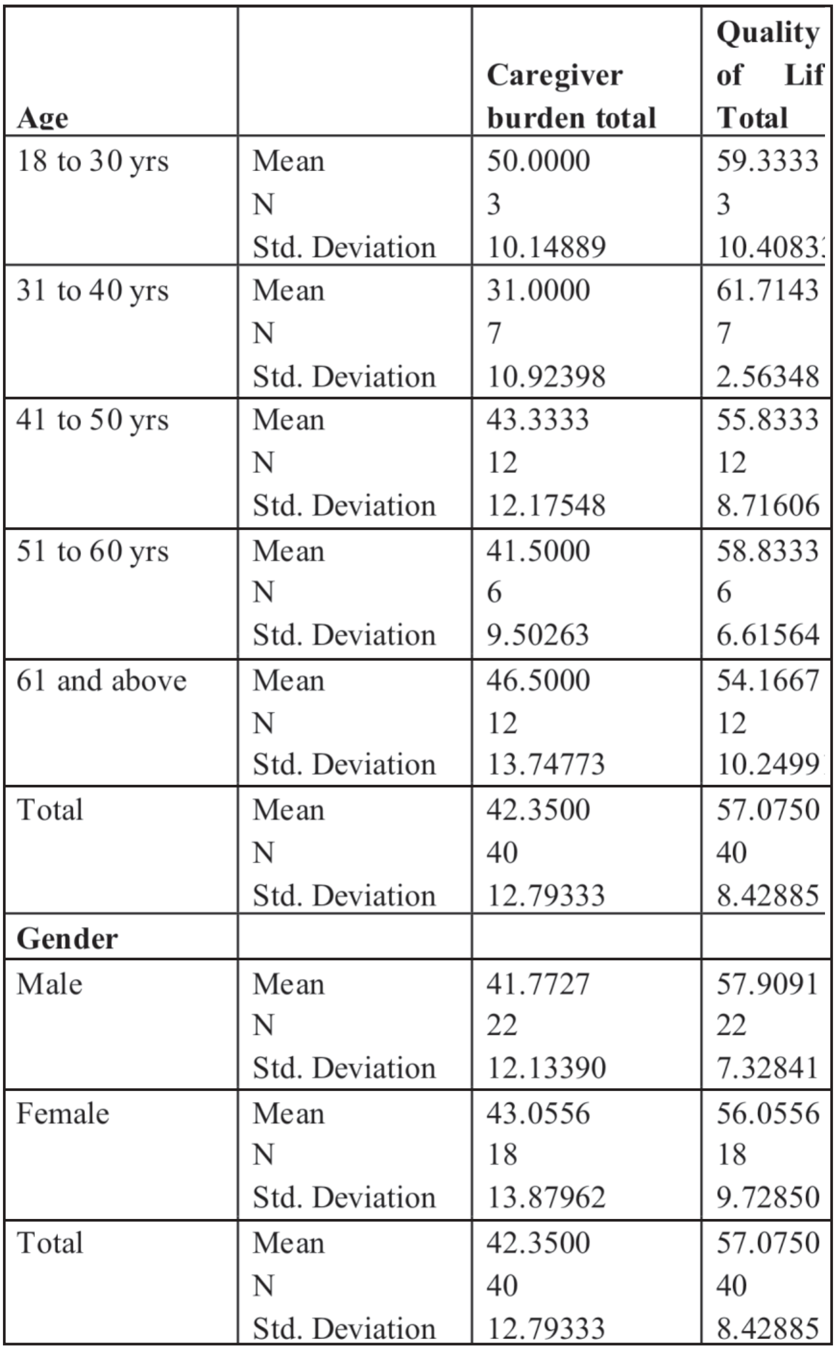
Above mentioned table shows details about caregiver's relative who is mentally ill and they are taking care of these person. This table illustrate mentally ill person's diagnosis, duration of illness, treatment and drug compliance. Findings on table -5 show that majority of severely mentally ill person are suffering from schizophrenia (62.5%) and 37.5% has bipolar affective disorder. Findings also show that majority of them has illness for 10 or more years (57.5%) and 85% of them are consistent in treatment and 72% shows good drug compliance

Table No. 6: Mean of Caregiver Burden and Quality of LifTable-6 shows mean score of caregiver burden and Quality of Life.

	N	**Minimum**	**Maximum**	**Mean**	
Caregiver burden total	40	11.00	64.00	42.3500	12.9333
Quality of Life Total	40	39.00	73.00	57.0750	8.42885

Finding shows that mean score for caregiver burden is 42.35 and for Quality of Life, the mean score is 57.07. These findings indicate that overall caregiver experience moderate to severe level of burden and have relatively lower quality of lifee

Table No. 7: Mean of Caregiver burden total, Quality of Life Total * Age, Gender



Age		Caregiver burden total	Quality of Lif Total
18 to 30 yrs	Mean N Std. Deviation	50.0000 3 10.14889	59.3333 3 10.4083
31 to 40 yrs	Mean N Std. Deviation	31.0000 7 10.92398	61.7143 7 2.56348
41 to 50 yrs	Mean N Std. Deviation	43.3333 12 12.17548	55.8333 12 8.71606
51 to 60 yrs	Mean N Std. Deviation	41.5000 6 9.50263	58.8333 6 6.61564
61 and above	Mean N Std. Deviation	46.5000 12 13.74773	54.1667 12 10.2499
Total	Mean N Std. Deviation	42.3500 40 12.79333	57.0750 40 8.42885
Gender			
Male	Mean N Std. Deviation	41.7727 22 12.13390	57.9091 22 7.32841
Female	Mean N Std. Deviation	43.0556 18 13.87962	56.0556 18 9.72850
Total	Mean N Std. Deviation	42.3500 40 12.79333	57.0750 40 8.42885

In above mentioned table-7, findings show that younger age caregiver (18 to 30 yrs.) experience highest caregiver burden (mean=50) and older age group caregiver (61 and above yrs.) experience lowest quality of life (54.16). However caregiver in the age group of 31 to 40 years has comparatively lower burden (mean=31) and better quality of life (mean=61). When we compare the mean of caregiver burden and QoL with gender, female experience slightly higher burden camper to male (Female- CB-43.05, Male-CB-41.77) and male caregiver has little better quality of life then female caregiver (male-57.90, female-56.05).

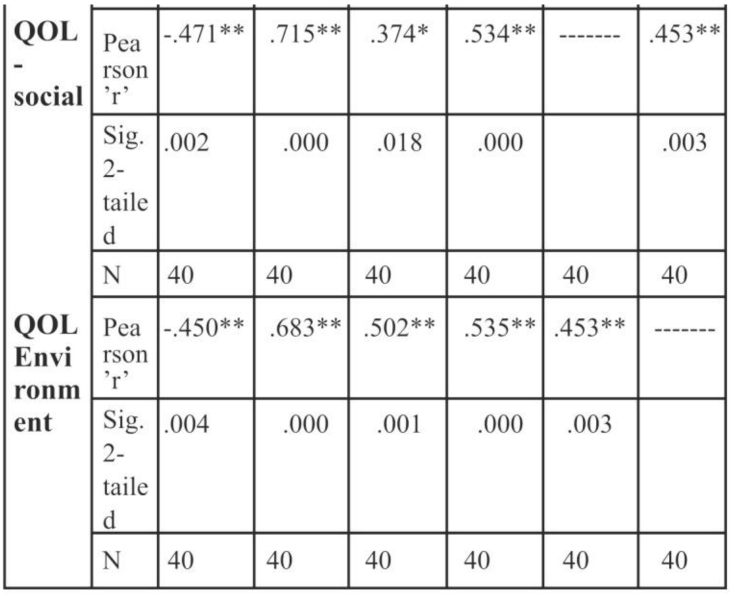
Table No. 8: Mean of Caregiver burden total, Quality of Life Total * Family type

Family type		**Caregiver burden total**	**Quality of Life Total**
Nuclear family	Mean N Std. Deviation	43.6296 27 14.18327	55.9630 27 9.15458
Joint family	Mean N Std. Deviation	41.1818 11 9.26087	58.4545 11 6.34608
Extended family	Mean N Std. Deviation	31.5000 2 .70711	64.5000 2 4.94975
Total	Mean N Std. Deviation	42.3500 40 12.79333	57.0750 40 8.42885

Findings in above mentioned table-8 shows that caregiver residing in nuclear family have higher burden experience compare to care giver living in joint or extended family. And when we look at quality of life, caregiver belonging to extended family enjoys much better quality of life compare to caregiver living in nuclear or joint family. This difference could be due to that in nuclear family there may be very little support available for caregiver and he/she might be burden with other family responsibility too. This could be possible reason for them to have higher caregiver burden. In extended family, however caregiver may have additional family support or help available which might resulted in their better adjustment and coping and thus them having lower burden in caregiving and better quality of life compare to other caregivers.

Table No. 9. Correlation between caregiver burden and quality of life

		CB total	**QOL Total**	**QOL-Phy.**	**QOL-Psy.**	**QOLSocial**	**QOL Environ.**
CB total	Pearson ’r’	–	-.653**	-4.33**	-559**	-471**	-450**
	Sig. 2-tailed		.000	.005	.000	.002	.004
	N	40	40	40	40	40	40
QOL Total	Pearson ’r’	-.653**	-----	.801**	.821**	.715**	.683**
	Sig. 2-tailed	.000		.000	.000	.000	.000
	N	40	40	40	40	40	40
QOL -Phy.	Pearson ’r’	-.433**	.801**	----	.735**	.374**	.502**
	Sig. 2-tailed	.005	.000		.000	.018	.001
	N	40	40	40	40	40	40
QOL -Psy.	Pearson ’r’	-.559**	.821**	.735**	-------	.534**	.535**
	Sig. 2-tailed	.000	.000	.000		.000	.000
	N	40	40	40	40	40	40



QOL - social	Pearson 'r'	-.471**	.715**	.374*	.534**	-------	.453**
	Sig. 2-tailed	.002	.000	.018	.000		.003
	N	40	40	40	40	40	40
QOL Environment	Pearson 'r'	-.450**	.683**	.502**	.535**	.453**	-------
	Sig. 2-tailed	.004	.000	.001	.000	.003	
	N	40	40	40	40	40	40

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Findings on table -9 show correlation between caregiver burden and quality of life. Findings indicate that caregiver burden is significantly negatively related to quality of life total score as well as with all the domains of QOL. Findings show that higher the caregiver have burden, his quality of life becomes lower or poorer. And when the caregiver burden is low then caregiver's quality of life is higher or better. Findings also show that all the domains of WHO-QOL, namely i) Physical domain, ii) Psychological domain iii) Social domain and iv) Environmental domains are negatively but significantly correlated with caregiver burden. This finding is in support with earlier research that higher caregiver burden has adverse impact on quality of life of caregivers. Alejendra et al(2009) reported that Decreased QOL may be associated with caregivers' burden, lack of social support, course of the disease and family relationships problems. In addition, in developing countries, QOL is affected by caregivers' economic burden.

Findings on correlation among various domains of quality of life show that all the domains are significantly positively correlated with one another that is when caregiver has good physical health he also enjoys better psychological health, better social support and has more healthy environment. All the domains are significantly positively correlated (significant at 0.001 level)with total score of Quality of life.

TableNo.10: Correlation between degree of burden and QOL

		Degree of burden	QOL Total	QOL-Phy.	QOL-Psy.	QOLSocial domai	QOL Environt.
Degree of burden experienced	Pearson ’r’	-----	-.634**	-.468**	-.496**	-.422**	-
	Sig. 2-tailed		.000	.002	.001	.007	.005
	N	40	40	40	40	40	40
QOL Total	Pearson ’r’	-.634**	----	.801**	.821**	.715**	.683**
	Sig. 2-tailed	.000		.000	.000	.000	.000
	N	40	40	40	40	40	40
QOL hy.	Pearson ’r’	-.468**	.801**	-----	.735**	.374*	.502**
	Sig. 2-tailed	.002	.000		.000	.018	.001
	N	40	40	40	40	40	40
QOL Psych	Pearson ’r’	-.496**	.821**	.735**	-------	.534**	.535**
	Sig. 2-tailed	.001	.000	.000		.000	.000
	N	40	40	40	40	40	40
QOL-Social domain	Pearson ’r’	-.422**	.715**	.374*	.534**	------	.453**
	Sig. 2-tailed	.007	.000	.018	.000		.003
	N	40	40	40	40	40	40
QOL-Environmental domain	Pearson Correlation	-.436**	.683**	.502**	.535**	.453**	-------
	Sig. 2-tailed	.005	.000	.001	.000	.003	
	N	40	40	40	40	40	40

Findings on table 10 show correlation between degree or severity of caregiver burden and quality of life. Result shows that degree or severity of caregiver burden has significantly but negatively correlated with quality of life (significant at 0.01 level).. These finding indicates that higher or severe the burden experienced by caregiver, his quality of life decreases.

CONCLUSION

It can be concluded from the present study that caregiver who experience higher burden, have lower Quality of life and caregiver aged 61 and above, residing in nuclear family and being a female gender have higher caregiver burden and relatively lower quality of life. Findings also indicate that caregiver burden have significant negative correlation with all the major aspects of quality of life that is physical, psychological, social or environmental.

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