

Burden and Quality of Life among Care Givers of Persons with Alcohol Dependence Syndrome - A Hospital based Interventional Study

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Abstract:

Back ground: Alcoholism is a disease which can affect not merely the alcohol dependent person but also his family. It can have a devastating effect on the entire family system. It adversely influences the emotional climate, identity, tasks and relationship of the family. Family interventions can help caregivers to recover from the trauma of negative consequences of substance use, as reported by earlier studies.

Aim: To assess the change in family burden and quality of life among the care givers of Persons with Alcohol Dependence Syndrome (PWADS), following Social Group Work Intervention (SGWI).

Methodology: A quasi experimental research design was used and an experimental group which received SGWI consisting of 25 care givers of PWADS and a control group of 25 care givers of PWADS who did not receive SGWI were compared. Follow up was done for 6 months. Sample was drawn from de-addiction centre of Dr. A V Baliga Memorial Hospital- Udupi, Karnataka and Dept of Psychiatry, KMC-Manipal University, and Manipal, Karnataka. The outcome measures were Family burden and Quality of life, which were assessed pre and post interventions using Family Burden Interview Schedule (FBIS) and WHO Quality of Life Scale (QOL) respectively. SGWI Module with different components was devised in consultation with the subject experts and after reviewing the literature.

Results: Mean age of Care givers was 39 years. Majority of care givers were female, married and home makers, hailing from lower socio economic status. The results revealed that, there is drastic reduction in care giver's burden after SGWI in experimental than the control group. Improvement in quality of life in experimental group after SGWI was maintained till the last follow up.

Conclusion: SGWI to caregivers helps in reducing the caregiver stress & burden caused by behaviours of PWADS and improves their quality of life.

Key Words: Persons with alcohol dependence syndrome, Caregivers, Social group work intervention, Family burden, Quality of life.

Running head: Burden and QOL among Care Givers of Persons with ADS

Conflict of interest: None

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I. INTRODUCTION

Alcohol is a major risk factor for burden of mortality and disability of disease and injury (Rehm et al., 2003a;2004). In total, 3.2% of deaths and 4.0% of the burden of disease as measured in disability adjusted life-years (DALYs) (Lopez et al., 2006) in the year 2000 was attributable to alcohol (WHO, 2002).

In India the estimated number of Alcohol users in 2005 were 62.5 million, out of them 10.5 million being dependent users (17.40%) and 20 -30 % of hospital admissions are due to Alcohol related problems (Girish et al, 2010 - NIMHANS). Nearly 30 – 35 % adult males and 5% of adult females are regular users of Alcohol, (Benegal et al, 2003 – NIMHANS).

Alcohol dependency is a disorder which affects not merely the PWADS but the members of the dependent's family or the care givers as well. The requirement of caring for any type of emotionally ill persons have both a mental and practical stress on the caregiver (Chakrabarti et al 1995; Provencher 1996) these have

been explained and specified by concepts of objective and subjective burden (Hoenig& Hamilton 1966). The reality that the disorder leaves a varying degree of impairment in the patient (De Jong et al 1985) and leads to disturbed behavior, hence management is associated with a severe burden in caring (Chakrabarti et al 1995; Gautam&Nijhawan 1984). As the PWADS becomes less predictable, less reliable, care givers lose self-confidence and isolate from external contact to protect themselves from further embarrassment. They suffer from monetary problems more over emotional problems like embarrassment, guilt, hurt, anger, frustration, loneliness, fear, hopelessness and grief. An individual's alcohol indulgence makes the family go through intense psychological suffering (Gururaj&Prathimamurthy, 2011).The traditional role of the family do change and the families are damaged socially, financially, emotionally and become dysfunctional (ShanthiRanganathan, 2000).

Any disorder unfavorably affects the person as well as their family members in the area of emotional, financial, and physical distress, and occupational and social dysfunction. This causes difficulties, problems or unfavorable events with direct effect on lives of the immediate family. Burden has been described by adverse impact. In the family of a PWADS, most of the areas of family life will be affected, *e.g.*, interpersonal, social relationships, finances and leisure time activities. Substance dependency often leads to conflicts; ill effects and burdens family members. The burden is more often related to disruptive activities of the PWADS, due financial crises. The families of PWADS, especially the life partner, have high risk of hardship in life, physical and emotional disorders, and more use of medical health care services. (Surendra Kumar Mattoo, et al, 2012).

Family members' quality of life is adversely affected due to burden/ disruptive behaviors of PWADS. Studies show, significant betterment in quality in life of family members' during the 12-month period after treatment is initiated. The betterment in quality of life is attributable to treatment and PWADS abstinence duration, (Hans Joachim,et al, 2012).

Working with PWADS is a challenging task. Frequent lapse and relapse contribute to care givers negative attitudes and therapeutic nihilism. One often faces the problem of dealing with any stigmatizing and self limiting illness. Expectations of the therapist and care givers should be from total abstinence to prolonged period of abstinence combined with enhanced quality of life and physical, psychological, social, financial, spiritual functioning which reduces burden.

There is paucity of studies in India which deal with interventions focusing the caregivers of PWADS and this study intends to assess the changes in family burden and quality of life among the care givers of PWADS, following SGWI.

II. MATERIALS & METHODS

2.1 Research Design:

This is a longitudinal study, which adopted a research design as quasi-experiment, comprising a control and an experimental group.

2.2 Setting & Sample:

The study was conducted at de-addiction centre, Department of Psychiatry, KMC Hospital, Manipal, and Dr. A. V. Baliga Memorial hospital, Udupi, Karnataka. The sample comprised of 50 caregivers of PWADS, seeking de-addiction treatment in these centres and those willing to participate in the study.

2.3 Ethical issues:

Confidentiality was assured and maintained by the researcher.

2.4 Inclusion Criteria: The researcher obtained approval from both the centres. Informed consent was taken from caregivers as well as PWADS

- Care givers being immediate family member of PWADS, who were hospitalized for de-addiction treatment
- Care givers aged between 18-60 years
- Consenting to participate in study and willing to come the next 6 months for follow up
- Not having any other psychiatric disorders and major cognitive impairment and substance abuse except tobacco.

2.5 Sampling:

- A sample of 25 care givers of PWADS was selected from the purposive pre-identified population of alcohol dependents, who were looking for de-addiction treatment. They were given SGWI and assessed before SGWI and assessed after 1st, 3rd & 6th month. These subjects formed the "Experimental Group".
- Those who were not willing to be in the experimental group, (not willing for SGWI) but willing to come for follow up were included in the control group. This group received pharmacological treatment and/or given regular hospital intervention as usual (regular counselling, one family meeting, and group activities). This group was not exposed to SGWI. These were assessed at base line, 1st, 3rd & 6th month after discharge.

2.6 Social Group Work Intervention package:

SGWI consisted of 5 sessions conducted in a week by the researcher. Each group consisted of 5 – 10 family members, preferably speaking the same language. Each session lasted for duration of 45 minutes to an hour. The SGWI imparted information in the area of:-

- Alcoholism as a disease
- Co-dependency, burden on family & remedies
- Role of family in de-addiction
- Handling of emergencies/crises
- Importance of medication and follow ups

2.7 Tools Used for assessment:

- Socio demographic Performa: A detailed questionnaire schedule covering social, economic and psychosocial characteristics of the PWADS and their care givers.
- Quality of Life Scale (QLS) (WHOQOL, 1996): The WHOQOL contains a total of 26 questions allows detailed assessment of each individual facet relating to quality of life.
- Family burden Interview schedule (Pai and Kapur, 1981): This interview schedule comprising twenty four items grouped under six areas was used for assessing the family burden perceived by the caregivers.

2.8 Data Collection:

Data was collected through semi- structured interview method from caregivers. Discussion with the experts and participatory observation were also used for gathering information. The scales were administered at base - line and at follow up for both the groups.

2.9 Statistical Analyses:

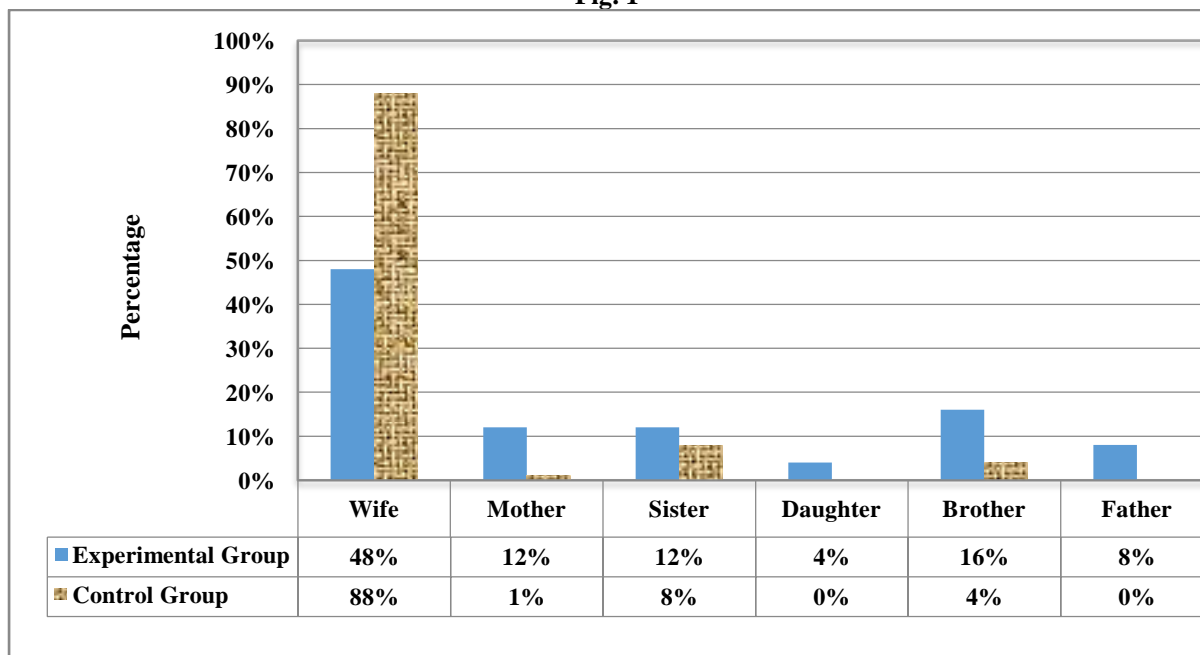
SPSS 16 version was used for statistical analysis. Repeated measures ANOVA with generalized estimating equation and two-way Friedman’s test used in view of skewed distribution of the data.

III. RESULTS

The total number of subjects were 50 caregivers of PWADS, out of which experimental and control group comprised of 25 subjects in each group.

Socio-Demographic profile

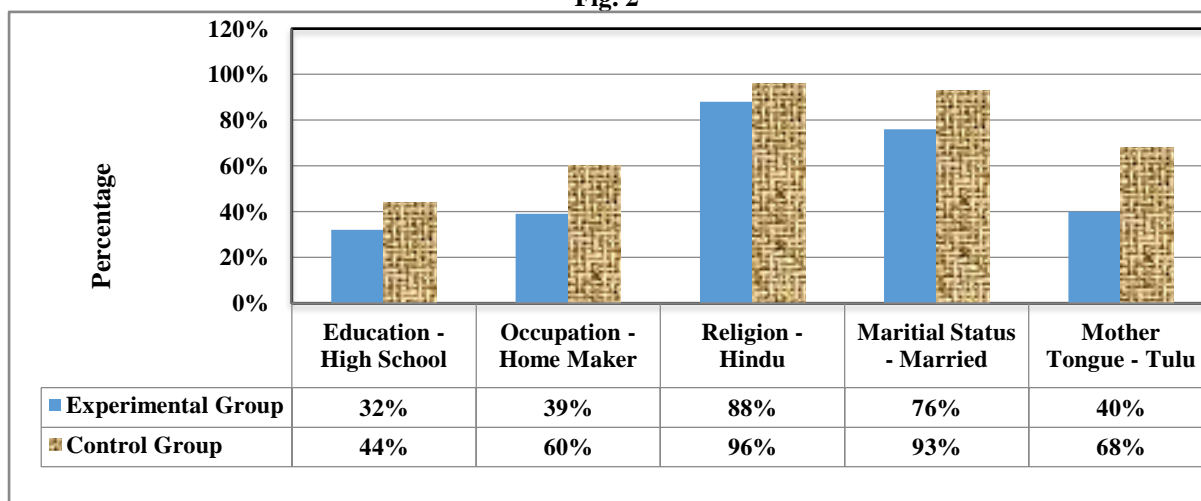
Fig. 1



Relationship Distribution

Fig. 1 shows majority of care givers were female, mostly wives 48% from experimental and 88% from control groups respectively.

Fig. 2

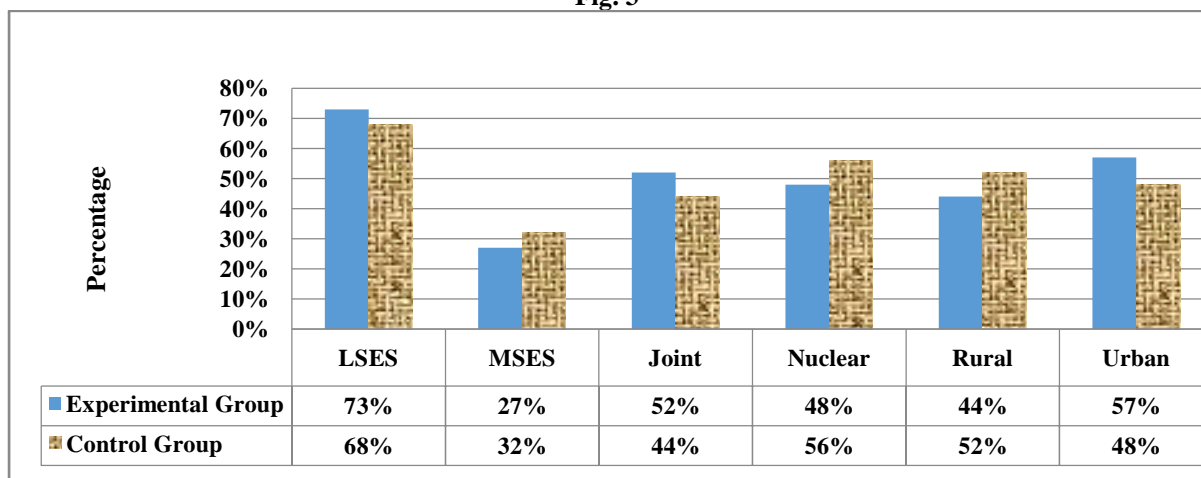


Socio – Demographic Details

Fig. 2 shows maximum numbers of caregivers are educated up to high school, i.e. 32% in experimental Group and 44% in control group. 39% & 60% caregivers are homemakers and 88% & 96% caregivers are Hindus from both the groups respectively. Majority of the caregivers, i.e. 76% & 93% are married. Majority of caregiver’s mother tongue is Tulu (local language), i.e. 40% & 68% in both groups respectively. 36% & 28% of caregivers in experimental & control group speak Kannada (state language).

Fig. 2 - socio demographic profile shows statistically significant difference (p<0.001)

Fig. 3



Socio – Demographic Details (Cont...)

Fig. 3 shows caregivers come from lower and middle socio economic status (p<0.465). Their living arrangements were almost equally distributed in joint and nuclear families (p<0.228). They hail from rural and urban areas (p<0.227).

Fig.3 shows no significant difference between groups.

TABLE 1: Family Burden Interview Schedule

Descriptions		Dimensions						
		FBIS -D1*	FBIS -D2*	FBIS -D3*	FBIS -D4*	FBIS -D5*	FBIS -D6*	FBIS -D7*
Pre Test	Experimental Group Mean & SD	7.7+ _{2.3}	6.0+ _{2.0}	4.8+ _{2.4}	5.9+ _{1.6}	1.5+ _{1.4}	1.9+ _{1.3}	1.5+ _{0.5}
	Control Group Mean & SD	8.2+ _{2.9}	7.7+ _{2.3}	5.4+ _{2.6}	5.7+ _{2.2}	2.8+ _{1.3}	2.3+ _{1.2}	1.6+ _{0.5}
	P – Value	P<0.990						

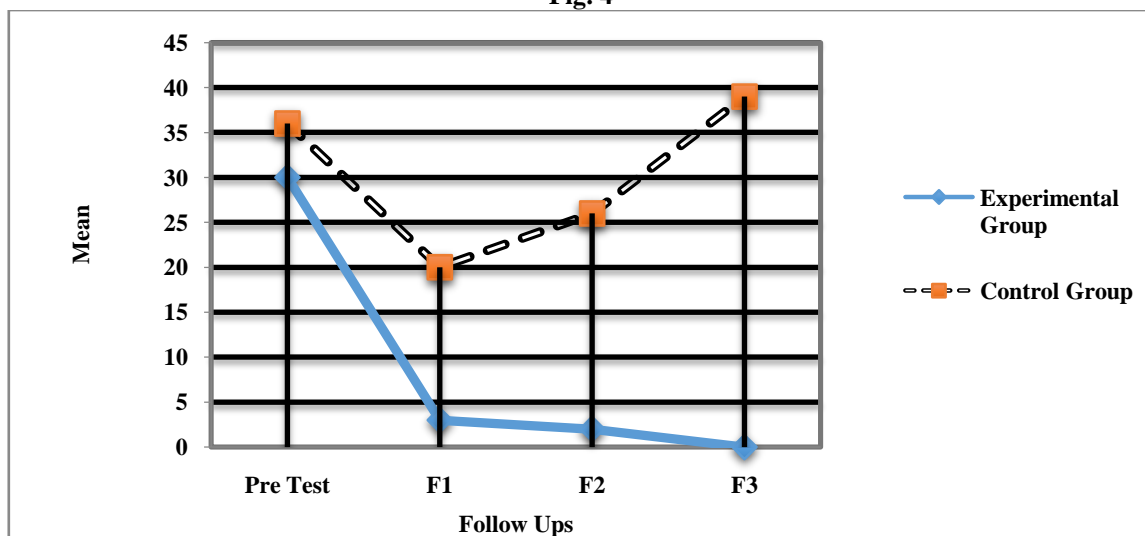
	P<0.05 (b/w gps)	(Not Sign)						
Follo w Up 1	Experimental Group Mean & SD	2.1+_1.9	1.2+_1.7	0.9+_1.2	1.0+_1.5	0.2+_0.6	0.2+_0.7	0.4+_0.5
	Control Group Mean & SD	5.9+_2.9	3.7+_3.1	3.8+_2.5	3.9+_2.2	1.6+_1.3	1.7+_1.1	1.1+_1.0
	P – Value P<0.05 (b/w gps)	P<0.001 (Sign)						
Follo w Up 2	Experimental Group Mean & SD	2.2+_3.3	1.6+_2.5	1.2+_2.4	1.5+_2.5	0.2+_0.6	0.4+_0.8	0.4+_0.6
	Control Group Mean & SD	6.3+_3.6	4.7+_3.7	4.3+_3.3	3.7+_3.1	1.8+_1.6	1.6+_1.5	1.0+_0.8
	P – Value P<0.05 (b/w gps)	P<0.001 (Sign)						
Follo w Up 3	Experimental Group Mean & SD	2.1+_3.7	1.7+_3.1	1.4+_2.9	1.4+_2.8	0.4+_1.0	0.4+_1.0	0.4+_0.7
	Control Group Mean & SD	6.6+_4.6	5.3+_4.3	4.5+_3.5	4.9+_3.7	2.0+_1.7	1.8+_1.6	1.2+_0.9
	P – Value P<0.05 (b/w gps)	P<0.001 (Sign)						

FBIS-D1* - Financial Burden
 FBIS-D2* - Disruption of routine Family Activities
 FBIS-D3* - Disruption of Family Leisure
 FBIS-D4* - Disruption of Family Interaction
 FBIS-D5* - Effect on Physical health
 FBIS-D6* - Effect on Mental health
 FBIS-D7* - Subjective burden
Higher the score, higher the Family Burden

Table 1 depicts the findings of family burden in the area of financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interaction, effect on physical health, effect on mental health and subjective burden.

Base line results (pre test) show no significant difference between experimental and control group $p < 0.99$.
 Follow up 1, 2 & 3 show significant difference between 2 groups $p < 0.011$, $p < 0.001$ & $p < 0.001$ respectively

Fig. 4



Overall distribution of FBIS

Higher the Score, Higher the Family Burden

Fig. 4 shows persistence of increase burden in control group than experimental group with significant difference between groups ($p < 0.005$).

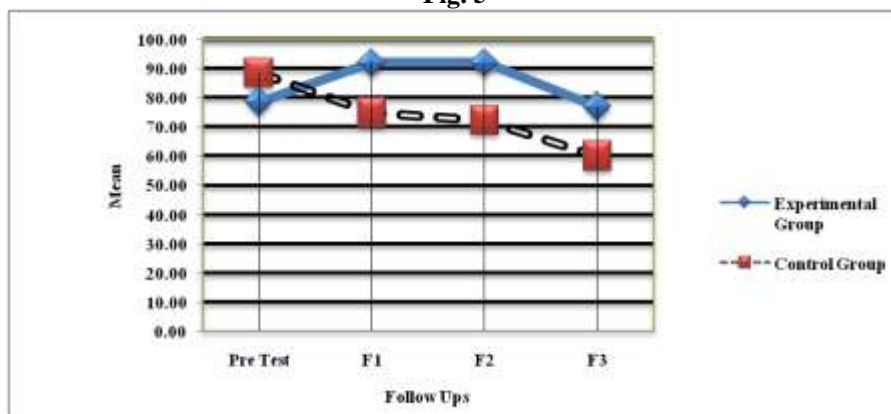
TABLE 2: WHO Quality of Life Scale

Descriptions		Dimensions					
		QOL-D1*	QOL-D2*	QOL-D3*	QOL-D4*	QOL-D5*	QOL-D6*
Pre Test	Experimental Group Mean & SD	2.3+_1.1	2.5+_1.1	21.5+_6.1	16.1+_5.8	9.3+_2.2	26.1+_5.4
	Control Group Mean & SD	2.1+_0.2	2.5+_1.2	19.0+_4.7	13.6+_4.5	9.1+_1.8	25.6+_5.3
	P – Value $P < 0.05$ (b/w gps)	P<0.115(Not Sign)					
Follow Up 1	Experimental Group Mean & SD	3.7+_0.6	3.7+_0.5	27.5+_3.4	23.5+_2.6	11.5+_5.5	30.8+_3.2
	Control Group Mean & SD	2.7+_0.9	2.9+_0.8	22.2+_5.1	18.0+_4.2	9.4+_1.6	25.8+_4.8
	P – Value $P < 0.05$ (b/w gps)	P<0.001(Sign)					
Follow Up 2	Experimental Group Mean & SD	3.8+_0.5	3.7+_0.6	28.3+_3.6	23.3+_3.3	10.2+_2.2	30.5+_3.8
	Control Group Mean & SD	2.6+_1.0	2.8+_0.9	22.1+_5.3	17.0+_5.2	9.0+_1.6	24.8+_4.3
	P – Value $P < 0.05$ (b/w gps)	P<0.001(Sign)					
Follow Up 3	Experimental Group Mean & SD	3.8+_0.8	3.8+_0.7	28.4+_4.5	23.6+_4.4	10.4+_2.4	29.6+_4.7
	Control Group Mean & SD	2.4+_1.3	2.7+_1.3	21.4+_7.5	16.4+_6.9	9.0+_2.02	24.1+_5.5
	P – Value $P < 0.05$ (b/w gps)	P<0.012(Sign)					

QOL-D1* - Quality of Life QOL-D2* - Satisfaction with health status QOL-D3* - Physical health
 QOL-D4* - Psychological Health QOL-D5* - Social Relationships QOL-D6* - Environment
Higher the score, better the Quality of Life

Table 2 depicts the findings on quality of life scale in various domains - the area of quality of life, satisfaction with health status, physical health, psychological health, social relationships, and environment. Base line data (Pre test) show there is no significant difference between two groups ($p < 0.115$). Follow up 1, 2 & 3 show there is significant difference with $p < 0.001$, $p < 0.001$ and 0.012 respectively.

Fig. 5



Overall distribution of QOL

Higher the Score, Better the Quality of Life

Figure 5 shows better quality of life in experimental group than control group with significant difference ($p < 0.026$).

IV. DISCUSSION

Alcoholism is an extensive public health problem around the world (WHO, 2010). There is prevailing agreement that the ill effects of alcohol dependency on the life partners and family members of PWADS are enormous (Rospenda et al 2010). The vastness of the problem in India significantly shows, our country is the second largest populated in the world, out of which 33% of its population is consuming alcohol (Gururaj, 2006).

Disturbances at home, occupational dysfunction, frequent relapses, frequent hospitalizations of alcoholics lead to caregivers stress, forced retirement, role changes, role strain/over load, the distancing from friends and the reduction of social activities, disruption of the usual routine and financial pressure, sources of social support and family rituals. All those changes might lead to limited daily physical and social activities and result in depression and poor QOL in both family caregivers and patients (Miranda et al 2006; Gonçalves&Galera2010).

In the current study the typical profile of the care giver was a female, usually the wife with a mean age of 39 years (SD +_ 11.6) in both groups. In her third decade, with primary to high school education, usually a house wife or engaged in some occupation with daily wages, from urban and rural areas hailing from LSES class. This is consistent with the strong presence of women looking after family members, who were usually wives, mothers, sisters or daughters (Miranda et al 2006; Marcon et al 2012; Mattoo,et al 2013; Senthil& Kiran 2015) found in the literature.

Burden and Quality of life has emerged as an important treatment outcome measure for alcohol dependence whose natural course comprises of remission and relapse. QOL is a multidimensional construct that incorporates the physical, mental, psychological, social and spiritual functioning of the individual. It helps to understand the effects of the disease on the patient (Guyatt et al., 1988) and their caregiver. QOL is an important parameter that provides an insight into how a disorder impacts life of those affected. Among various psychiatric disorders, alcohol- related disorders significantly affect QOL, but this area has not been extensively studied.

In the current study the base line scores on burden in caregivers was quite high and reduced significantly with SGWI, after the first session in almost all domains. However it was noted that there were no further changes in the subsequent sessions and the improvement was maintained till the last follow up with statistically significant difference between groups of $p < 0.001$ at both the follow ups. This finding is consistent with other studies (Swain et al 1997).

Follow up 1 shows great decrease in burden scores in both groups. Follow up 2 & 3 show drastic positive change in experimental group compared to control group with significant difference ($p < 0.001$) between groups. This is in similar with earlier studies (Rospenda, &Minich 2013; Mannelli 2013).

The present study demonstrated that substantial impairment in QOL in all the domain scores before treatment initiation and improvements in QOL of care givers immediately after the first session of SGWI which was sustained till the last follow up. Earlier studies reported similar trends (Marcon et al – 2012; Salize et al 2012; Mannelli 2013).

Several patient related factors could explain the improvement in QOL of care givers: i.e. complete abstinence, effective control of withdrawal symptoms, feedback about damage in liver function tests and other medical complications, enhancement of patient's motivational levels, utilizing patient friendly therapy facilities, nominal charges for the treatment, outpatients consultations services, effective management in psychiatric co morbidity and medical complications and addressing caregiver's issues (stress, marital or family related), family meetings, suggestions about stress busters for care giver using a multi disciplinary approach in a secondary/tertiary care hospital.

This study demonstrates that it is possible to improve quality in life of caregivers with SGWI along with regular pharmacological treatment. The routine participation of caregivers in the treatment plan enhances PWADS to adherence to treatment as well as to continue to work.

V. CONCLUSION

Finding of the present study provides evidence for the positive effect of SGWI in reducing the burden and improving the QOL among caregivers of PWADS.

VI. LIMITATIONS

The study has limited the follow up for only six months period post SGWI. The study has not looked into the co relation of PWADS related factors with the outcome.

Considering the paucity of studies related to this theme, the further follow up with this population is necessary, in order to investigate consequences of lapse/relapses of PWADS and fluctuations in quality of life and family burden in the care givers.

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