

“Association of Burden of care in Caregivers of patients of Schizophrenia & Alcohol use Disorder with Anxiety, depression & quality of life: A cross Sectional Study”

Apoorva Yadav¹, Dr. P.B Behere²

¹Junior Resident of Psychiatry department , Jawaharlal Nehru Medical College, Datta Meghe Institute of Medical Sciences, Deemed to be University,

²Director & Professor, Department of Psychiatry, Jawaharlal Nehru Medical College, Datta Meghe Institute of Medical Sciences, Deemed to be University

Email: ¹apoorva2915@gmail.com, ²pbbhere@gmail.com

Corresponding author's name and address: Dr. Apoorva Yadav

Corresponding author's email id: apoorva2915@gmail.com

Contact number (preferably mobile number) of the corresponding author: 9910775717

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Abstract:

Background: Caregivers have a massive responsibility as they work nearly 365 days of the year but in contrast to these responsibilities there is lack of support given to them due to inappropriate resources. Due to lack of required resources at the community based mental health systems the caregivers are bound to take additional responsibilities and tasks. The most prevalent negative outcome of providing care is the emotional burden leading to symptoms like depression, emotional exhaustion, anxiousness, helplessness and lowered morale

AIM:

1. To assess the severity of burden of care and its association with depression, anxiety and quality of life among primary caregivers of patients with Alcohol Use Disorder (AUD) and Schizophrenia.
2. To compare the burden experienced by primary care givers of patients in both the groups Schizophrenia or Alcohol Use Disorder (AUD)."

Methodology:

Study Design: Cross-sectional, Observational hospital based study **Study Setting:** The research setting is at the Inpatient and outpatient departments of Psychiatry, Acharya Vinoba Bhave Rural Hospital (AVBRH), Sawangi (Meghe), Wardha **Sample Size :** 120. Sample Size comes to 112; therefore round up figure of 120 (60 each of caregivers of Schizophrenia and AUD) will be taken. It was rounded up to 120 because many of the patients may either drop out from the study or refuse to participate midway. The caregivers of the patients will then be subjected to the following questionnaires:

1. The Hospital Anxiety Depression Scale (HADS)

2. (WHOQOL-BREF) SCALE
3. (ZBI) INTERVIEW SCALE
4. Pollack & Perlick Method (Pollack CP et al., 1991)

Clearance from the ethics committee will be obtained. Informed written consent of the patients/caregivers will be taken in local language. Socioeconomic data of the patients will be collected.

Expected results: We will be able to assess at the conclusion of the study whether the caregivers of patients with AUD face a load of treatment is same as or higher or lower than that of patients with schizophrenia. It will address if caregivers have more chances to have a depression, high levels of anxiety and inferior life quality with a high care burden.

Conclusion: We will get to know Burden of caring in Carers of Schizophrenia and Disorder of alcohol use and relations with variables involved viz. Anxiety, Depression and life's quality. This will help in future planning for Research in this area.

Keywords: Burden of care, quality of life, schizophrenia, alcohol use disorder.

INTRODUCTION:

An essential role is carried in terms of overall well being of friends and family as it is the basic unit of society(1). Caregivers have a huge responsibility on their shoulders as they work nearly 365 days of the year but in contrast to these responsibilities there is lack of support provided to them due to lack of resources(2). The caregivers are bound to take extra duties and roles because of the lack of required services in community based mental health systems (3) The most common negative effect of providing care is the emotional stress that contribute to symptoms such as depression, emotional fatigue, anxiety, helplessness and decreased morale (4).

Family burden is very frequently under estimated by health care professionals despite the fact that people who provide care themselves suffer from a lot of, stress frequently(5). Alcohol use disorder (AUD) involves signs such as withdrawal, addiction and craving(6). This disorder may take a huge toll and make a huge difference in the lives of their family members(7). Because such patients are distinctly uncertain and unreliable, it contributes to a lot of tension in their caregivers (8). Unfortunately family faces all kinds of violence's like physical verbal and sexual(9). Schizophrenia refers to cognitive, behavioural and emotional impairment(10) and can lead to continuing disability(11)(11). As a result caregivers do not get the personal space they require and it hinders with their personal freedom(12) Studies conducted previously have reported that caregivers of individuals of schizophrenia have an increased incidence of depression, stress and anxiety(13),(14). Our research will help us to find out the magnitude of the weight

of care among providers of Care of people with AUD and schizophrenia, and their relationship with levels of anxiety, depression and life's quality.

Rationale:

While working in this area, we would be able to establish differences of Quality of Burden in Alcohol Use Disorders and Schizophrenia in care givers. Its relationship with different variables viz. age, sex, occupation status of care givers.

Aim :

- 1.To assess the severity of burden of care and its association with depression, anxiety and quality of life among primary caregivers of patients with Alcohol Use Disorder (AUD) and Schizophrenia.
2. To compare the burden experienced by primary care givers of patients in both the groups Schizophrenia or Alcohol Use Disorder (AUD).

OBJECTIVES:

1. To identify the severity of burden in care givers of Schizophrenia and Alcohol Use Disorders as diagnosed by ICD-10 criteria (WHO 1992).
2. To find whether quality of burden differs in both the groups.
3. To find out whether severity of burden differ in care giver of either sexes.

METHODS:

Cross-sectional, Observational hospital based study

Study Setting: The research setting is at the Inpatient and outpatient departments of Psychiatry, JNMC (AVBRH), Sawangi (Meghe), Wardha.

Sample Size :120

Inclusion criteria for participants:

1. If a diagnosis of schizophrenia or AUD has been made for more than a year in patients chosen for the study
2. Age from 18 to 70 years of age.
3. Care givers who are living for more than 1 year with the patients before the start of the study.
4. Care givers who are intimately involved in patients' overall daily activities
5. Care givers who give written informed consent for their active involvement of the study.

Exclusion criteria for participants :

1. Carer of patients with any psychotic condition other than schizophrenia.
2. Schizophrenia patients with alcohol use.
3. Care givers having any psychiatric illnesses like bipolar mood disorder.
4. Care givers who is not able to deliver response when asked and is unable to give consent.

Sample Size - Sample Size :120

Used formula

$$N = [(Z\alpha + Z\beta)/C]^2 + 3$$

In which

The standard normal deviate for $\alpha = Z_\alpha = 1.96$

The standard normal deviate for $\beta = Z_\beta = 1.282$

$$C = 0.5 * \ln[(1+r)/(1-r)]$$

$$= 0.5 * \ln[1.30/0.70]$$

$$= 0.5 * 0.619$$

$$= 0.309$$

$$\begin{aligned}
 N &= [(1.96 + 1.282) / 0.309]^2 + 3 \\
 &= [3.242 / 0.309]^2 + 3 \\
 &= 109.71 + 3 \\
 &= 112.71
 \end{aligned}$$

For tests of association using bivariate correlations, a moderate correlation between severity of increased load of care with depression, anxiety and life's quality in AUD along with schizophrenia will be deemed significant. In order to find out a moderate correlation ($r = 0.20$), a sample of 113 subjects will give us 90% power to discover that the correlation is significantly different from there being no correlation (i.e. that the correlation would be zero) at the 0.05 level.

Sample Size comes to 112; therefore round up figure of 120 (60 each of caregivers of Schizophrenia and AUD) will be taken. It was rounded up to 120 because many of the patients may either drop out from the study or refuse to participate midway.

METHODOLOGY:

120 caregivers of Schizophrenia and Alcohol use disorder will be enrolled in study between the year January 2021-June 2022, If the patient has more than one year of history of Schizophrenia or Alcohol use disorder. Caregiver is intimately involved in patients daily activities.

Caregivers will be put to the following caregiver burden questionnaires and will be scaled accordingly.

1. HADS scale
2. Quality of life scale by WHO-BREF
3. ZBI interview scale for burden
4. Pollack & Perlick Method (Pollack CP et al., 1991)

Assessment tools :-

1. **The Hospital Anxiety Depression Scale (HADS)** : This scale is used to evaluate depression and anxiety in hospital. The scale contains 14 items with two subscales which further have 7 questions each. It tells us symptoms over the past 1 week. The odd number items measure levels of anxiety and even number items measure depression. The reply to every question ranges from zero till four. Summed up score are from 0 to 21 in every subscale. If the score is on the higher level then it means that the symptoms are chronic. 0-7 sub score indicates that there are no symptoms present, 8-10 indicates borderline and 11-21 indicates case of anxiety or depression.
2. **Zarit Burden Interview**: Contains total of 22 items. For every response the carer gives the range varies from 0 to 4. The total score which can be made possible using the scale is between 0 to 88. If the scores come to be on the higher side then it reflects high burden which is experienced by the carers. Subsequently if the score ranges from 0 to 20 then it shows very less amount of burden or no burden at all. A score between 21-40 reflects mild to moderate load experienced by caregivers and 41-60 means in between moderate to severe and at last 61-88 represents severe levels of load.

WHOQOL-BREF SCALE: It is questionnaire with 26-item, which measures quality of life in last two weeks. It mainly has 4 categories in which it measures the quality of life which are physical health (seven items), psychological health (six items), social relationships (three items) and environmental health (eight items). For overall quality of life and general health, it also consists of two other elements. Each item on the scale is scored from 1 to 5; to calculate a raw score in each category, the scores of items for each domain are added. If the score is on the higher side then it means that the quality of life is high.

Pollak&Perlick (1991) Method: In this method, The carer is the one who satisfies at least 3 of the following 5 criteria:

1. Husband or wife, mother or father or someone who is equally involved in patient's life as the parents or spouse.
2. Most regularly in contact with the patient.
3. Monetarily supports the patient.
4. Who is involved actively and on frequent basis with the treatment of the patient.

STATISTICAL ANALYSIS :

Descriptive statistics will be examined with SPSS version 17.0 software. Continuous variables will be presented as mean \pm SD. Categorical variables will be expressed as frequencies and percentages. The Pearson's chi-square test or the chi-square test of association will be used to determine if there is a relationship between two categorical variables. Spearman/Pearson correlation will be used between the correlation between severity of caregiver burden with depression, anxiety and overall life's quality in AUD and schizophrenia patients. Normally distributed continuous variables will be compared between the groups (caregivers with low and high burden) by the use of unpaired t test and The Mann-Whitney U test will be taken only for the variables which are not distributed. $P < 0.05$ will be considered statistically significant.

OUTCOMES/RESULTS:

We would be able to assess at the conclusion of the study whether the caregivers of patients with AUD face a load of treatment equal to or more or less than that of patients with schizophrenia. It will discuss whether caregivers with a heavy care burden have more chances of depression, anxiety and poor life quality.

DISCUSSION: In 1995, Morris et al and Shulz discovered that behavioural issues add to the workload of caregivers and this can lead to high levels of stress in caregivers (15). In their reports, Gilleard et al, O'Connor et al have also clarified that failure or total lack of contact can also contribute to a burden on caregivers (16). Hoeing & Hamilton (1966) identified 2 types of burdens, namely Subjective and Objective Burden, further divided into Type 1 and Type 2 burdens, in which type 1 was divided into type 1 and type 2 burdens.

Hoeing & Hamilton (1966) identified 2 types of burdens, namely Subjective and Objective Burden, further divided into Type 1 and Type 2 burden, in which Type 1 burden was a 3-point s

cale and was used to rate certain areas of family life, while Type 2 burden was a 4point scale and was assessed based on the occurrence of certain particular characteristics in patients (17). According to a study done by Mc Williams S. in 2007, he discovered that, in terms of information interpreted by caregivers when psychoeducating them, there are discrepancies dependent on gender. It was found in the study that in contrast to their male counterparts, female caregivers represent better information (18). In 1978, Gilhooly discovered that male caregivers have a more realistic approach to caregiving and can adopt behavioural care well. (19) Another 2001 study by Angermeyer et al stated that symptoms such as insomnia, easy weariness and pain were the most common effects of caregivers who were mainly parents of patients in some areas such as the neck and shoulder (20). A research carried out by Birchwood and Cochrane on 90 families of individuals with schizophrenia found that 38% of these families' caregivers experienced stress at 'pathological level' largely due to the actions of individuals (21). A study of around 1000 informal caregivers of patients with different health conditions showed that nearly half of these caregivers felt they would be less satisfied if anyone else were granted their responsibility (22). A number of related studies were reported (23-25). Sandhu and Nagrale conducted computed tomography evaluation of brain in chronic alcoholics (26). Studies on Innovation in Community Psychiatry for the Delivery of Mental Health Services were reported (27, 28).

Key results: At the end of the study we will be able to ascertain whether the carers of patients having AUD undergo care giving burden as much as that of carers of subjects having schizophrenia. It will answer whether carers having increased burden of care are more susceptible to depression, levels of anxiety and inferior life's quality.

LIMITATIONS:

1. A cross-sectional design of study.
2. Sample size not being too huge.
3. Study will be conducted in the hospital so it will only take patients from one centre only.

CONCLUSION: At the end of the research, as diagnosed by ICD10 criteria (WHO 1992), we will be able to classify the burden levels in carers of schizophrenia and Alcohol Use Disorders and whether burden consistency varies in both categories. We would also be able to assess if the magnitude of the burden differs between caregivers of both sexes.

ETHICAL OR OTHER IMPLICATIONS:

1. All participants will be assured confidentiality. Participants will be required to give a written, informed consent before taking part in this study. They will be informed of their opportunity to withdraw consent at any time, thereby being excluded from the study.
2. The participants will be told the aims of study and samples will be taken on a voluntary basis
3. Clearance by the ethics committee will be obtained from the Institutional ethical committee.

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