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A qualitative study on the needs of care givers of patients with alcohol related delirium tremens

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Abstract

Alcohol Dependence Syndrome (ADS) is known to affect the individual and the family as well. Several studies have highlighted the impact of family members who provide care to individuals with chronic or disabling conditions are at risk of developing emotional, mental, and physical health problems. There is a paucity of literature when it comes to the needs of the care givers for persons with ADS. The current study aimed to explore the psycho-social needs of care givers of patients with Delirium Tremens (DT) from India. The study is registered in the Clinical Trials Registry of India (CTRI/2015/02/005564). Following consent, twenty five caregivers whose family member was undergoing treatment for Alcohol withdrawal DT at the Centre for Addiction Medicine, NIMHANS, participated in this qualitative explorative study. The interviews were audio recorded and later transcribed. Data analysis was performed using the General Inductive Approach which generated five themes: management of illness; follow up services; informational needs; personal needs; and miscellaneous. The results indicate that care givers in India have certain needs that must be addressed simultaneously during the treatment of persons with ADT. Knowing that care givers are prone to problems as a result of care giving, care must be taken to identify and address their needs at the earliest.

Keywords: Caregivers, Alcohol Dependence Syndrome, Delirium Tremens, Needs.

Introduction

Family caregivers in India play an important role in the treatment and recovery of the person with mental illness[1]. Patients live with their family members who are involved in their care giving[2]. Care giving an individual with mental illness can result in psychosocial problems to the care givers in the form of financial constraints, lack of social support, and disruption of family functioning, stigma, discrimination, and patients' disruptive behaviour[3]. Research so far has examined family and the family process as a causal entity that affects the client's substance use[4]. Substance dependence is considered as a family disease[5] resulting in significant amount of burden as a result of care giving[6]. Unmet needs of the patients have been found to be significantly related to caregiver burden[7]. Meeting these needs would help in decreasing the burden of family members[8]. However there is a paucity of literature on the needs of care givers of persons with Alcohol Dependence Syndrome in India. Therefore, it is necessary to understand their needs and to develop specific interventions to help reduce caregiver burden[9]. The present study was an attempt to explore the needs of caregivers of patients with Alcohol related Delirium Tremens (ADT) attending a tertiary mental health centre in Bangalore.

Methodology

Ethical statement: This study is part of the initial phase of an ongoing doctoral study titled "Intensive case management for persons with severe alcohol dependence: a feasibility study (Clinical Trials Registry India no: CTRI/2015/02/005564)". The ethical approval for this study was obtained from the institutional Human Ethics Committee. The participants were explained about the study and its procedures and a written informed consent was obtained from all the respondents.

Design: We used a qualitative approach to assess the needs of caregivers as it is useful in tapping a broader range of needs that are specific to the context in which it is used. Studying the needs of caregivers involves probing of sensitive, emotional and personal themes of needs, which is more suited to a qualitative approach[10]. Semi-structured face-to-face interviews were used for data collection and the general inductive approach[11] was adopted for analyzing the data. This approach proposes simple steps in qualitative data analysis, which summarizes large raw textual data into concise results, and establishes clear relationships with research objectives[11].

Setting and participants: The study was carried out at the Centre for Addiction Medicine (CAM), Department of Psychiatry, NIMHANS, Bengaluru, Karnataka, India. Male patients aged ≥18 years to 50 years; diagnosed with ADS as per the International Classification of Diseases (ICD-10)[12], presenting with Alcohol related Delirium Tremens (ADT), able to converse in either English or Kannada; and not using any other substance (except nicotine) were included. Persons with co-morbid or unstable medical or neurological conditions were excluded. A spouse/caregiver living with the patient since the last one year, able to converse in English or Kannada and who were not consuming any substances nor had a severe mental illness were included in the study. In this paper we present the psycho-social needs of the care givers of persons with ADT.

Interviews and data collection: Face-to-face interviews were conducted on understanding the needs of the care givers using open ended questions such as, “What are your current needs and concerns of with respect to the patient? Or what kind of help are you expecting from the doctors?” Appropriate probes were used if they were unable to give spontaneous responses. For this purpose a check-list was prepared in consultation with eight mental health professionals who were not part of the current study and belonged to Psychiatric Social Work (3), Psychiatry (3), Psychology (2) and Anthropology (1) disciplines. They were selected based on their experience in working in the field of addiction medicine or possessing the knowledge of qualitative research methods.

Data analysis: The 25 audio recordings were transcribed into English text and field observation notes were added. Later the transcripts were imported into and coded with the assistance of QDA Miner Lite. A single researcher is sufficient to carry out the analysis if they are well immersed in the process of data collection and analysis[13,14] which was carried out by the first author as depicted in Figure-1. The general inductive approach[11] was used to a guide the qualitative data analysis. During coding, the text segments that depicted the needs were critically analyzed and codes were created initially for ten transcripts. It was revised, refined with new insights, checked for consistency and later assigned under the meaningful themes. This was further discussed with two peer researchers to sort out and cross-check the consistency of the codes with the assigned themes. The differences were resolved after clarifications and discussion. Though saturation was achieved at 15 interviews the analysis for all 25 interviews was completed.

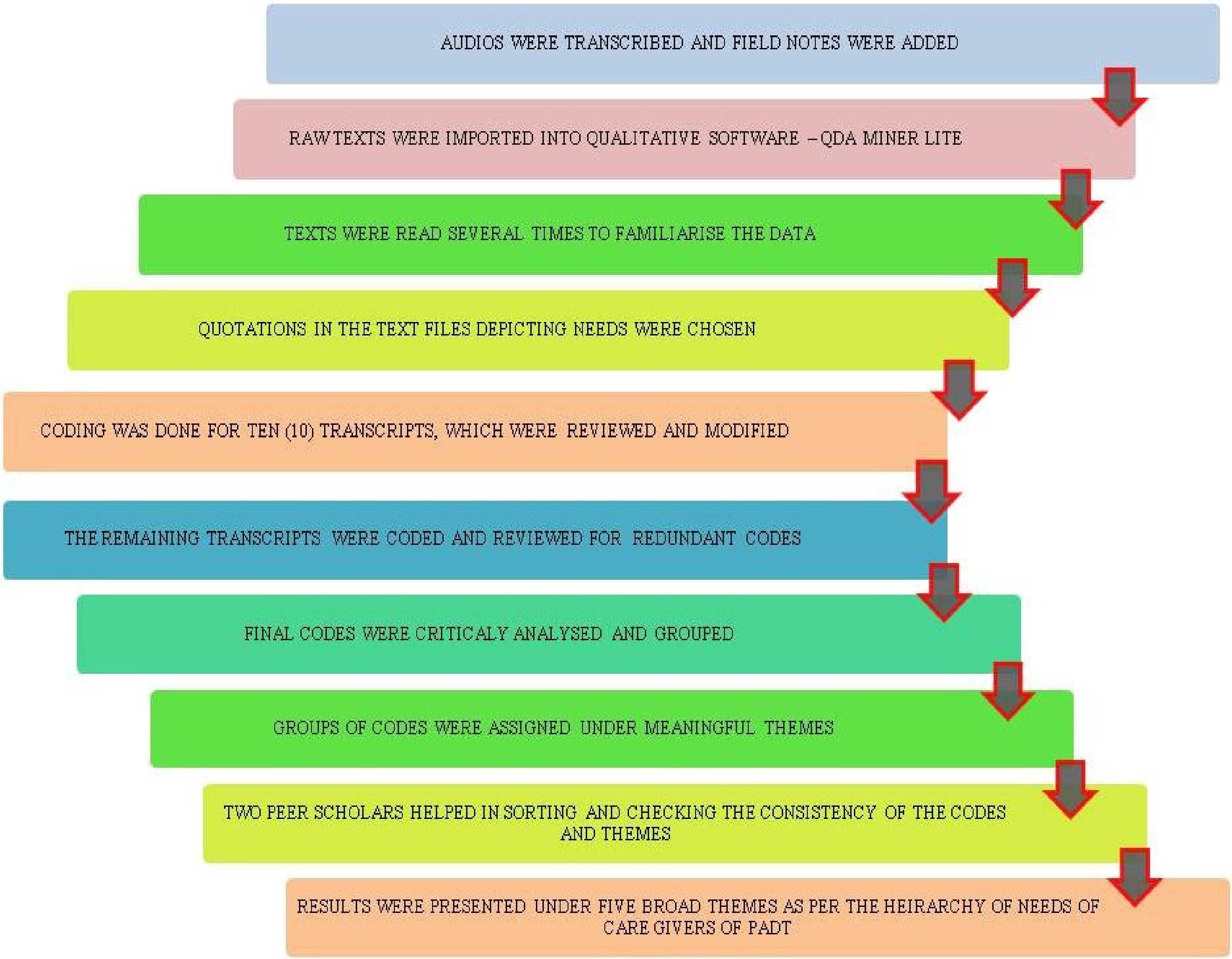

Figure-1: Process involved in qualitative data analysis.

Results and discussion

Socio-demographic characteristics: The socio-demographic and clinical characteristics of the 25 caregivers (Spouse=21 (84%) and Mothers = 4 (16%) along with the patients who participated in this study are depicted in Table 1. Most of the participants belonged to Nuclear families (n=15), Hindus (n=21) and hailed from an urban background (n=16). The mean age of the Caregivers of patients with ADT was 36.48 years and that of the patients were 36.28 years respectively.

Table-1: Socio demographic profile of the caregivers and patients with ADT.

Variable		Caregivers	Patients
		Mean (SD)	Mean (SD)
Age		36.48 ± 12.78	36.28 ± 6.3
Years of education		6.72 ± 4.50	7.40 ± 4.15
		N (%)	N (%)
Education	Illiterate	6(24%)	2(8%)
	Primary school	1(4%)	7(28%)
	Middle school	4(16%)	3(12%)
	High school	11(44%)	9(36%)
	Intermediate / Diploma	2(8%)	2(8%)
	Graduate or Post Graduate	1(4%)	2(8%)
Monthly Family Income (INR)	1601-4809	1(4%)	1(4%)
	4810-8009	4(16%)	4(16%)
	8010-12019	11(44%)	11(44%)
	12020-16019	6(24%)	6(24%)
	16020-32049	3(12%)	3(12%)
Occupation	Unemployed	11(44%)	4(16%)
	Unskilled Worker	9(36%)	11(44%)
	Semi-Skilled Worker	3(12%)	4(16%)
	Skilled Worker	-	2(8%)
	Clerical, Shop Owner, Farmer	2(8%)	4(16%)
Socio economic status	Upper Middle	2(8%)	2(8%)
	Middle / Lower Middle	8(32%)	8(32%)
	Lower / Upper Middle	15(60%)	15(60%)
Marital status	Unmarried	-	4(16%)
	Married	21(84%)	21(84%)
	Widow	4(16%)	-

The clinical characteristics of the PADT are depicted in Table-2. The mean age of initiating alcohol use was 19.48 years; age of developing dependence on alcohol was 23.80 years; total duration of dependence on alcohol was 12.96 years; and the maximum period of abstinence from alcohol in the past was 4.80 months.

Table-2: Clinical characteristic of Patients with ADT.

Variable	Mean (SD)
Amount of money spent on alcohol on a typical day (in Rupees)	272 ± 97.98 (Median = 300)
Units of alcohol consumed on a typical day (1 unit =30 ml of alcohol)	18 ± 4.97 (Median = 18)
Age of initiation of first drink	19.48 ± 4.35 (Median = 19)
Age of harmful use of alcohol	23.68 ± 4.69 (Median = 25)
Age of onset of dependence on alcohol	23.80 ± 4.62 (Median = 25)
Duration of untreated dependence in years	12.24 ± 7.90 (Median = 10)
Total Duration of Dependence in years	12.96 ± 7.73 (Median = 12)
Maximum period of Abstinence in months	4.80 ± 2.78 (Median = 4)
Recovery from the DT episode in days	4.04 ± 1.02 (Median = 4)
Number of Inpatient admission days	19.12 ± 7.51 (Median = 17)

Psychosocial needs of the care givers of persons with alcohol delirium tremens: Five themes emerged from the qualitative data analyses which are presented under the relevant themes based on the total number of times the care givers emphasized on each of the themes (Table-3). The detailed description of each theme and their quotes are mentioned below:

Managing high risk situations: The caregivers had a wide range of expectations from the mental health professionals. Most of caregivers were spouses and predominantly wanted their husbands to stop drinking and how they could help the patient achieve abstinence. The following are some examples:

"He does not know what to do when he gets an urge (craving)….at times he is able to manage it….but few times he is not able to do so. I need your (Mental Health Professionals) help to teach him to manage his craving ***(Participant 5).***

"He spends a lot of his time with his friends….he knows that if he meets them he will drink again but he cannot avoid them. Could you tell me what I should do during this time to make not meet his friends? At times if I tell him he gets upset and argues with me" ***(Participant 7).***

"My husband does not work due to health problems. He is bored most of the day and as a result he spends his time in drinking. The doctors should help us to engage him with work….it will be helpful to meet our daily expenses as well" ***(Participant 12).***

Informational needs: The care givers wanted to know about the reason for the current episode, prognosis, treatment and side effects of medication. They also wanted information on the investigations done and if the patient would get better. Their quotes are as follows:

"My husband was not well and so he stopped drinking…after that he started acting 'mad'. I want to know why he was behaving like this. Will this problem come again?" ***(Participant 1).***

"He is not able to think clearly and forgets many things…I have to keep reminding him….Is there any treatment for this? Will he become better? ***(Participant 11).***

"The doctors have taken a MRI scan and also done some other tests… we want to know if the reports are okay" ***(Participant 17).***

"The doctor advised him (patient) to take the medications for one year. I want to know if it is it okay to take medications for so long, will it affect his body. In case he drinks should I give him the medication? Will there be any problem? ***(Participant 24).***

Follow-up Services: The caregivers were very keen accompanying the patients for follow up to the hospital. They also wanted a support group for family members. Some of their quotes are as follows:

"There should be regular group meetings for care givers also. I want to know how other family members are handling these problems" ***(Participant 3).***

"My husband does not allow me to come to the hospital along with him…you (mental health professionals) should advice him (patient) to bring their family members during follow up. If he comes alone he will not tell the truth…instead I could tell you his progress" ***(Participant 14).***

"It is difficult for us to come to the hospital every 2 weeks….is it possible for us to inform you about his progress?…in case there is any problem we can call you and bring him for check up when you tell us" ***(Participant 19).***

Personal Needs: The caregivers did not stress on their personal needs but their main priority was to see that the patient gets better. They wished for better communication patterns and healthy family rituals.

"When he (Husband) was abstinent from alcohol, we used to go out as a family... but now all that has stopped. I wish we could be spend time together like before" ***(Participant 4).***

"I am very afraid when my husband drinks (alcohol). Even if I am quiet, he starts shouting at me for no reason. We need your help in handling this behaviour" ***(Participant 13).***

"I find it difficult to take care of all the responsibilities at home…now I have to look after him (husband) as well. Because of this I don't have time for myself. I want to know how to manage all these situations" ***(Participant 22).***

Miscellaneous needs: Some of the caregivers wanted help in provision of free medications and had difficulty in payment of the hospital expenditures. Also, a few of them asked for more attention from professionals to address patients' needs and the need for home visits.

"The doctors advised him to take medication for a year…we do not have the money to buy medications. Could you help us in this regard?" ***(Participant 7).***

"The doctor told us to get a MRI scan…we do not have any money to pay for this…I have borrowed money from my relatives to pay for his treatment, they will not give me money…I need your help in this matter" ***(Participant 16).***

"The doctors only check about my son…sometimes they should check about how we are doing and listen to our problems." ***(Participant 18).***

"It is difficult for us to come for to the hospital for follow up regularly as we are daily wage workers. You should visit our house to see how he (patient) is doing after getting discharged from the hospital" ***(Participant 23).***

Discussion: This study highlights the needs of care givers of patients with ADT in India. From the qualitative analysis, five major themes emerged from the data: (1) Managing illness, (2) Informational needs, (3) Follow-up services, (4) Personal needs, and (5) Miscellaneous needs. Alcohol use disorders are chronic and known to be relapsing in nature. Despite several attempts at abstinence and various treatments offered, patients find it difficult to abstain from alcohol for longer durations. If not adequately addressed the patients substance use behaviours would cause disruption of the family functioning and increased care giver burden[6]. In order to manage high risk situations, handling craving and avoiding peers, the care givers felt that this was the most important need to be addressed and wanted help in this regard. Results from a study involving care givers of persons with schizophrenia also reported the similar need of managing the patient's illness[15] which consistent with findings of the present study.

Care givers are known to want information relating to the illness and in managing problematic behaviour of the ill individuals[16]. Care givers of persons with schizophrenia[15] and terminally ill patients[17,18] also reported of wanting information related to the patient's illness. These findings are in tune with the results of the current study where care givers of persons with ADT expressed the need for information pertaining to the illness, medications, side effects and information related to the reports and investigations. Providing information about the illness to care givers would help them in understanding the needs of the patients and help them in the process of recovery.

Attending support group meetings where each one could share their experiences, ventilation of feelings and seek solutions for their problems from other care givers was the third most important need highlighted by the care givers. Support groups such as Al-Anon, have been beneficial and helped family members cope more adaptively, experience less depression, anger, and family conflict, and more family cohesion and relationship satisfaction[19,20]. Few of the care givers wanted to be involved in treatment decisions as well[16] by wanting to accompany them during the follow up visits to the hospital. Most of the care givers were daily wage workers belonging to a rural back ground making it difficult visit the hospital frequently, therefore requesting for telephonic interventions. Telephonic based care is known to remove such barriers[21] and have been found beneficial for care givers of persons with mental disorders[22]. The evidence from India suggests that people use telephonic consultations for seeking advice, follow-ups and access to other services[23].

Table-3: Hierarchy of needs of caregivers of PDT.

Hierarchy	THEMES	No. of participants	CODES
1	Managing illness	19	Handling craving; staying away from bad company; taking medicine regularly, identifying and managing high risk situations.
2	Informational needs	15	Information about the illness; prognosis; reports and investigations and medications.
3	Follow-up services	12	Telephonic consultations; coming for follow up; and meeting similar families.
4	Personal needs	7	Help in communication; help in coping, spending quality time with family.
5	Miscellaneous needs	4	Help in providing free medication & treatment, home visits, more time to be spent by treating team

The need for better communication patterns, family rituals and personal time was the fourth most important need of the care givers as these were lacking due to the direct involvement of the patients alcohol use. This resulted in additional responsibilities for the care givers. A study on family burden with care givers of substance dependence from India reported that there was a disruption of family routine, family interactions and family leisure time as a result of the client's substance use[6] which is similar to the results in the current study. Like any illness that affects the family, care givers of persons with mental illness, highlight issues of cost relating to treatment[24].

Care givers in the current study reported of financial problems in meeting the treatment costs and medication. Majority of the care givers belonged to a Below Poverty Line (BPL) and were daily wage labourers which explains why they experienced financial difficulties. The Health care costs for families with member diagnosed with Alcohol Dependence Syndrome are twice as compared to those for families without one [25] 1988) and if not addressed these medical costs could increase[26]. Research shows that care givers experience burden as a result the family member's addiction.

Though there are no studies that look at specifically the needs of care givers of persons with alcohol dependence syndrome, the results of the current study highlight the need of the care givers is similar to those of other disorders. Given that treatment outcomes specifically focus on the patients substance use, mental health professionals can also look into the needs of care givers and address them specifically.

Conclusion

The current study has some limitations where participants consisted predominantly from lower socio-economic status. Rigorous methods in qualitative research such as multiple coders, member checks and data triangulation through FGDs could have enriched the study results further. However this is the first study that has assessed the needs of the care givers of persons with ADT, qualitatively. The in-depth interviews have added a considerable amount of strength to the study where the care givers have listed and ranked their needs without the influence of the researcher. Alcohol dependence is known to affect the entire family. Care givers are known to experience a significant amount of burden which could lead to various other health related complications. Given the understanding that several studies have pointed out the effects of care giving on the family member, our study on exploring the needs of care givers of patients with ADT is of great clinical and research importance. Majority of treatment interventions focus exclusively on the patient and almost if not neglecting the care giver. Highlighting the need to involve caregivers of patients with severe mental disorders is important from a public health perspective. Thus, understanding their specific needs might help us to formulate suitable interventions so as to reduce the burden as well as help in developing healthy coping strategies.

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