ORIGINAL ARTICLE BEHIND THE BURDEN: A QUALITATIVE STUDY ON CAREGIVING FOR SUBSTANCE USE DISORDER IN PAKISTAN

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> Background: Substance Use Disorder (SUD) poses severe challenges for both individuals with addiction and their caregivers. Caregivers in Pakistan experience psychological distress together with economic hardship and social discrimination which healthcare systems fail to recognize and address. Through this research both practical and emotional aspects of caregiving life of people who care for addicts (PWSUD) in Pakistan were studied. Methods: This qualitative study recruited 50 informal caregivers (male: 38, female: 12) through snowball sampling. The research team gathered information through advanced interviews that examined caregivers' experiences with caregiving roles while investigating treatment option awareness and obstacles to medical assistance. Research participants participated interviews conducted in Urdu followed by transcription and translation and data analysis through Braun and Clarke's thematic analysis methodology. Results: Stigma and social rejection enhanced emotional distress among caregivers who experienced symptoms of anxiety depression and helplessness. Thematic analysis identified three primary themes: The research uncovered three main themes which encompass socioeconomic challenges such as social isolation and lack of educational resources beside economic struggles together with survival skill deficits. Financial instability arose for caregivers because of continuous care responsibilities which restricted their access to professional treatments for their family members. Caregivers suffered from mental health problems because social stigma surrounding addiction both kept them isolated and prevented them from getting external support. **Conclusion:** The individuals who care for people with substance use disorders in Pakistan experience heavy emotional and social burdens together with financial stress while receiving almost no support. Accessible mental health services together with financial support programmes and stigma reduction interventions represent essential elements in supporting caregiver health and enhancing treatment results for individuals with Substance Use Disorder (PWSUD).

> **Keywords:** Substance Use Disorder; Caregiving; Mental Health; Stigma; Financial Burden; Qualitative Research; Pakistan

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INTRODUCTION

The substance use disorder problem affects public health worldwide and creates difficulties for both SUD patients and their family caregivers who take care of them. Primary caregivers of SUD sufferers receive little recognition while managing essential duties and handling multiple burdens of caring for their loved one.1,2 Pakistan's community faces mounting difficulties when supporting substance users because of deep-rooted stigma and scarce access to mental health services and caregiving resources.^{3,4} People who care for individuals with SUD develop mental distress and experience anxiety, depression plus a sense of losing control.5,6 Research shows that many caregivers from this group develop depression and anxiety while mental health support systems stay empty since they are unaware of how to access the help, they need due to social stigma.^{7,8}

Caregivers face increased emotional hardship because their feeling of isolation and community rejection from stigma worsen their situation.^{9,10} Individuals who are care givers come across various mental health problems. They also face financial constraints along with joblessness.^{11,12} The high costs of treatment place greater financial stress on Pakistani caregivers because there are no formal support systems to help them pay for treatment.¹³ The challenging work of caregiving prevents many caregivers from earning money which increases their money problems.¹⁴ Our research examines what life is like for SUD caregivers in Pakistan and their mental health problems as well as economic and social obstacles. Healthcare system leaders can develop better patient support plans when they understand the challenges faced by caregivers of substance use disorder patients in Pakistan. The conceptual framework of study is given in Figure-1.



Figure 1-: Conceptual framework of study

MATERIAL AND METHODS

Participants were approached through local community, and publicity in local and social media. Participants were recruited through snow ball sampling method. Data collection stopped after achieving data saturation at 50 participants. The study sample included informal carers (N = 50) of PWSUDs (i.e., relative or friend who is looking after them) in the capital territory of Pakistan. The sample was recruited from community. Sample included both males (N = 38) and females (N = 12). Inclusion criteria was individuals caring for a PWSUD for at least six months with age 18 years and above. And living with PWSUD. Exclusion criteria was individuals who were never diagnosed with a SUD and are not going through any psychiatric illness at the time of data collection. Two instruments were used in the study i.e., study demographic information sheet and interview guide for qualitative interviews with informal carers of PWSUDs .Demographic Information Sheet .It included questions pertaining to age, gender, relationship with PWSUD, highest qualification, marital status, number of children if married, onset of caring for PWSUD, onset of substance abuse of the cared for PWSUD, number of times treatment sought for SUD, history of relapse(s), any other mental or physical ailment PWSUD has. Interview Guide covered the following areas like perception of effect of SUD on PWSUD's life., perception of effects of SUDs on carer's life, perception of causes of substance abuse in general and for PWSUD related to them, Awareness and knowledge about treatment options for SUDs in Pakistan, details of availing treatment for SUD for PWSUD related to them, anything which facilitated or hindered patients' treatment of substance abuse. Data was collected in qualitative study fashion. Before conducting qualitative interviews informed consent was obtained from all participants which included their consent to be audio recorded during the interview. It was ascertained in written form from literate participants (N=22) of study. However, from illiterate participants (N=28) it was ascertained orally in the presence of any of

their literate family member or friend. All interviews were audio recorded. Participants were requested to provide as much information as they can on each issue being asked in the questions. Interviews were conducted at mutually convenient place and time, which was coordinated and agreed upon before conducting the interview. On average each interview took 30 minutes to complete. Data was analyzed using six step framework of thematic content analysis given by Braun & Clarke. Data analysis was driven by a combination of both theoretical thematic (top-down) and inductive (bottomup) approaches (Braun & Clarke, 2012) as it included data regarding specific questions of interview guide along with additional information which emerged during the interviews pertaining to PWSUDs experiences. All data was provided in Urdu (national language) because participants were not proficient in English and Urdu was the only choice to collect data. Therefore, before analyzing data participants' verbatim was first transcribed in Urdu, then translated in English and back translated in Urdu to achieve standard translation. Afterwards, semantic analysis was conducted in which codes, sub-themes, and themes emerged from data in a six-step format. It focused on the apparent meaning and interrelationship of the verbatim of the participants

RESULTS

The demographic information of participants of study is given in Table 1.

Different themes and themes and subthemes emerged from analysis of the qualitative data. Themes and subthemes are described in Table 2.

Carers of PWSUD informed about a number of socio-cultural and economic outcomes of the person's substance abuse on their own and their relatives' lives. The details are described in the sub-categories below. Carers of PWSUD reported that they experience social seclusion and insecurities due to their relative's substance abuse issues: "Due to my husband's addiction my in laws disconnected with us. They say it is disgrace for us to be associated with such person (who is an addict). But how I or my children are at fault for his misconduct (substance abuse)" (Wife of a heroin abuser). "We live in combine family system. My husband became addict and he stopped working. He used to contribute in household expenses but after his addiction he could not contribute. His brothers beat him a lot to make him stop (substance abuse). Then they stopped providing anything to us. We were outcasted and treated very poorly by all of them. My family is not well off. My parents ask me to come to them but they cannot take my children. You tell me how a mother can go for her betterment and leave her children in trouble. I work like a servant for all of them to earn bread for my children" (Wife of marijuana abuser). "My son is an addict of cannabis. I have two sons and three daughters other than him. Two of my daughters are

unmarried. He is also single. But my worries and apprehension are increasing day by day regarding my daughters' future. You know no one likes to have relationship with people who have an addict in their family" (Father of a cannabis abuser). "My son is alcoholic. His wife left him because he used to beat her a lot, she could not tolerate it anymore and left. She has taken daughters with her. He has three daughters and four sons. His sons work on daily wages as laborers. I always worry about my son and grandsons. Anybody can harm them and there will be no one to take care of them. I am a widowed and my son was the only provider and protector of the family. I am an old woman I'll die in such insecurities" (Mother of an alcoholic).

It was reported that PWSUD lack education and survival skills, it has been attributed as both an effect and cause of substance abuse: "He (substance abuser) was born after 11 years of our marriage. He is my only son. He was born after years of our prayers to Allah, "mazars," and "dargahs" (shrines). We provided him everything he wished for. He has always been very pampered. But such excessive pampering spoiled him. He left school despite all our convincing he did not continue his education. Then I asked him to start helping me at my shop. He used to go there off and on. But mostly he used to spend time with his friends. I could never imagine that he would indulge in such activities (substance abuse). I always regret about giving in to his decision of discontinuing his education or nor acquiring any skills for employment. If he remained busy in academic or skillful activities things might have been different" (father of a poly substance abuser). "He started substance abuse when he was in school. He didn't acquire any "hunar" (working skill). That's why now he is dependent on us for survival and drugs as well. But we have our own families we give him money as much we can afford. Obviously, it is not enough for him. It is inflation and everything including illegal drugs are very expensive. I have seen him begging as well. It breaks my heart. But I cannot help him anymore" (brother of a heroin addict). "Due to bad influence in college, he started substance abuse. Therefore, he couldn't continue his education. We took him to treatment centers several times. But he ran away from treatment all the times. My father is very concerned about him that how would he survive if he would not be able to support him" (brother of marijuana addict). "I placed him at the workshop, we are poor people we cannot afford sending our children to school that's why I have placed all my children to different workshops and shops. I don't know how did he trapped in the addiction. He could not continue his work and I couldn't afford education. I beat him for his addiction. He ran away from home. Now he comes home occasionally, I don't scold him anymore. I cannot see him in such bad shape, but what can I do? I cannot provide him either. I don't know how he is meeting ends but I have other children also to support. I do facilitate him a bit but can't do much" (father of a heroin addict). "My son has been caught a number of times by police when they at the hubs of drug addicts they take them to jail. I have been bringing him out by bribing police. I do not have enough resources to keep paying for his bails and addiction. Police by now know us. I fear the day they'll raid our home to take him I will not be able to face anyone after such happening and respect in the community will be tarnished" (father of a heroin addict).

It was noted that carers have superstitious beliefs regarding causes and effects of substance abuse: "Evil eve has affected our family very badly" (mother of heroin addict). My "jithani" (wife of brother-in-law) casted jadu (magic) on us. I have found a doll made of cloth buried in a new grave of a young man. There was needle pricked in its chest. It is after that, that my husband's health started deteriorating and our home became a mess" (wife of a heroin addict). We took duties to monitor who was doing this all. But we could not figure it out. It continued for a long time. We later came to know that someone is casting black magic on us and all these practices are part of it. They were doing it through help of Jins. It was during that time that two of my sons became addict" (father of marijuana and heroin abusers).

Widespread effects on interpersonal relation of PWSUD were reported in the interviews. Carers of PWSUD reported that PWSUD either belonged to a broken family or their substance abuse led to a broken home: "I am widowed. I raised my children with great hardship. My husband died when I was only 22 years old. I never remarried so that my children should not be affected. I have been a domestic worker. I have two sons. They were my hope that they will be my support when grow up. But unfortunately, one of my sons is unemployed. And the other has become drug addict" (mother of a heroin addict). "My brother used to torture his wife physically and mentally and demand money from his in law for his drug addiction. They kept proving him money as long as they could, Ultimately, they became worn off of providing him money for his addiction. The torture was his blackmailing tactic to get money from them as they had no other option except to support their sister and protect her from his wrath. We always tried to convince him that he is doing wrong and should mend his ways but he would never listen to us. Finally, his in laws gave up and decided to stop this abuse and took their sister back to their home. He instead of learning lesson and trying to reconcile became furious and divorce his wife in retaliation" (brother of a heroin addict). "My husband is an alcoholic. I have four sons but all of them have left home, because their father is very violent and abusive. He used to extort money from them for his addiction, they are young men having their own needs and responsibilities. They left home to get rid of

their father. I have become a vendor. I make little crafts and sell them. Sometimes, people give extra money to help. That's very kind of them. He beats me as well to get money from me. I don't have any place to go that's why bound to live with him" (wife of an alcoholic). "My husband expelled me along with my (addict) son. He thinks it's effect of bad upbringing that our son has become an addict. I have faced a double-edged sword; separated from husband and loss of my son as he is no more the same person after addiction" (mother of a heroin addict). "My daughter-in-law left my son. My son lost his job long ago due to his addiction. His wife was supporting whole family financially.

It was reported that controlling and abusive relative were one of the causes of substance abuse: "My husband is responsible for my son's drug addiction. I always forbade him from being so inconsiderate and strict towards kids. They are grown up and it is a different era youngster do not obey their parent blindly. But he believed in his way or no way. He wanted to impose his writ. He used to give them beating as well even in their teen age. It had its toll and our youngest son became addict the other also different problems but addiction affected only one. Even after that my husband never accepted his fault, he blames everything on my either my upbringing or my children's disobedient nature" (mother of a heroin addict). "Our mother was raised us as a single parent. She was a widowed. She was insecure because she a single mother she wanted to have control over our lives completely. She always maintained a strict routine for us. There was lack of friendliness and understanding between us and out mother. She did all this for our well being but my younger brother was more sensitive. He always used to remain worried and fearful of mother being unhappy with him. His worried ultimately lead him to wrong people who exploit such youngsters and he became an addict" (brother of a heroin addict). "We live in combine family. My husband along with his three brothers give their salaries to their father who is responsible for running the house and provide money to everyone according to his requirements. My husband has a very good job as compared to his brothers. But due to combine family my children get nominal money for their expenses. All children differ, some can compromise others don't. That's what happened to one of my three sons. He used to retaliate a lot when we couldn't fulfill his desires. He used to feel competition with class fellows and friends. Such small deprivations led him to depression and he became trapped in this illness as well (substance abuse)" (mother of marijuana addict).

Carers of PWSUD described different approaches towards treatment of SUD. Details of their opinions in this regard is mentioned in the sub-themes below. It was noted that carers of PWSUD consider homeo-pathic and herbal treatment as an option for SUD: "My brother did not continue his medical treatment for

drug addiction. One of my acquaintances recommended a very reputable homeo-pathic doctor. His relative had got relieved from substance abuse with the help of that homeo-pathic doctor. Therefore, I am now taking treatment for my brother from a homeo-pathic doctors. The doctor suggested that treatment will take time as it is slow treatment, but it will ultimately eliminate drug addiction from my brother" (brother of marijuana addict). "Homeopathy is a reliable treatment option for all illnesses. Its medicines have no side effects. My cousin is a homeopathic doctor. We are getting treatment for my uncle from him" (nephew of a cannabis addict). "Homeopathic medicine require consistency in follow-up and regularity in usage. People do not understand that therefore, majority is deprived of its benefits. My brother is getting homeo-pathic treatment for his addiction" (brother of a marijuana abuser). "The homeopathic doctor our whole family consults is qualified and well equipped. He has scanner machine, with which he scans whole body of the patients and can tell what deficiencies he has or what is condition of his internal organs. He has a very high success rate. People visit him from all over Pakistan. There is "shifa" (cure) in his hand. My father is older and he cannot sustain medical treatment which is physically painful for an old person. Therefore, we are seeking homeopathic treatment for him from the specialist doctor. He is improving gradually" (son of a cannabis addict). "My cousin's son got better with hakeem's (herbalist) medicine. I am taking my son to him for his addiction" (father of a heroin addict).

Carers of PWSUD had information about medical treatment of SUD: "I took my husband to a nearby government hospital. They gave him some medicine which helps is relieving his body aches that his drug causes him. They have asked to take him to Islamabad or Rawalpindi and hospitalize him for complete treatment. We are poor cannot afford travelling and admission expenses" (wife of a heroin addict). "My brother is admitted in a rehabilitation center in Islamabad. I visit him once fortnightly. He is improving. The doctors are very good. They are giving he very good quality medicines. He is admitted first time for treatment. He was resistant to take treatment. That's why couldn't take him to treatment earlier" (brother of heroin addict). "My son was treated at a treatment center for drug addicts. They admitted him for three months. He came back recovered. He left addiction completely. He was weak physically after return but he was clean from drug. He spent a few months healthy. I kept an eye on him vigilantly. He was doing good so I became satisfied and less vigilant. Unfortunately, he again started mixing with bad people and restarted drugs. I am again planning to admit him in the same treatment center. I am collecting money for his treatment at the moment" (father of marijuana addict).

It was noted that carers have been indulged in spiritual malpractice for healing of the PWSUD: "We

have been taking our son to Peshawar to "dargahs" which are well known for removing evil spirits from the effected. We believe that he has been possessed by evil spirits and he'll be fine if they leave him. There is no other way to get rid of them except taking him to "dargahs" (shrines) (father of marijuana addict). "I have heard that eating langar (free meal served at shrines) from "barri Sarkar" (a reputed shrine in Islamabad) has healing effect. I regularly go to barri Sarkar (a reputed shrine in Islamabad) and brig "niaaz" (free eatables served at shrines) for my brother. Sometime, I take him with me and leave him there and ask him to eat and drink from there. He always feels good when he visits barri Sarkar. I am sure one day barri Sarkar will heal him completely. "I have been taking my son to a 'pir sahib" (spiritual healer) in Mansehra. He is well known for treating substance abuse issues. Many people have been cured with their "karamatt" (healing powers). He does not charge anything which shows that he is reliable person. It depends on the visitors if they willingly give some "haddiya" (donation). He gives us salt which has his "dumm" (spiritual words casted on something or someone for healing) on it. It makes a big difference. My son is always better after taking that salt. Pir sahib is the only person whom he wants to visit happily. Otherwise, he always resisted and retaliated if I convince him to stop drug or start taking treatment" (mother of a heroin addict).

Table-1: Demographic information of participants of study.

of study.				
Participants characteristics (N=50)	Values			
Age in years Mean (min-max)	28.24 (27-62)			
Gender				
Male	38			
Female	12			
Qualification				
Uneducated	28			
Primary	4			
Middle	10			
Matric	2			
Intermediate	1			
Graduate	5			
Marital status				
Married	42			
Unmarried	-			
Widowed	3			
Divorced	5			
Onset of SUD in years, Mean (min-max)	1.74 (5-13)			
Number of times treatment sought (min-max)	1-7			
Number of relapses (min-max)	2-5			
Care provision time span years (min-max)	3-13			

Initial themes and sul	o-themes (step-two & three	1	after further analysis (step	Final themes and sub-themes (step	
of thematic content analysis)		four of thematic content analysis)		five of thematic content analysis)	
Themes	Sub-themes	Themes	Sub-themes	Themes	Sub-themes
1. Socio-cultural	1. Social seclusion	1. Socio-cultural and	1. Social seclusion and	1 Same	1. Social seclusion
aspects		economic dimensions	insecurities		and insecurities
2. Economic	2. Shame and stigma	2. Interpersonal relations	2. Lack of education and	2. Same	2. Lack of education
dimensions			survival skills		and survival skills
3. Religious practices	3. Lack of education and	3. Perception of SUD	3. Threats and fear	3. Same	3. Superstitions
	skills for survival	treatment			
4. Familial norms	4. Constant fear		Economic insecurities		4. Broken families
			and exploitation		
5. perception of SUD	5. Financial constraints		5. Superstitions		Controlling and
treatment					abusive relatives
	6. Child labor		6. Religious malpractices		6. Herbal and homeo-
					pathic treatment
	7. Economic exploitation		7. Magic, witchcraft, and		7. Medical treatment
			evil eye		
	8. Homelessness		Broken families		8. Spiritual
					malpractices
	9. Superstitions		9. Controlling and abusive		
			relatives		
	10. Religious malpractices		10. Herbal and homeo-		
			pathic treatment		
	11. Magic, witchcraft, and		 Medical treatment 		
	evil eye				
	12. Broken families		12. Spiritual malpractices		
	13. Controlling relatives		13. Sanctity of shrines and		
	14. Herbal and homeo-		spiritual healers		
	pathic treatment				
	15. Medical treatment				
	16. Spiritual malpractices				
	17. Sanctity of shrines and				
	spiritual healers				

Table-2: Development of themes and sub-themes in study

DISCUSSION

Substance Use Disorder (SUD) in Pakistan harms the health of patients and caregivers who deal with serious emotional, mental, and social problems. Recent studies show that people who care for SUD patients experience mental distress plus financial and social difficulties.¹⁵ Beyond giving physical care, caregiving involves fighting mental health problems along with social stigma and weakens family connections. Individuals who support persons with SUD in Pakistan undergo intense mental health problems. Carers at the Baluchistan Institute of Psychiatry & Behavioral Sciences showed signs of depression in 68.33% of cases and anxiety in 44.17% of cases according to research findings.¹⁶ When caregivers work with patients over long periods, they face higher rates of burnout alongside post-traumatic stress symptoms and mental weariness.¹⁷ Caregivers face increased psychological distress when substance users unpredictably behave poorly, relapse often, and show difficult signs of addiction.¹⁸ How caregivers express their emotions strongly affects their mental health. Research finds high Expressed Emotions including negative attitudes and excessive involvement hurt the mental health of people with Substance Use Disorder and their caregivers.¹⁹ According to Pakistani research higher EE levels in caregivers lead to increased psychological distress and helplessness feelings.²⁰ Building self-care skills and emotional strength helps reduce these damaging results. Studies show.²¹ Caregivers of substance users face great financial hardship in Pakistan because quality mental healthcare services are not widely available. Many patient advocates must spend their own resources on treatment costs which create extreme financial stress for their families.²². Recent studies show caregivers lose their financial stability because caregiving responsibilities make them work less and sometimes lose their jobs entirely.²³ Social attitudes toward substance use make life harder for those who care for people with these problems. In Pakistan substance abusers and their caregivers experience social rejection because people see drug problems as ethical breakdowns rather than health issues.²⁴ According to a research analysis on caregivers' stories numerous participants expressed that they felt stigmatized and distanced from society because others saw addiction as a weakness.²⁵ Caregivers resist asking for help because social stigma about their situation makes their emotional pain and psychological stress even harder to manage.²⁶ The research shows that specific coping methods lessen caregiver stress during their support role. According to research the way caregivers handle stress improves when they get social support and practice healthy habits as part of their recovery process.²⁷ Research shows that counseling and educational programs for families make caregivers healthier and more successful at helping people with substance disorders.²⁸ Our country urgently needs specific programs to help those who care for people with substance use disorders. Public agencies at all levels should make mental health and community support their highest priorities while offering both financial help and caregiver assistance programs.²⁹ Better treatment of addiction through awareness programs and social acceptance will help caregivers live better lives.

CONCLUSION

People who care for SUD patients in Pakistan endure extreme stress emotionally, economically, and socially through their experience. Solving these problems demands combined solutions through mental health services plus community education and cash aid. When we help caregivers get the support, they need they feel better and help patients with SUD achieve better recovery results.

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AUTHORS'CONTRIBUTIONS

AHA and IG prepared instruments for data collection. LFM, IA, AS, and SAU collected data and wrote introduction and methods sections of the manuscript. UG compiled, reported and discussed results in the manuscript. AHA, SAU and PW analyzed data. IG reviewed the manuscript. All authors read and approved the final manuscript.

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Ethical approval and consent to participate

Ethical approval was ascertained from internal review board of Health Services academy to conduct the present study. Written consent was taken from all the participants of the study prior to their participation in the study.

Consent for publication

Not Applicable.

Competing interests

I confirm that the authors have no competing interests as defined by JAMC, or other interests that might be perceived to influence the results and / or discussion reported in this paper

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