

Illness narratives of substance users from urban India

The untold stories of their ‘afflictions’

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Abstract

Reading Veena Das’s book *Affliction: Health, Disease, Poverty* was a journey of revelations for me as a health professional. The various dialects of illness that are spoken in the rapidly urbanizing Indian community become coherent, lending a voice to the distinctive sociocultural distress of the men and women who form a part of it. A discussion of the social aspects of illness brings certain questions to mind: Does the medical community fully understand those it tries to help? Is the therapeutic dialogue about the social dimensions of medical problems or vice versa? How do we bridge the mental health gender gap in our societies? To try and find some answers, I present the illness stories of two women who sought treatment at drug abuse treatment clinics in the urban slums of New Delhi. This think piece describes substance use disorder in the context of the cultural processes that have shaped these women, their families, and society.

Keywords

developing countries, socioeconomic factors, substance-related disorders, community-institution relations, women

An illness says a lot about the sufferer and her community. A person's illness experience could work in tandem with a medical disorder, or it might digress from the biomedical brief and become a physical manifestation of life's many struggles. The work of Veena Das and her colleagues helps us understand the social and psychological facets of illness in Indian society. Das's book, *Affliction: Health, Disease, Poverty* (2015), gives stirring accounts of the lives of individuals struggling with problems, all of which are channeled into their bodily symptoms.

Patients' narratives of illness and the discovery of a 'mental health gender gap' in the urban Indian community (Das et al. 2012) have led me, as a mental health professional, to think about the contemporary approach towards illness. Are we able to fully grasp the cultural expressions of distress by patients? Do we need to ask more and listen more to understand all aspects of their illness? Here I present the illness stories of two women who sought treatment at drug abuse treatment clinics in the Indian capital, New Delhi. The narratives that the women tell are ostensibly an account of their substance abuse but they also contain cultural expressions of distress experienced by these women and their families.

I focus on the stories of Indian women because their mental health is overlooked. A glaring indicator of the neglect of women's rights in India is the nation's sex ratio: in 2011 there were 915 females to every 1000 males (Paul and Saha 2015). Gangoli (2016), in his book on Indian feminism (2016) explains how high rates of violence against women at home, in public spaces, and at workplaces have led to restricted freedom and rights in the name of safety. Social factors that increase the risk of mental health problems and substance abuse in this demographic are yet to be fully understood. While illicit substance use is less prevalent among women the same cannot be said for prescription drug abuse. The rate of use of opioid analgesics and tranquilizers is higher among women than men (CDC 2013; Frenk et al. 2015; Simoni-Wastila et al. 2004). Injecting drug use among female substance users in India is highly prevalent. A countrywide survey of 1865 female substance users showed that 61 percent abuse opioids, and 25 percent had injected drugs once in their lifetime (Murthy 2008). Studies of drug use among women were carried out at three sites in India in 2001–2002 and found that 40 percent of the women who use illicit drugs are injecting drug users (Ray 2004). The number of women in India who are seeking treatment for their substance use has gradually risen, probably paralleling the increase in drug use rates (Nebhinani et al. 2013). The research on the 'mental health gender gap' by Veena Das and her colleagues (2012) makes an important contribution towards developing an understanding of the factors that shape Indian women's mental health problems, including substance use disorders. Their work captures the poor mental health outcomes of women residing in urban households. Men and women differ in how they react to distress, which is reflected in the dissimilar mental health scores of age-matched women and men, a dissimilarity that is more apparent during women's reproductive years. Das and colleagues (2012) note that the lives of women

in poor households in developing countries are mired in adverse reproductive events such as miscarriages, stillbirths, and infant deaths. Social and familial factors such as support from the natal family, marital harmony, and relationships with in-laws also determine women's well-being to a much greater extent than men. All these experiences appear in the illness stories of women.

One of the important insights of Das's book *Affliction: Health, Disease, Poverty* is that although disease manifests in individual bodies, it is constituted by and dispersed in the social relations in which the individual is embedded. What then is the difference between ordinary women living in resource-poor settings who face adverse life events and those who resort to substance abuse? There are striking similarities between narratives of mental distress as reported by Das et al. (2012) and female substance abusers being treated at the community clinic in an urban slum. Das and colleagues demonstrate that the dynamics of women's substance use could be better understood if seen in the context of their family dynamics, support systems, and adverse events.

While substance abuse has yet to become a public health priority in India, it has become a major focus area for the psychiatry department at All India Institute of Medical Sciences (AIIMS) through the efforts of the National Drug Dependence Treatment Center (NDDTC). NDDTC runs three community outreach clinics for drug abuse treatment that have been specially set up in parts of Delhi where prevalence of drug use is high and treatment-seeking tendencies and treatment opportunities are low. These are areas that are rife with poverty and homelessness, and they are a hotbed of crime in the capital.

The clinics primarily provide treatment for heroin dependence, offering treatment to those suffering from drug abuse quite literally at their doorstep. The goal is to retain the substance users in treatment by offering medical treatment with opioid agonists and opportunities for rehabilitation. This community-based care approach is a less common method of caring for substance users in a country where specialized medical care is only available at the few tertiary health centers, while community health centers are comprised of walk-in clinics that provide basic care and referral services to these 'higher' centers. In contrast to the hurried interactions that take place in the busy outpatient clinics of crowded, multispecialty hospitals, those seeking treatment at the outreach clinics are more candid about their problems and their daily activities, and freely share intimate details of their lives. This is a result of the conscious efforts of the staff, who are aware that the management of drug-abuse-related issues requires an open and honest dialogue between the therapist and the client. The treating team includes doctors and social workers, who carry out home visits to get a sense of the patient's social situation and ensure treatment adherence. Family members are

encouraged to visit the clinic along with the patient to play a role in the treatment process and to participate in family-based interventions.

I now present case histories of Shabana and Meera, who began to abuse substances in very different circumstances. All of the interviews presented here took place in the NDDTC community-outreach clinics, and participants' names have been changed. The two vignettes exemplify some of the problems faced by women in ordinary urban households, showing that what is considered the pathology of addiction is paradoxically embedded in everyday family relations.

Shabana came to the treatment center along with her mother. She was a wiry young woman, all of twenty-three years, who had eloped with a senior at school when she was fifteen and moved to a different city. Her father and uncles were heroin dependent and she felt that getting away from her dysfunctional family would show her better days. She explained: '*Ghar mein koi bada nabi tha . . . koi poochne waala nabi tha*' (There were no elders in the family . . . no one was concerned about me and there was no one who I was answerable to).

She began to use heroin upon her partner's insistence and became an intravenous drug user when she was sixteen. Shabana describes her initiation into substance use in a passive manner, '*usne zabardasti nashe ki lat laga di*' (he forcefully started my drug-use habit against my wishes). This indicates her feeling of helplessness regarding life choices. She went on to recount how the next six years went by in a haze as the severity of her opioid dependency increased. Apart from the personal sense of inadequacy and distress that she was experiencing all the time she also felt vulnerable, as she had lost contact with her mother and sister, who were, she said, 'the only family I had'. It is worth noting that Shabana was unable to relate to her father and uncle as family members, indicating that her affective family is different (and smaller) than her total family. She recalled: '*Nashe ki wajah se mujhse mere apne bichhad gaye, mujhe meri ammi aur behen ki bahut yaad aati thi. Main apni behen ki shaadi mein bhi shaamil nahi hui, meri ammi ko sab kuchh akele hi karna padaa*' (I lost touch with my loved ones due to drugs. I used to constantly miss my sister and mother and I could not even attend my sister's wedding. My mother had to make all the arrangements by herself).

In 2015, Shabana returned to her maternal home to start afresh and began to work as a cleaning lady. On returning home she learnt that her father and uncle had died of drug overdoses. She marked this realization as the moment when she resolved to seek treatment for her drug dependence. During discussions with Shabana about the risk and protective factors that could lead to future drug use, she brought up earlier events. Both Shabana and her mother blamed the absence of '*baap ka saaya*' (shadow of a fatherly figure) for the decisions she made in her life, and both felt that the men in their family had failed in their role as providers. They linked this failure to Shabana becoming vulnerable to the influence

of men outside her family. Shabana and her mother suggested that marriage could be a protective factor, as it would ensure that she would never have to resort to drug use again and it would help her regain a respectable position in society. The mother-daughter duo softened when they talked about future marriage plans for Shabana. On being reminded that she was HIV positive and that it would be difficult to find her a life partner, her mother suggested that she could find her an HIV-positive partner.

Despite her unusual and problematic past, Shabana and her mother were able to envision her rehabilitation into society through marriage. Shabana's mother did not criticize her daughter's life decisions or pass judgment on her actions. Instead, they displayed intimacy; her mother was effusive in her concern and affection towards Shabana. This resonated with the observations made in *Affliction* that women display a strong investment in their roles as caregivers, especially for their children, and tend to blame themselves for adverse events in their children's lives. Shabana's mother saw herself as the sole caregiver, and felt responsible to play that role relentlessly. On being asked about what caused her daughter's substance use problem, her mother replied:

Shabana aur iski behen ko main kabhi ghar se bahar nikalne hi nahi deti, par jab ladkiyan school jayegi toh mahaul ka asar to hoga hi. Iske Abbu bhi smackiya the, isliye kamzor ho gaye the. Kabhi isko toka hi nahi isliye yeh bichari bigad gayi (I would have never allowed Shabana and her sister to go outside the house, but they had to go to school. There the bad environment in the community got to her. Their father being a heroin addict was too 'weak' to stop her from getting influenced and so the poor girl got spoilt).

Her husband's substance use had perhaps altered her perspective on her daughter's addiction, and she understood the futility of blaming her daughter for what had already happened. She blames herself for exposing her daughters to the existing risk factors in their environment.

The second case is of Meera, a twenty-seven-year-old housewife who came to the outpatient facility because of prescription drug abuse. Three years earlier, Meera had begun to experience an intense dull aching pain in the soles of her feet, which was aggravated by sustained physical activity. She described her pain as a '*kbichav*', a 'stretching' sensation that originated in her heels and spread to her calves. She gave a graphic portrayal of her pain to convey its intensity: '*Aisa lagta hain jaise tango ka maans phat jayega*' (it feels as if the flesh on my calves is going to burst open). She initially sent her eight-year-old son to the local chemist for over-the-counter painkillers, but these provided only momentary relief. She then consulted a local '*dakter*', a local term for the medical practitioners, who asked her to undergo some tests (which were inconclusive) and prescribed more medicines. The

psychosomatic aspect of her complaints was not explored, as the role of the medical practitioners was to simply provide medicines. They were not expected to explore beyond the physical aspects of the illness, and it would perhaps be a bit perplexing and uncomfortable for both the practitioner and the client if this began to happen on a regular basis!

Meera experienced substantial relief from her pain when she started using the prescribed opioid analgesics. She realized that these medicines were stronger as they caused 'heat generation' in her body (*dawaiyan kafi garmi karti thi*).¹ She sent her son to get refills on the initial prescription from the local chemist shop. It would be unthinkable for the local chemist to ask for a renewal of the prescription, especially when the patient is local and known to the chemist. Thus Meera's use of opioid analgesics gradually increased to follow the characteristic pattern of substance dependence. She began to take the drug to feel relaxed and overcome feelings of anxiety. Meera felt that she needed to take a certain number of pills every day to reach a threshold at which she could perform household duties. Her parents brought her in for treatment when they began to receive complaints from her in-laws and husband that she had begun to neglect her household responsibilities due to her pain.

In *Affliction*, Das observes that young women occupy a lower position in the conjugal family, and that women in urban communities often self-medicate with painkillers and even narcotic analgesics by getting old prescriptions refilled. Their ability to carry out the daily responsibilities of cooking, cleaning, and caring is often seen as a marker of the health and well-being of not only the women but the whole family. As soon as Meera became negligent in performing her roles as a wife, mother, and housewife, her illness became visible to her family members and her natal family was summoned to rectify the situation. Her husband accompanied her on subsequent visits to the hospital.

It proved to be quite difficult to part Meera from her pills. Her pain would flare up dramatically when tapering off of the opioids was attempted. During family therapy sessions it became clear that the couple was not ready to accept that Meera's pain had a psychological basis. Their nonchalant attitude towards her drug abuse did not sit well with the alarmingly large number of painkillers (around one hundred pills per day) she was taking. The husband's only expression of distress regarding Meera's drug dependence was his contriteness about not working 'hard enough' to cater to his family's needs. He denied any

¹ This is a common belief in India regarding allopathic medicines, originating from Ayurvedic and Unani ideas that ingestion of certain types of food creates heat in the body.

possibility of Meera having any emotional problems as she was ‘well looked after’. On being asked to spend some more time at home so as to help with Meera’s drug tapering, he said:

Ghar pe kamaane waala main hi hoon, main ghar pe baith jaaonga toh mere bacchhe kya khayenge. Isko maine kaha hain ki apni behen ko bula le, iska man bhi bahal jaayega aur who ghar ke kaam madad bhi kar degi. Agar main aur mahnet karoon toh iske liye acchhi dawai ka intezam kar paaonga. Kya pata aur mehenga test karwane se bimari ka asli karan pataa lag jaye (I am the only earning member of the family, who will feed my children if I sit at home? I have often asked her to invite her sister over to our house for a few days, she will have someone to talk to and her sister can help in the household chores as well. If I work hard enough I will be able to earn more money and buy better medicines for Meera’s pain. Maybe we will then be able to afford more expensive tests to find out the actual cause of her pain).

Meera’s husband’s narrative fits in with the general observation that men view themselves as the providers for their family. He was not receptive to the idea that he should be more attentive to his wife’s emotional needs, and Meera had to limit discussion about her psychological troubles with her other relatives. While the couple was keen on continuing the physiotherapy sessions for the heel pain, they were unwilling to discuss their marital problems, which could have led to Meera’s heel pain and her subsequent substance abuse. It was as if the couple derived comfort in their assigned roles and only desired help to the extent where it will allow them to play the social roles assigned to them.

There is a cultural context that partly explains the stigmatizing attitudes of Indian society towards the mentally ill. Many Indians hold magico-religious beliefs about the etiology of mental disorders (Ram, Patil, and Gowdappa 2016). Some illness narratives include popular explanatory models for the onset and progression of substance abuse in the community. Subash is a middle-aged man who has been on opioid substitution therapy at the community outreach center for the past decade. While discussing a recent relapse, he and his wife described how the spirit of an old friend who had passed away due to a drug overdose had possessed his body and induced a craving for the drug. As a result, Subash suddenly had to leave home and purchase heroin. He reported that his deceased friend had been coming in his dreams for a few nights before the relapse, asking him to take some heroin for old times’ sake. Subash’s wife explained that this had happened before and they had sought the services of a black magic practitioner to successfully rid him of his friend’s spirit. Subash resumed opioid substitution therapy at the clinic, and attributed his recovery to the spirit leaving his body. His self-efficacy at abstinence was improved, he said, by the family holding prayers at the local temple, and by carrying out of certain rituals at home to ward off spirits.

Addiction as a disorder produces polarized reactions within Indian society. Publicly, substance users are labeled as social deviants who represent all that is wrong within a community, but a closer look at how substance users are perceived paints a different picture. While women seek treatment for substance use, or treatment is sought for them, when they are unable to do household chores, men come for treatment when their bodies no longer allow them to earn their wages. Where there is visible despair about substance abuse within a community, there is also acceptance of drug use as an enabling agent for men who work in tough conditions: rickshaw pullers and taxi drivers who work for sixteen to twenty hours every day in extreme temperatures, daily wage laborers who work on construction sites and in workshops and factories for long hours on small meals, and sanitation workers who are forced to work in unhygienic conditions. Many young men begin taking drugs when they take a job that requires a lot of manual work, and it is thought that heroin is needed to manage the body's aches after a hard day of work. A man who earned his livelihood sorting through garbage in the city dumps pointed out that it is impossible to work amidst the stench and the heat without using heroin and/or alcohol. These accounts starkly contrast with the perspectives of medical professionals and community members regarding drug use. What is termed 'misuse' of the drug by the treating team is considered proper use of the drug by those working in inhospitable conditions. The substance user's family understands that the men need to use heroin to rid their bodies and minds of the tiredness so that they can go to work the next day. Even after treatment for substance abuse is started, doubts may linger in the minds of the male substance user and his family, who wonder whether he was eating and sleeping better when he was taking drugs, and whether he might need to use drugs to work efficiently. An understanding of these perspectives helps us to match treatment to our clients' needs.

Indian society is slowly recognizing the problem of substance use among women. Academia has responded to this problem by analyzing associated demographic and clinical variables but there is a need for further qualitative studies of Indian women who use substances. It is important to look at substance abuse, especially female substance abuse, not as an incidental life event, but rather as a trajectory that a person is propelled onto due to several influences. Investigating the origins and processes of substance abuse from an anthropological perspective brings out the power imbalances, violence, inequality, and lack of autonomy that plague rapidly urbanizing Indian society (Garriott and Raikhel 2015). The study of substance abuse can help us better understand the social context within which these problems arise.

Angela Garcia's (2008) take on modern addiction through her portrayal of heroin abuse highlights the interdependency between social malignancies and drug abuse. At present, society expects women to play certain roles, such as mother, wife, sexual partner, and caregiver. Substance use by a woman is seen as a clear derailment from her expected role, which makes her more vulnerable to desertion when she needs help the most. A woman

with a substance use disorder therefore faces abandonment and abuse from society both before and after she has become dependent on drugs. She is plucked out of the social fabric when she needs it the most and this rejection compounds the specific factors that propel her further into addiction. Illness narratives of women who use substances can illuminate the role that detrimental psychosocial, economic, and environmental influences – as embedded in their everyday lives – play in their addiction. Understanding this can help to generate holistic solutions to the problem of drug abuse, and explain the gendered and cultural perspectives of the region on this issue.

The substance-use behaviors of the two women I have written about here demonstrate that the behavior of female substance users can be better understood by clinicians if it is interpreted in the context of family dynamics and cultural expectations as well as the stress and psychosocial pressure the women experience. In both cases presented here, the traditional model of managing a substance use disorder might be insufficient for meeting treatment goals. The treatment provider should understand the cultural expressions of distress of men and women with substance use disorders. The right questions need to be asked so that the client feels that the treatment provider is sensitized towards their problems. Strengthening mental health services that find, reach out to, and most importantly understand the milieu in which substance abuse arises is necessary. An in-depth analysis, such as the one offered by Das, that delves into the psyche of the Indian family makes it easier for the current generation of mental health professionals to understand the origin of the problems. The essence of Das's findings is that the focus needs to shift from the discrete problems that an individual presents within the clinic to cumulative adverse life-events as these fold into individual pathology. This would require constant improvisation on existing interventions based on each individual's needs. This personalized approach may not be currently feasible in all treatment settings but can nonetheless be used to inspire and guide practice.

The key hurdle that might be faced is the impracticality of trying to elicit such conversations in the hospital setting, where shortage of time due to high caseloads prohibits long interactions. Also, the established protocol in most treatment settings in India is that the medical practitioner is someone who writes prescriptions to treat the reported physical symptom. This practical and functional approach has so far proved to be convenient for both treatment seekers and providers. The onus of augmenting this approach with a more personalized interaction lies with the treating team. The families of women with substance use problems might need to be drawn out of their denial regarding the issue in some cases. The narratives described here show how the natal family can play the role of facilitators and mediators in the treatment of women's substance use problems. This is important in the resource-poor settings of developing nations, where structured psychosocial support services

usually do not exist and families are the existing social support structure. I am grateful for the efforts of Das and her colleagues and their success in writing moving accounts of the lives of the urban poor in India, which have helped me arrive at these conclusions. Her work is an authentic representation of the problems faced by communities that mostly stay muted by poverty and neglect. It has been an invaluable learning experience to study her findings and understand how illness can speak on behalf of an entire society.

About the author

Dr. Shalini Singh is a fellow in addiction medicine at the National Drug Dependence Treatment Center, All India Institute of Medical Sciences, New Delhi, India. As part of her training she worked at community-based clinics for drug abuse treatment in the urban slums of New Delhi, where she carried out clinical and psychosocial management of substance use disorders and trained in operational aspects of setting up and managing community-based drug abuse treatment clinics. She has an interest in understanding the sociocultural nuances of drug use in India, and in personalizing the management of substance use disorders to the needs of the individual and their family. Her research interests include exploring the bio-psycho-socio-spiritual aspects of addiction.

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