COMMENT

Mental health services: indigenous models of care in the community

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Measures of mental health services, including rehabilitation initiatives, have been pronounced to be inadequate the world over. Indicators such as mental health policy or legislation, financing of mental health care, availability of community mental health services, mental hospital beds, general hospital psychiatry beds and numbers of mental health professionals indicate a worse situation in low-income as compared to high- and middle-income countries (1). There has been some improvement in the situation between 2001 and 2004. However financial, infrastructural and human resources remain inadequate.

In an ideal world, acute care for psychiatric disorders should move seamlessly through maintenance treatment to rehabilitation. "The goal of psychiatric rehabilitation is to help disabled individuals to develop the emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support." This definition by Wulf Rossler (2) signposts the way to two intervention strategies: the first aimed at developing the patient's capacity to deal with the environment, and the second focusing on developing environmental resources to reduce potential stressors.

In Vellore town the numbers of destitute mentally ill persons, with conditions such that a casual passer-by would identify as a diseased state, has risen dramatically over the last three or four years. New initiatives by the state have been conspicuous by their absence. Apart from the beds in Christian Medical College, Vellore, the only in-patient beds available to patients from Vellore district, are in Kilpauk, Chennai. Charitable organisations for the destitute, elderly or mentally retarded individuals do not admit those with mental illness. Psychiatric medication is available only in district hospitals. Primary health centres have resisted stocking antidepressants and anti-psychotics on the basis that they could lead to addiction. The average citizen would baulk at invoking the legal system to admit a violent patient. Even if a disturbed psychotic individual is taken to Kilpauk, it is the responsibility of the person who brings the patient to apply for an admission order through a magistrate.

The majority of people who come to the Christian Medical College Hospital (CMCH), Vellore, for psychiatric care are poor. A significant majority cannot afford to undertake the cost of travel and the loss of income consequent to missing a day's work. Those with severe deficits are least likely to be able to afford to attend on a daily basis. Heavy workloads make it impossible for clinicians to provide formal psychosocial intervention for all who need it. Lack of social workers and shortage of occupational therapists limits non-medical interventions.

Against this picture of constraints and inadequacy, glimpses of care *by* the community, *for* the community, and *of* the community stand out in stark contrast. Almost invisible to those who work in the halls of academia is a network of people reaching out to help each other.

Goaded and coerced by a local one-man social work organisation called Udhavum Ullangal, run by a Mr Chandrasekhar, I submitted to his proposal that we study people on the streets who are in need of psychiatric care. Mr Chandrasekhar and I conducted rounds on five Saturday mornings, along a three-kilometre stretch of road in the periphery of Vellore town. The area studied lies centred on the academic general hospital psychiatry unit, and stretches into a rural area on one side and in a semi urban area on the other.

We stopped and talked to anyone who showed signs of mental illness. People of the community gathered round within a few minutes of our initiating a conversation. At least one person knew some details about the background of each individual. It became quickly apparent that every destitute person was being fed, clothed, and in some cases given a haircut and shave periodically. Children playing in the vicinity were able to tell us how far each person wandered and what particular talent each person harboured. We discovered that the "people of the street" eat only once in two or three days even if they are offered food more regularly. They come back to the same shopkeeper or household to ask for food. They take shelter in empty school buildings or doorsteps in inclement weather. They bathe by standing out in the rain fully clothed.

Acceptance of differences

Among others, we met Jeba (name changed). To a casual passer-by she is a middle-aged woman who has been living under a tree on the side of Arni Road outside a pawnbroker's shop for the past 20 years. She once functioned as a domestic help and lived alone in a self-sufficient manner. Over the last couple of decades the ravages of schizophrenia have rendered her unable to work, caused a constriction of her social circle such that she trusts no one but the pawnbroker, and has removed all instincts for grooming. She sits on a pile of bricks among the stray dogs that she feeds, scribbling in a

notebook whenever she is not shouting at invisible persecutors in foul language. She believes she is keeping accounts for the government treasury. She preserves, with a level of care that she does not waste on herself, a pile of about 20 books of unintelligible scribble. Her hair is gathered together in a dishevelled manner in a prominent topknot. Her clothes are not clean and her mouth is tobacco stained, but she does not smell bad and does not manifest any obvious signs of disease.

The pawnbroker, a middle-aged man from a lower middle socio-economic background, describes her as a blessing. He values the fact that she keeps intruders away from his shop and religiously sweeps the pavement outside. He involved her in the celebrations of his son's marriage and gives her sufficient money on a daily basis to ensure that she can buy what food she needs from a nearby stall. He understands that she is suspicious and does not accept cooked food even from him. His one regret is that she does not accept his offer of a cupboard to hold her notebooks and the spare clothes she possesses. When asked what will happen if Jeba falls unconscious or the highways department widens the road and demolishes her "residence", he points to the sky and says, "God will take care."

Jeba is being enabled to live with as much self-respect and autonomy as is practical in the circumstances. The attitude of her caregivers in their tolerance and acceptance is more sophisticated than the restrictive conventions of a professionally-run shelter or treatment facility for people with this severity of mental disease and financial deprivation. Previous acquaintances who tried to offer her medicines know that she will never accept treatment of her own accord.

Jeba's story poses a question to those of us who are mental health professionals: would it be more correct to enforce admission to a mental health facility and medical management? Should she be given a more "acceptable" role than her chosen one?

Neighbourhood watch

When Mr Chandrasekhar of Udhavum Ullangal picked up Ashok (name changed), an adult male shuffling along on his bottom on the streets of Vellore, he had been missing from his home for about five years. A small-time shopkeeper had noticed the wounded and crippled beggar and phoned for help.

His history was pieced together from bits of information that Ashok volunteered after he started talking, and led to the location of his family. It was discovered that Ashok had travelled from Bilaspur. His two remaining relatives revealed that he had been mentally unwell for about 10 years prior to the day he ran away from home. His social support had dwindled after his siblings died of mental illness and his parents of old age. He took to the streets in a state of severe psychosis.

When he was discovered in Vellore, he had depressed scars on his forehead and bony deformities on his left foot, suggestive of recovery from a serious injury. His right leg was covered between ankle and knee in an open festering wound discharging maggots, which Ashok was seen eating. He could not stand up or walk and spoke nothing more than a few words of Hindi. When taken into hospital, he made animal-like forays to the rubbish bin in the ward in search of food although he was being provided a healthy diet. Bladder and bowel incontinence made care difficult.

On Mr Chandrasekhar's request, Ashok was admitted to the Ida Scudder Ward in CMCH, Vellore. Since there were no relatives available to stay with him, Mr Chandrasekhar arranged for a young woman from a nearby village to help with his care. She was grateful for the Rs 100 per day she was paid for her services. Although she spoke no Hindi and knew no nursing, she made a relationship with Ashok that allowed her to overcome his resistance to being bathed, toileted and treated. The wife of a fellow patient who spoke Hindi helped translate when Ashok started talking and prepared, with her own extremely meagre resources, the north Indian dishes that he asked for.

Ashok's wound was beginning to heal when he succumbed to a cerebrovascular bleed and died. In two short weeks he had won the hearts of his doctors and nurses, and fellow patients. He had begun talking and singing Hindi songs as his psychosis receded. The last thing he did the night before he died was to promise to take his attendant on a guided tour of his hometown in a taxi just as soon he was released from hospital.

Ashok's story clearly highlights the inbuilt system of monitoring that exists in this community and the capacity for people to care for others. The shopkeeper who first noticed Ashok, the women who stepped into the breach to care for him, and Mr Chandrasekhar networked seamlessly, complementing the work of the doctors. Without this network Ashok would not have been found and could not have been admitted to CMCH.

Strengths exist within communities that, when integrated with formal services, reduce the burden of work and perhaps increase the efficiency of the system.

Human rights violations or practical response?

Ravi is a young adult with chronic schizophrenia who is kept restrained with an iron ring around his ankle, chained to the main support post of the thatched hut in which he lives. His parents have the financial means to look after him, but are unable to do so because of age and infirmity. Cardiac disease, cerebrovascular thrombosis and cervical spondylosis have rendered them unable to deal with his violence and agitation, disregard for hygiene, voracious appetite, and insatiable demands for biscuits and *beedis*. They have taken him to all known government-run mental institutions, and records show that he received treatment from CMCH, Vellore, as well. When no treatment was successful, they handed him over to a religious centre where they felt he was being looked after well. Post-Errawadi (the notorious incident where a fire gutted a religious establishment and killed shackled mentally ill residents), the government raided this centre and released all residents. Ravi ran away from his home in a short while. He was traced to a village in neighbouring state when a passer-by found him, having collapsed on the roadside, after suffering

a fracture of his humerus in a road traffic accident. The only option available to his ageing parents was to pay distant relatives to look after him on a piece of land that they owned in a neighbouring village. The couple farmed the land, and reared goats, chicken and Ravi.

Ravi empties his bowel and bladder whenever and wherever he feels like it. He has to be given a bath and dressed forcibly. He eats messily and gorges himself on any given quantity of food. In spite of his disregard for hygiene, his guardians keep his immediate confines clean. He is never left alone. He shows no signs of abuse or starvation. Oblivious to the tragic situation Ravi focuses his energy on accosting passers-by and demanding *beedis*. In order to do this more effectively, he climbs on to the roof of his hut unencumbered by his non-united fracture or the chain around one leg.

Attempts to give him medication or involve him in activities produced no success. Parenteral depot anti-psychotics made no difference to psychopathology. Psychological intervention was limited by the paucity of Ravi's speech, comprehension and concentration. It would not have been possible to admit him to CMCH because no relatives were available to live with him in the family ward system. The relatives refused to take him back to the government hospital because of unhappy past experiences.

Ravi's story would be grist to the mill of human rights activists. In recent times the Errawadi incident has thrown a pall of suspicion upon indigenous initiative in the area of providing care to those who have mental illnesses and whose families are unable too cope. However, when we pontificate and rush to release restrained sufferers, we forget that they were there because there were no alternatives.

Relatives keep seeking treatment within the bounds of what can be afforded. They are not blind to the abuse and neglect that is fostered in large mental institutions. Perhaps recent press has not dwelt upon the state of our government mental hospitals. One hears that overcrowding, unhygienic environments, sexual and physical abuse, mentoring in antisocial behaviour, and near-starvation conditions are de rigueur within these halls. Even more hidden is the reality about how difficult it is to be admitted into one of these institutions.

If places like Errawadi exist, it is only because of the lack of feasible and effective alternatives. The choice between suffering unending physical violence at the hands of mentally ill offspring and availing any possible socially acceptable respite is no choice at all.

A home for the homeless

In Thirupathur 26 men obviously suffering from mental illnesses who live on the streets of Vellore district have been gathered together and given food, shelter and protection against the risks and complications of their diseases. The man who coordinates this effort was mentored by Mr Chandrasekhar, and had already established a branch of Udhavum Ullangal in Thirupathur. He was so moved by the plight of the homeless mentally ill in his hometown that he jettisoned a career in computer applications in order to help them. Armed only with the conviction that they needed to be helped, Mr Ramesh moved the government to give permission, raised the required funds, and recruited untrained compatriots to help run the home. He organised careful records of admission and treatment, administered whatever medicines were prescribed by visiting doctors, provided occupation, generated incomes from the handiwork of the residents, and deposited money earned into savings accounts in the local post office. He and his team of seven have proved that they are able to make a relationship with men who do not speak, or speak only north Indian languages, and who suffer from delusions and hallucinations. He realises that left to themselves they would do nothing but smoke or wander aimlessly, and that it is highly unlikely that he will receive thanks for his efforts. Not satisfied with looking after their bodily needs, this home has given its residents horse rides, motorcycle rides, meals at local restaurants, special food and new clothes on festival days. Mr Ramesh prays with them and offers them opportunity to apply the same *chandanam* that he uses on their forehead as well. Valiant and repeated attempts are made to trace the families of the residents. Even in the rare event that the family is found, poverty and old age among relatives limits the residents' return to their homes. In some cases relatives have forbidden the sharing of information of their whereabouts with the resident because of the level of conflict that had existed in the past.

This care is provided on a monthly budget of Rs 2,000 per person. Mr Ramesh values the medical consultation that the department of psychiatry provides, but this amounted to three hours once in a week for the first year, and once a month currently. All he seems to need in order to do this magnificent work is the access to guidance and instruction. He brings to the table the initiative, resourcefulness, empathy and courage required to accomplish a project of this nature.

On a smaller scale

Kalyani is a 40-year-old uneducated woman who works as a domestic help in an upper-class household. Her husband contributes little to the care of their three daughters or his wife's household. In spite of having to manage her family on a salary that is far less than adequate, she has taken on the care of a 20-year-old mentally retarded daughter of a man who abandoned her after he married for the second time. Kalyani takes the girl with her to the house where she works and, with tact that would put an occupational therapist to shame, cajoles her to help with simple chores. When a temper tantrum looms on the horizon, a tea break is allowed. Deficiencies are glossed over and buffered rather than criticised or judged. When reviews are required for management of seizures and psychosis, Kalyani brings the girl to the doctor and gives a better report than the father himself. She independently recognises extra-pyramidal symptoms. She is able to accept a response to treatment that is far short of complete recovery. She supervises medicines and self-care gently in the best traditions of rehabilitation.

Why does she do this? Kalyani says she could not bear to see the girl neglected and wandering the streets. What is the probability of a professional being able to work with the flexibility and understanding that that this relationship displays, and, above all, for little or no remuneration?

Lessons from these stories

These samples of the culture of care cannot be allowed to conceal the neglect, abuse and persecution of the mentally ill that lurk out there, in the cracks between these "idyllic" stories. The undeniable reality of the rich resource that coexists with the deficiencies is the fuel line to which professionals could seek to connect. It is possible that when science filters through the hearts and minds of the community, and when professional endeavour is guided by social norms and culture, we will witness a fine-tuning of "service-to-need" that is lacking today. If, in addressing the pathology of those who have fallen along the wayside, territorial instincts and academic gratification are subjugated to the fulfilment of need, it is possible that we will succeed in making much more of a difference with the limited resources that we have.

The recognition of the central role of the patient's perceptions and preferences as a relevant mission in rehabilitation is gaining ground (3). In cultures where the individual continues to be rooted within a family and community, the lead given by those who form the support networks can scarcely be ignored.

The messages from the community are at least two-fold. The first is that a wealth of resource already exists in our communities. The second is that where basic amenities essential to human life are in short supply, providing these resources to those in greatest need is more of an imperative than instituting sophisticated treatment facilities.

The nature of care

Many levels of care exist in the community. From the point of view of a medical model, or in the ethicist's eyes, there would be much to be desired within some levels. In the absence of these levels of care, however, sufferers would probably be worse off than they are today. While we await the advent of adequate care, would it be worthwhile empowering those who toil?

The process of empowering those people who toil translates into access to diagnosis, prescription and a listening ear. Not many demands are made. A tired mother wants to cry a while. A father wants to ask why fate is so cruel. A spouse wants efforts to be validated. An absent offspring wants to be forgiven. Parents want to ask what will happen to their suffering offspring after their time. With open access to this sort of discussion, interviews last less than 15 minutes.

People like Mr Chandrasekhar and Mr Ramesh approach the mentally ill with respect and compassion. The community reaches out in socio-culturally appropriate ways, and in ways that are within their means.

Village women who had formed a self-help group were asked what would make it worth their while to liaise with psychiatrists and supervise the treatment of the mentally ill in their village. A quick consensus was reached on the princely sum of Rs 300 per month.

Previous efforts to take care into the community may have lost momentum because human resource was being fitted into scientifically prescribed strategies. It is possible that being led by already existing initiatives, vital energy can be more successfully kindled to greater effect.

Focus of care

The burden of severe and urgent need in a country like ours is the lack of basic amenities. These can be supplied by redirecting resources and including willing untrained hearts.

Affordable medicines and subsidised transport to hospital may do more to hasten a return to social reintegration than social skills training. Local daycare facilities, however basic, would reduce the burden of caregivers by allowing them to return to work, perhaps more effectively than family counselling. For some strata of mentally ill, one square meal a day would be much more protective of their souls than medication.

Conclusion

Rehabilitation in psychiatry would be wealthier if it were informed by already existing systems of care in the community. The nature and priority focus of non-professional initiatives seem to be more in tune with the needs of the people. The adherence of these models to socio-cultural norms and financial constraints predicts greater sustainability.

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