MENTALLY-CHALLENGED WOMEN AND THE MENTAL HEALTH POLICY OF INDIA

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ABSTRACT

Objective: *We studied the role of a rural non-profit agency in enhancing social life of the mentally-challenged women in Gujarat State, India.*

Material and Method: *Between January and August 2009, 94 women who were diagnosed of mental retardation from mild to severe condition were observed to collect data on the age, background, origin (village/town), duration of stay, IQ level, social characteristics, and individual case histories from 1987 to 2008.*

Results: *The average duration of stay of women in the shelter was 11.5±4.7 years (range 1-22 years) and 57% of them stayed for over 10 years. During the interviews, the women expressed their intention to remain in the shelter since they felt more secured to live in a caring social setting.*

Conclusion: *We recommend the government to make mental health policy reforms so that better long-term care can be accessed by the mentally-challenged women at the grassroots across India.*

Key Words: *Mental health, psychology, policy, reform, women, rehabilitation.* ***Nobel Med 2014; 10(2): 50-54***

HİNDİSTAN'DAKİ ZİHİNSEL ÖZÜRLÜ KADINLAR VE AKIL VE RUH SAĞLIĞI POLİTİKASI

ÖZET

Amaç: Çalışmamızda kar amacı gütmeyen bir ajansın Hindistan'ın kırsal bölgelerinden olan Gujarat bölgesindeki zihinsel özürlü kadınların sosyal hayatını iyileştirmekteki rolünü inceledik.

Materyal ve Metod: Yaş, arkaplan, köken, barınakta kalma süresi, IQ seviyesi, sosyal karakteristik özellikleri, ve 1987-2008 tarihleri arasındaki bireysel olgu geçmişleri hakkında bilgi almak amacıyla hafif veya yüksek dereceli zihinsel retardasyonlu 94 kadın Ocak ve Ağustos 2009 tarihleri arasında gözlemlendi.

Bulgular: Kadınların barınakta ortalama kalış süreleri 11.5±4.7 yıl (1-22 yıl aralığında) idi ve %57'si 10 yılın üzerinde kalmışlardı. Görüşmeler sırasında kadınlar barınakta kalmak istemelerini sosyal olarak önemsendikleri ortamda daha güvende hissetmeleri olarak açıkladılar.

Sonuç: Hükümetin zihinsel sağlık politikasi konusunda zihinsel özürlü kadınların Hindistan'da daha uzun sureli bakıma erişim sağlamaları için reform yapmasını öneriyoruz.

Anahtar Kelimeler: Akıl ve ruh sağlığı, psikoloji, politika, reform, kadın, rehabilitasyon **Nobel Med 2014; 10(2): 50-54**

INTRODUCTION

People with mental retardation are not treated equally and with respect in society. As a result, they seldom have access to public health care. India's first hospital for the mentally ill was started in Mumbai in 1745.[1] The colonial administrators in India enacted the Lunacy Act in 1858 when India was under British rule. The mental hospitals came under the management of Civil Surgeons instead of Prison Managers only in 1912. Seventy five years later, the Lunacy Act was rephrased as 'Mental Health Act 1987'.[2] Medical experts argue that shortage of staff and lack of special rehabilitation shelters continue to pelage the country's mental health infrastructure.[3,4]

According to the mental health statistics, a total of 60 to 70 million people suffer from serious mental disorders across India.[5] The mentally-retarded women suffer the most since they have fewer opportunities to access public health care including professional rehabilitation shelters. Besides, poverty, homelessness and social stigma further complicate their access to better life. According to a report published in 2004, all of the women with disabilities in India's eastern Odisha state were beaten at home; 25% of them had been raped while 6% of them had been forcibly sterilized.[6] Nonetheless, if the society, especially the government, non-government and corporate sectors provide better opportunities via better-managed professional shelter, the mentally challenged women can expand their social skills and support network to enhance their lives. Furthermore, the professional rehabilitation shelters can provide safer environment for their long-term care and survival.

In this paper, we present data on the work of a non-profit agency that provides free long-term professional care for the mentally-challenged women in Gujarat State, India. We also recommend mental health policy reforms so that better support can be provided to the women across India.

MATERIAL and METHOD

The present study was conducted at the Muni Seva Ashram located in Goraj near Vadodara city (22º 17' 59' N, 73º 15'18' E) in Gujarat State, India. It harbors 300 acres of natural landscape that includes farm, forest, river and ravine with facilities such as shelter for mentally-challenged women, orphanage, home for elderly, animal shelter, kindergarten, high school, nursing college, and cancer research centre and hospital that provides cost-effective treatment. Between 8 January and 26 August 2009, the mentally-challenged women shelter was visited and interviews of social workers, psychiatrists, managers, and residents were carried out to collect data on the history of patients and their activities.[7] A total of 94 women were diagnosed of mental retardation from mild to severe condition and data on age, background, origin (village/town), duration of stay, IQ level, social characteristics, and case histories from 1987 to 2008 were pooled from the archives of the shelter. Statistical Analysis System software was used for data analysis and all mean values are presented as ± 1 standard deviation.[8]

The authors obtained ethics and welfare committee approval (date: 2 January 2009, reference number: MSA/EC/026) for this study from the Muni Seva Ashram that manages the shelter for the mentally-challenged woman. The authors interviewed participants only after obtaining their consents in the presence of the resident psychiatrists and social workers.

RESULTS

After a patient was admitted in the shelter, an evaluation was carried out by a team of experts that include psychiatrists, physicians, and social workers led by the Chairman to understand the mental, physical and social abilities. Four social workers took turns to care for the women round the clock. They were supported by four special educators trained in psychiatry, sociology, healthcare and social work, and they taught the women basic skills necessary for mental development. The educators had been working for over 2, 4, 6 and 9 years, respectively while the chief psychiatrist had 15 years of experience. The long-term association of staff and the mentally-challenged women appears to play a crucial role in fostering social relationships. In addition, 11 technical personnel provided services such as cooking, cleaning, gardening, laundry and maintenance work. All women went through tests in numerology, psychology, hearing, speech, vision and special education, and then specialists analyzed the results to develop a treatment plan to enhance basic skills.

The shelter had 25 rooms and four women shared a room (size 48 m^2). The building was well ventilated with windows and doors; the rooms were equipped with closets, beds, blankets, pillows, fans and tables. The selection of roommates was based on IQ levels where low, medium and high IQ individuals were mixed so that those with higher IQ could assist others. Arguments and fights occurred at times and social workers and educators intervened to mitigate the crisis. The arguing parties were later given counseling to improve social relationship.

The daily schedule during the study was as follows: 6:00 am: Wake up call followed by a prayer for 5 minutes. 6:00 to 7:30 am: Getting ready for the day. About 25 participants needed some sort of →

Table 1: The age at enrollment, period of stay till date (year) and the average IQ scores for 94 mentally-challenged girls came from town or villages.

	n	Age at Enrollment (y)			Period of Stay (y)			IQ level		
		Mean		SD	Mean		SD	Mean		SD
Town	64	29.5	±	7.7	11.7	±	4.7	39.7	±	15.1
Village	30	26.0	±	8.3	10.9	±	4.8	41.2	±	16.9
Mean	94	28.4	±	8.1	11.5	±	4.7	40.2	±	15.7

help in taking bath or brushing so social workers took turn to assist. 7:30 to 8:30 am: Breakfast was served at the dining hall; nutritionally-balanced diet recommended by physicians was given that included vegetables, beans, rice, wheat, bread, milk, tea, etc. 8:00 to 9:30 am: Participants were divided into sub-groups led by social workers and educators to participate in activities such as cutting vegetables, preparing food, cleaning rooms, cleaning yards, cleaning the campus roads, gardening etc. Participants moved around the entire ashram and interacted with people while working. 9:30 to 9:45 am: Break time for clean up. 9:45 to 10:15 am: Yoga class with simple physical/breathing exercise. 10:15 to 11:00 am: Class room study included reading, writing and story telling. 11:00 to 12:00 pm: Lunch. 12:00 to 2:00 pm: Group activity guided by educators. The participants produced various types of handicrafts and paintings; the art works were displayed in the entrance and guest rooms of the shelter. They were taught to assist workers with cooking, milking cows, cleaning, and gardening regularly and they enjoyed the helping activities. 2:00 to 3:00 pm: return to room for rest. 3:00 to 3:45 pm: Tea time (milk, malt, tea, cookies, and snacks). 3:45 to 4:30 pm: Drama session where educators engaged them in drama. 4:30 to 5:30 pm: Sports included hide-and-seek, badminton, balancing games, sack race, running, jumping, and tug-of-war. 5:30 to 6:30 pm: Free time to move freely in the campus to interact with people. 6:30 to 7:30 pm: Dinner. 7:30 to 8:30 pm: Watched television or engaged in singing and dancing. 8:30 to 8:45 pm: Back in the room for prayer and the women reviewed their day's activities. 8:45 to 9:00 pm: Participants brushed and used salt water for gargling to avoid throat infection, and got ready to sleep. 9:00 to 10:00 pm: Bed time. About 20 of them suffered from epileptic seizures while an additional 24 took some sort of medication for mental illness daily while the rest did not take regular medication.

From 1987 till 2008, 94 women joined the home and 58.5% arrived between 1997 and 2002. The average IQ scores was 40.2 (±15.8, range 20-75). The average age at the time of enrollment was 28.4±8.1 years and 20.2% of them joined before the age of 20 (Table 1). The youngest joined at the age of 16 and the eldest at the age of 45. Local law enforcement officials brought 20 orphans abandoned by their families with no background information. Six died natural deaths during the last two decades and were cremated. The shelter promotes sustainable living and all facilities have solar lighting and heating facilities. In fact, the Muni Seva Ashram has launched a prototype of the world's first solar crematorium. It promotes organic living and all the food items eaten by the participants, staff and visitors are organically grown at the eco-farm.

The women who came from towns were slightly older (29.5±7.7, n=64) than those from villages (26.0±8.3) and the difference was not significant ($p>0.05$). The average duration of stay was 11.5±4.7 years (range 1-22 years, Table 1) and 57% of them stayed more than 10 years that showed the role of the shelter in providing better long-tern care for the mentally-disabled. During the interviews, all the women participants expressed their desire to remain at the shelter for the rest of their lives; they felt secured with the caring social atmosphere. They said that the staffs give them freedom so they are free to move around the campus, and also visit relatives whenever necessary. In addition, the participants are given a month long vacation (annually in May) to spend time with their families. The ashram takes all participants on a picnic for 2-3 days annually to some touristic locations within Gujarat or elsewhere. The managers did not collect fee for housing the participants from their families; they also did not receive financial aid from state and federal agencies. The shelter has been raising funds through overseas friends, mainly from USA to cover the operational costs. At present, 150 women have been in the waiting list to be admitted, but due to lack of funds, they are unable to be accommodated.

When the participants expressed negative behaviors, educators taught them positive behaviors. For example, when a 15-year old participant arrived in 1999, she broke 10 glass windows on the first day. She scratched her arms, hands and legs till bleeding. Staff knew her likeness for music so they played music to divert attention. They also taught her on the technique to make jewelries out of beads, which she liked, and thus she was able to redirect her self-destructive attitude towards constructive work. The root cause for the aggression lied in the way she was brought up in an impoverished family of farm workers with an elder brother and two sisters. Whenever she fought with siblings, she was beaten by the brother with stick. On arrival, she was unable to speak. During the interview, she spoke with confidence, showed her writings and handicrafts, and answered questions, which shows that the social environment and better care in the shelter might have helped with the mental development. →

Prior to arrival, all women had a history of some sort of family negligence, abuse and violence. After spending time in a social setting at the shelter, they have greatly improved their mental and social abilities.

During interviews, all women stated that they were safe, comfortable, and secured in a social setting; they did not plan to return to their relatives. When asked why they had no interest to return home, they replied that the shelter was their home, and the staff their family. Every time when they passed through the Chairman's office, they all greeted passionately and called him 'dad'. Recent findings reinforce this observation and the importance of individuals with mental retardation to form relationships with individuals without mental retardation for two reasons.[9] They must first participate in normal social situations so that they could learn socially appropriate ways of behaving. Secondly, by allowing individuals with-and-without mental retardation to initiate relationships, social stigmas and associated stress may decrease. Moreover, social relationships play a key role in bringing happiness, self-esteem, and psychological functioning besides enabling individuals to cope with life transitions, crises, and day-to-day anxieties.[10,11] Unfortunately, over half of India's government-run mental institutions do not have specialized rehabilitation facilities to promote social skills.[12] Furthermore, research shows that living among those with disabilities in non-judgmental atmosphere enhances self-esteem and social skills.[13] Our observations confirm with studies from other countries that mentally-challenged women could interact with others to expand social support network, and to increase a sense of self-determination.[14-16]

DISCUSSION

India has recorded rapid economic growth in recent years. But according to a recent survey, it ranks the lowest with only 0.9 beds per 1000 people surveyed by among seven countries that include US, UK, China and Singapore.[17] So the country must invest more to build hospitals to meet the WHO mandate of minimum 3 beds per 1000 people. The vast majority of people (70%) in India inhabit rural areas that often lack trained doctors, psychiatrists and basic sanitation.[18] To make matters worst, most private hospitals require money before service leading to serious financial burden on the impoverished rural people. Although the Mental Health Act encourages state governments in India to help the mentally challenged people, the problems at the grassroots have not been solved till date. Many states were unable to implement the law due to budget constrains and lack of support from politicians and bureaucrats.[19]

Moreover, the Mental Health Act states that voluntary admissions can occur only in designated psychiatric hospitals and involuntary admission requires the counsel of a psychiatrist and two medical practitioners. But in reality, most psychiatric hospitals do not have a psychiatrist and two general practitioners at one given time. The incompetence of the act was exposed when India's Supreme Court intervened in two landmark judgments. It ordered an enquiry into the poor management of government-run mental hospitals with human rights violations. The second intervention occurred after the '2001 Erwadi incident' in Tamil Nadu State where an accidental fire killed 28 mentally-challenged people since their legs were chained to stone pillars.[20]

After the court reviewed the brutal incident, it handed over the monitoring of mental hospitals to the National Human Rights Commission. But the question is: Can the National Human Rights Commission ensure safety for the mentally-challenged women? The following stories show the difficult path ahead. A mentally-challenged young woman orphan was raped by a security guard in the government-run shelter in Chandigarh (Punjab State) in March 2009. Later, pregnancy was detected in May 2009. Under the pressure of local media, the case went to the Supreme Court. The court ruled that the victim could carry on with her pregnancy.[21]

Later the rapist security guard was arrested since his DNA matched the victim's infant. Similarly, a 36-old mentally-challenged woman was raped by an employee of the government-run mental hospital in Kolkata, West Bengal State.[22]

So, it is about time that the government must provide a comprehensive social security system for the mentally-challenged women so that they can be protected in society. Even India's capital city, New Delhi lacks professional shelter for the mentally-challenged girls.[23]

Likewise rehabilitation centers to care for the mentally-challenged women are not common across many states of the country. This shows the apparent inadequacy of monitoring by the National Human Rights Commission and the lack of enforcing Mental Health Act across India. But this problem can be solved if the government initiates policy reforms to incorporate healthcare NGOs and corporations so that the mentally-challenged can be helped at grassroots level. The defenselessness of mentally-disabled women towards terrorism, diseases like HIV-AIDS, and incest are rarely discussed in India. Also, incest issues are not publicly discussed so data are lacking →

on the number of incest cases involving the mentally-disabled women in India. Families tend to abandon the mentally-disabled women because it's deep-rooted taboo bringing only shame. Also, there are no statistics available on the government websites on the number of rapes involving the mentally-disabled women. Social activists argue that the mentally-disabled victims' testimonies are often fractured owing to impairment while their testimonies are not taken with due importance by either the police or the courts. Nevertheless, the situation may change in future since the Justice Verma Commission had suggested changes to the law specifically for disabled rape survivors and the recommendations were included in the special ordinance on sexual violence contained in the Criminal Law Amendment Bill 2013.[24]

As a matter of fact, the government alone cannot mitigate the crisis involving trained staff in mental hospitals, so we recommend policy reforms to incorporate an effective government-corporate-NGO partnership that can resolve the crisis timely. Healthcare NGOs can be added to the partnership to raise funds, train staff, and build more shelters so that mental illnesses can be identified at rural levels at a faster rate.

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