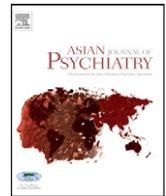




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## Overcoming cultural barriers to deliver comprehensive rural community mental health care in Southern India<sup>☆</sup>

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### ABSTRACT

**Aim:** To describe obstacles overcome in establishing and implementing a comprehensive community psychiatry program in rural India.

**Background:** Studies in low income countries point to a significant association of common mental disorders with female gender, low education, poverty, lack of access to running water in the home, and experiencing hunger. Gynecological complaints are associated with an increased risk of mental disorders. Suicide is a major public health problem with women outnumbering men in completed suicides in India. Among barriers to care are low value given to mental health by individuals in society, high prevalence of mental and neurological problems, apathy toward psychosocial aspects of health and development, and chronic lack of resources.

**Design/methods:** We developed and implemented a program of care delivery thus (a) targeting the indigent women in the region; (b) integrating mental health care with primary care; (c) making care affordable and accessible; and (d) sustaining the program long term. I also review pertinent articles to demonstrate our success.

**Results:** We provided mental healthcare for the indigent using a successful and vibrant model that overcame hurdles to treat patients from 187 villages in Southern India. Of note are low resource use, and the lack of accessibility, comprehensive care, the use of indigenous case workers and primary care professionals.

**Conclusions:** Rural mental health care must be culturally congruent, integrate primary care and local community workers for success.

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### 1. Introduction/background

Two thirds of India's households are in rural areas. More than one-third of India's population (35%) is under age 15. Twenty eight percent of the rural population is in the lowest wealth quintile. Forty one percent of women aged 15–49 have never been schooled. Thirty five percent of women have experienced physical or sexual violence, including married women. Of 43% of married women who were employed, a quarter received no payment for their work and 12% were paid only in kind (International Institute for Population Sciences and Macro International, 2007).

Low income countries have limited resources for mental health care. Given the poor congruence of mental health research, practice, policy and services in comparison to developed countries,

as well as the lack of specific study instruments, support from scientific journals, community participation, and poor policy, the vast majority of the citizenry are deprived from obtaining psychiatric care.

Mental disorders are highly prevalent, have greater effects on role functioning than other chronic physical illnesses. Across the world, such disorders have a substantial role in disability. Seventy six and 0.3–85.4% of serious cases in less developed countries received no treatment in the year before assessment, often due to structural barriers. The reallocation of treatment resources is recommended by the World Health Organization to substantially decrease the problem of unmet needs for treatment (WHO, 2004).

A study from four low income countries points toward a significant association of common mental disorders with female gender, low education, poverty, lack of access to running water in the home, experiencing hunger, and difficulties making ends meet. Gynecological complaints are associated with an increased risk and this association remains evident after adjustment for socio-economic factors.

Suicide is a major public health problem. Suicides stem from interpersonal problems, domestic disputes, and financial problems

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as the underlying causes. Women, as well, outnumber men in completed suicides in India (Isaac and Chand, 2007).

Sartorius in 2002 has pointed to barriers to treatment. Among them are low value given to mental health by individuals in society, high prevalence of mental and neurological problems, apathy toward psychosocial aspects of health and development, and chronic lack of resources. Methodological problems and the proper use of instruments that are appropriately translated to the local language are other drawbacks (Sartorius et al., 1986; Isaacs et al., 2006).

Isaacs and others recommend that mental health research and practice should be tied to programs dealing with physical health, which are currently lacking. Anxiety and depression in women present commonly as physical symptoms. The appearance of anxiety and depression as predominantly somatic concerns is a cultural mode of illness expression (Isaacs et al., 2006).

Developing and implementing a program of care delivery would therefore require (a) targeting the women in the region; (b) integrating mental health care with primary care; (c) making care affordable and accessible; and (d) sustaining the program long term.

Our initial goal was to identify the needs of the indigent mentally ill in rural areas, followed by the development of the program. We needed to fund the program, train personnel, and streamline a process of care delivery to meet the needs of the indigent.

We conducted an initial epidemiologic survey of 25 villages in 2003. The results are published in earlier papers (Isaacs et al., 2006; Srinivasan, 2006). Details of the epidemiological survey and outcome assessments are described in those papers.

In 2003, of 12,886 persons, 574 suspect patients were identified, of whom 181 were males (31.5%) and 393 were females (68.5%). Of the 242 patients who were evaluated in the clinic between March and July 2003, depressive disorder was the primary diagnosis in a majority of patients ( $n = 176$ , 90%), while fewer subjects had a diagnosis of anxiety disorder ( $n = 16$ , 8%) and somatization disorder ( $n = 4$ , 2%). Most women were in the age group 21–40 years. The most common co-morbid psychiatric diagnosis was anxiety disorder. One hundred twenty two patients (62%) reported significant ongoing life stressors. Interpersonal difficulties, especially with the mother-in-law ( $n = 78$ , 40%), financial problems ( $n = 53$ , 27%), alcoholism in spouse ( $n = 37$ , 19%) and bereavement ( $n = 27$ , 14%) were the most commonly reported stressors. Fifty seven patients (29%) had co-morbid medical conditions.

In a subsequent study, in 2006, outcome was assessed in 300 randomly selected patients of 650 individuals who responded positively to questions on common mental disorders. Final data on 196 patients were analyzed. Details are in our published paper. We used a structured interview, a standard of living index, depression rating and quality of life scales\*. Of 154 subjects, lack of transport, financial difficulties, and inability to take time off work were causes of noncompliance. Logistic regression analysis pointed to comorbid medical conditions, and life stressors as significant variables predicting a poorer outcome, while past psychiatric illness predicted a better outcome. Co-morbid psychiatric disorders, especially anxiety, were associated with incomplete resolution of symptoms and a poorer quality of life. Non-compliance was subsequently addressed through outreach, thereby improving outcomes for depressed women.

(\*Schedule for Clinical Interview for DSM4 R, Standard of Living Index, Hamilton Depression Rating Scale, World Health Organization Quality of Life scale.)

This paper focuses on the cultural obstacles we had to overcome to deliver such care.

## 2. Methods

We conducted a Pubmed and Scopus search to identify key articles that discussed mental health and primary care of indigent women in underdeveloped countries using the search terms noted above. We compared our methods to others noted in selecting village women as caseworkers, using the existing infrastructure and an outreach model to accomplish care delivery. (Since no human subject research is involved in this manuscript, there was no Institutional Review Board (IRB) approval solicited. However, all work published earlier was reviewed by the IRB).

## 3. Results

### 3.1. Project and care delivery

Rotary International is a humanitarian service non-religious organization, open to all persons regardless of race, color or creed.

In 2002, the Rotary Club of Columbia, Maryland undertook the task of providing mental health services in rural Southern India, 30 km outside of Bangalore, in a village called Mugalur. Funds were raised, a partnership established with local clubs, and a linkage consolidated with St. Johns Medical College, Departments of Psychiatry and Community Health. Initial epidemiological surveys of 12,000 households and the prevalence of common mental disorders are the subjects of papers published earlier (Isaacs et al., 2006; Srinivasan, 2006).

The established clinic called Maanasi (meaning strong minded woman) took into consideration the assimilation of psychiatric care into primary health care, use of trusted care providers, a 'walk-in' setting, regular clinic hours and 24 h emergency care; we employed locally residing female case workers well versed in the local languages and culture and trained at the medical school; also, efforts were all voluntary, service was free or charged a nominal affordable fee; junior faculty evaluated patients to provide continuity of care and supervision and outreach was instituted to address non compliance and relapse. Screening by a resident primary care doctor was the first step for every patient in order to address multiple needs and to rule out somatic disorders. Grant funds are overseen by Rotarians who are provided a monthly report. Admissions are sent to a hospital attached to the medical school by grant funded transportation.

Currently the clinic has around 1490 registered patients, drawn from 187 villages, and continues to serve many in a comprehensive manner.

### 3.2. Obstacles overcome

To establish a system of care delivery, we had to overcome several culturally related obstacles. The program was funded and overseen by leadership from the United States and used a model from the Johns Hopkins Hospital community psychiatry program.

Broadly, the barriers consisted of resistance from care-givers and care-obtainers, cultural obstacles and pitfalls in the process of care access and delivery, the need for adequately trained caseworkers who would bring in potential patients, and finally, sustaining the entire venture in continued mental illness management.

#### 3.2.1. Resistance from care obtainers

*Needs assessment:* First, we identified stakeholders who resided in the key villages, who would be drivers in care acceptance by the villagers.

Obstacles overcome to implement care delivery were many. Our first planned initiative was to conduct an epidemiological survey to assess 'caseness' among the local households in 25 villages (12,000+ persons), the targeted number. To conduct the survey, we had to obtain the consent of the village 'panchayat', a local self governing council with traditional authority over villagers. This was required to encourage widespread participation. In doing so, we recognized untreated illness in one panchayat member who became our strong advocate. Over 12,000 households were surveyed during the first wave (Isaacs et al., 2006).

The cultural norm is to approach women who are the families' caregivers, are reachable at home during the day, and are to be interviewed by other women who live within the largely agrarian community. We chose four female caseworkers who had a high school education, spoke several of the local languages and were willing to serve the mentally ill. These caseworkers had to be women of good standing in the community, married (single women going door to door interviewing men would not be accepted) and perceived as leaders by others. Our caseworkers led the 'Mahila Mandals', or women's cooperatives, held monthly in the villages. We took advantage of these cooperatives that drew women in leadership positions from many villages to educate them about mental illness (Vlassoff, 1982).

We ascertained who would be delivering care by researching primary health care center locations, subsidies available (which were none), and willingness to serve the mentally ill. We did a 'market analysis' by identifying our potential patients, informally surveying the villagers during meetings with the cooperatives, aligning the payment structure with the socio-economic status of most villagers, and establishing a sliding fee scale. Poor patients were provided free care. We accomplished this by emphasizing the humanitarian nature of our venture, with demonstration of fund availability. We recognized that we would have to provide all training and funding needed. All funds were raised by volunteer efforts by the author and fellow Rotarians. Skepticism about the venture was raised by medical colleagues, village leaders and contributors.

We organized medication needs and noted cultural threats to non compliance with medications. For example, a myth was perpetuated by some villagers that antidepressant medications would cause blindness. Village mafia members threatened some patients who were encouraged to stop drinking because they could not sell liquor at inflated prices. Other faulty local practices such as an unqualified pharmacy owner giving advice on medications, skipping clinic visits because of 'shame' in accepting free medications, or abusive treatment by mothers-in-law with whom the depressed women lived; all were addressed by our case workers through home visits. The triage function of the primary care physician at Mugalur facilitated the de-stigmatization and promoted seamless patient entry.

*Case examples: Padma's husband suffered from Schizophrenia, drank, and physically abused her when drunk. Our case workers visited her home several times and finally persuaded her husband to come to the clinic for treatment. When he was symptom free, he stopped drinking. Padma herself was diagnosed with Major Depression. Since medications were given free of charge for her husband, she declined to take free care for herself because she was ashamed to receive so much charity. We made a home visit to encourage her to be treated in order to better care for her husband, to which she later agreed. They were both then able to eke out a livelihood as farmers to support themselves.*

*Banu, a young, newly married woman who was depressed and suicidal, was mistreated by her mother-in-law who made her shoulder much of the physical household work. Banu and her husband were interviewed at the clinic and the social worker made a visit to her home. Interventions made were educating her husband and mother-in-law*

*about depression, its physical signs and symptoms, termed 'bejaar kayile' in the local language by our caseworkers, regular home visits by them, and guided assistance in structuring Banu's day with lowered expectations of her until she was well.*

We addressed the need for follow up and discussion of illnesses such as depression through repeated outreach. We educated villagers in women's cooperatives called *Mahila Mandals*, where women gather in villages once a month for group discussions on micro-lending for their small business enterprises using their own funds and government subsidies.

### 3.2.2. Resistance from care givers

We overcame the resistance from qualified faculty at the nearest medical school in receiving funding from abroad. They feared that their experience with the local culture and known management strategies that were culturally congruent would be overlooked. Western ways and a direct approach would not have worked. For example, one chairperson noted that he need not learn from foreign visitors despite their Indian origin, because he had elected to live in the country and work with the poor, whereas others had left the country for greener pastures. So, we had to be diplomatic and negotiate fund provision/transportation first, stress the humanitarian nature of our interest and allow their faculty leadership to guide us by acknowledging their expertise.

'Respect' is a traditional concept, and needs to be addressed to pave the way to other ventures (Munusamy et al., 2007). For example, when screening for possible mental illness, we interviewed the designated 'head' of each household, without which access to the rest of the family would not be possible. Often this was an older male member of the household. So senior faculty, village leaders, and local school principals were approached to endorse the project. Without such support, an extensive foray into the villages would not be possible.

We established a liaison between the Departments of Community Medicine and Psychiatry at St. Johns Medical College, about 23 km away from the target village. The former department led the way since they had made inroads in the areas of maternal and child health, and successfully executed programs to address anemia, childhood vaccination, and hearing and vision impairment. Psychiatrists could not work alone without the support of community medicine physicians who had decades of experience with the villagers' understanding of illness and recovery (Srinivasan and Issacs, 2010). For example, villagers ask for 'injections' for the perceived cure of many ailments. We were venturing into an unknown area for mental health care. Hence, we needed to piggyback on earlier successes, with known care-providers.

### 3.2.3. Providing a process of care delivery

There was no existing infrastructure. Paved roads were non existent. Public transportation was scarce, not always obtainable to care-givers. We had to identify transportation needs, and provide a 4-wheeler that would be able to negotiate unpaved roads. We purchased a van and two two-wheelers for caseworkers. Our caseworkers resisted wearing a protective helmet for example, because it was not part of their traditional attire. We had to coax them and provide insurance to permit use of the 2-wheelers.

Next, we identified the primary health care needs which were at times indistinguishable from mental health needs. Given that most presenting complaints for anxiety and depression were expressed by women in somatic terms, it was imperative that they were all screened by an internist first to rule out medical illnesses (Padmashree and Isaacs, 2007; Vikram et al., 2006).

To overcome the stigma of mental illness, we had to promote the perception of total health rather than emphasize mental disorders. We began disseminating information through our caseworkers about total maternal and child health. We set up a clinic once a week for 5 h, registered patients, obtained addresses

The screenshot displays a 'Clinical Record Management' software window. The main area is titled 'Patient Registration' and contains a comprehensive form. At the top, there are fields for Patient ID, Name, Age, Date of Birth, Gender, Address 1, Address 2, and Village. Below this, there are sections for 'Distance from Clinic', 'Pin code', 'Mobile', 'Public Booth', 'Neighbour's No', 'Sub-Centre', 'Primary Health Centre', 'Religion', 'Caste', and 'Caste Others'. Further down, there are fields for 'Education', 'Occupation Category', 'Occupation', 'SLI Value', 'SLI', 'Poverty Status', and 'Salary'. The form also includes sections for 'Medical History', 'Psychiatric History', 'Psychiatric History Details', 'Concession', 'Marital Status', 'Family Type', 'No of Family Members', and 'No of Children'. There are specific sections for 'Past Psychiatric history of Suicidal attempts' (Suicide H/O, Lethality, Intentionality, Context of Suicide) and 'Sexual H/O' (Sexual H/O Details, Family H/O, Family H/O Details, Premorbid personality / Traits). The 'Past Treatment History' section includes a table with columns for Sl.No, Medication, Dosage, Duration, and Side Effects. The 'Present Complaints' section has a table with Sl.No and Complaint. The 'Mental State examination' section includes 'General appearance and psychomotor activity' and a table for 'Speech', 'Affect', 'Thought', 'Perception', 'Cognitive functions', and 'Insight'. The 'Diagnosis: ICD - 10' section includes a grid for Axis 1A through Axis 3. The 'Referral' section includes 'Psych. Social Work', 'Psychological', 'Doctor's Name', and 'Next Visit date'. The 'Pharmacological - Medication Dose' section includes a table with columns for Sl.No, Medication, Dosage, Frequency (M, A, N), and Duration. The 'Problem List' section includes a table with Sl.No, Problem, and Reported Date. The bottom of the window shows a Windows taskbar with the 'start' button, 'Login', and 'Clinical Record Manag...' icons, and a system tray showing the time as 2:30 AM.

Fig. 1. Screen shot of case record.

and contact names, and trained caseworkers to screen villagers using standardized instruments translated into the local languages. We supervise our caseworkers regularly, and our faculty travel with them to deliver outreach to patients' homes weekly.

Additionally, we have organized medication needs, and accept nominal charges for paying patients, although care is free in general.

Medication compliance is influenced by the culture.

Faulty local practices exist, such as an unqualified "pharmacy" owner giving advice on medications, or a rumor started in one village that the medicines cause vaginal discharge. *One female patient who was depressed stopped her medications because she felt "ashamed" to accept free medications. One woman who was standing in line at her village to obtain drinking water from the only public source of water was insulted by another woman. She felt deep embarrassment and shame at being publicly insulted.* Shame is an Eastern concept that greatly affects the process of psychiatric care, and can play a role in noncompliance. Misperceptions exist about the interactions of medications with indigenous treatments given by temple priests, or other self proclaimed 'medical' providers.

### 3.2.4. Education about disease and treatment

We devised educational strategies to promote understanding of disease and treatment through street plays that include our patients during village festivals. This is a culturally accepted method of teaching through entertainment. Festivals draw villagers from many key areas. Receptivity is greater during such festivities when a work routine is not interrupted.

To date, we treat 1400 patients on a regular basis; many have been discharged from the clinic, and new patients continue to be identified.

We have covered the population of 187 villages by our outreach efforts, keeping in mind safety issues for our four female caseworkers. They are fully trained to use several well known instruments such as the General Health Questionnaire, the Family Burden Scale and so on. The translations were slow and

painstaking (Koller et al., 2007; Pai and Kapur, 1981; Goldberg, 1972; Goldberg et al., 1970). Case workers know the villagers well, are allowed into their homes without resistance, and are treated with gratitude for taking the extra step to approach either potential or established patients.

The clinic has been in existence for 12 years. Research and teaching of medical students, residents, and nurses is incorporated into the clinic and grant applications for further work are planned. The clinic database has been computerized (Fig. 1).

## 4. Discussion

Thara reports that organizing mental health services for a primarily rural population in a country of over 1 billion people is a daunting task. Low budgetary resources, the presence of conflicting healing systems, scarcity of research personnel, the brain drain to other countries, and the stigma of mental illness are noted obstacles to care delivery. The need to build the capacity of primary health care staff is advised (Thornicroft et al., 2010; Kermod et al., 2009; Ganasen et al., 2008). As well, these authors caution care providers about involving family members who play an active role in bearing the burden of treatment; they advocate training multi-purpose health workers who are the mainstay of health services in rural regions in the care of common mental health problems, including among the elderly. The use of low cost, accessible resources, teaching and training, and using community interventions are recommended (Patel and Cohen, 2003; Thara et al., 2008; Srinivasan et al., 2001; Padmavathi et al., 1998; Moussavi et al., 2007; Thornicroft and Tansella, 2004). Also, any psychotherapy that is practiced must be congruent with the culture and accepted within the socio-philosophical background of the patient. For example, Thippiah, a religious village leader who suffered from somatic delusions interpreted them as suffering for his past 'karma'. We, in turn, explained that it was through Divine grace that solutions for his suffering were available through our program and that he needed to avail himself of them. Thippiah continues to

be a compliant patient, satisfied with the results. These sentiments are echoed by Patel and Thornicroft, who advise the use of primary care with specialist back up in low resource areas (Mathers and Loncar, 2006; Aaron et al., 2004; Patel and Cohen, 2003).

Of major importance is the treatment of unipolar depression, one of the 3 leading causes of disease burden, especially in women as projected by the World Health Organization (Goldberg et al., 1970). Suicides among young women are significantly higher than in men and the mean suicide rate is 95.2/100K, more than 10 times the rate in the US (Thara et al., 2008; Srinivasan et al., 2001).

Treatment, therefore, in the Maanasi clinic includes outreach to those with lack of access to care, with suicidal ideation, with alcohol related disorders, and those suffering from acute psychosocial stressors, as well as to the elderly.

## 5. Conclusions

The major public health problem of the indigent mentally ill was adequately addressed by our program that continues to operate successfully since 2002. The role of a humanitarian organization such as Rotary International in providing much needed funding and manpower exemplifies one way to render innovative, collaborative care and program building with academic institutions such as St. Johns Medical College that is committed to comprehensive and preventative treatment of the indigent in rural areas. We have demonstrated that community psychiatry can indeed make a major difference in the lives of women and children in low income areas with humanitarian efforts supported by locally trained personnel who volunteer efforts using limited funding, community participation and family involvement. Addressing cultural barriers to treatment is critical in sustaining the clinic in a culturally congruent manner. Affordable interventions and piggy backing on primary care is key to our success (Patel, 2007).

Although other such projects have failed, our work remains sustainable through committed support from humanitarians, academicians, and the villagers themselves (Joseph et al., 2003; Jacob, 2001). The Maanasi clinic is a prime example of applying transatlantic innovation to community psychiatry.

## Disclosures

I had been consulted once by Janssen, last year, on community psychiatry as an advisor.

## Conflict of interest

None.

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