HUMAN INTEREST STORY

Birth of a community mental health project in a rural mission hospital

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Abstract
Mental health is often not considered a priority area in rural centres and mission hospitals. A widespread misconception exists, even among medical professionals that these disorders are rare, difficult to diagnose and expensive to treat. In this article we challenge these assumptions and describe the birth and development of a Community Mental Health project at Padhar Hospital, a Lutheran mission hospital in Madhya Pradesh over the past one year. The purpose of this article is to illustrate that effective community mental health intervention programs are not only essential in rural mission hospital settings, but also incredibly cost-effective in terms of financial and human resources.

Two stories: (Names have been changed to protect identity)

1. Goddess in human form
Priya, the second daughter of a teaching assistant in a primary school, was a normal, cheerful and playful little girl in a village primarily consisting of Gond tribals. She developed normally till about 5 years of age, and her parents reported that she could recite the alphabets in English and Hindi, and was capable of identifying pictures in books and was toilet trained fairly well. When she was three years old, she started having attacks of epilepsy. Due to the superstitious belief system prevalent among the village elders, the community believed that these attacks came because she was a goddess in human form and possessed supernatural powers. As a result of these beliefs, she was never treated. The frequency of seizures gradually increased and on one particular day when she was 5 years old, she had up to 15 attacks within a few hours. Following that, she became developmentally retarded, and has remained so ever since. She also developed hyperactivity associated with repetitive stereotypical movements and speech. Her speech now consisted only of one or two bi-syllabic words. She was completely dependent on her parents for all self care, soiling her clothes up to ten or fifteen times a day, and having erratic mealtimes. She also developed aggressive behaviour towards herself and others in response to various stimuli.

2. Demon-possessed
Dhanush was a regular student and appeared to have a bright future. While he was preparing for his tenth standard examinations, a profound and sudden change overcame him. He did not appear for his exams. He started roaming around aimlessly and undressing himself in public and hit people with stones. His family members tied him up...
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with iron chains in their house. He started withdrawing from everybody and even neglected his personal hygiene and care. He was taken to a private doctor for treatment but his condition remained the same. He was taken to several religious places as well and they met several sages and witchcraft practitioners. This state of affairs went on for about four years. As per the rural belief systems prevailing in the local area, he was considered as being possessed by a demon. (‘Two stories’ – continued at the end of the article)

Introduction:

Mental, neurological, and substance use disorders account for 13% of the total global burden of disease. In low and middle income countries, 76% - 85% of people with severe mental disorders do not receive any treatment.[1]

As per the National Mental Health Program in India, the median prevalence of mental disorders is 65.4 / 1000 individuals at any given time. This translates into nearly 70 million individuals across the country currently requiring mental health interventions – an amount almost equal to the entire population of Germany, Europe’s most populous country. [2] To tackle this immense burden, there are currently only 0.3 psychiatrists for every 100,000 people in India[3], which is a total of less than 4000 for the entire country. 75% of these psychiatrists work in urban areas, where less than 40% of the population lives. [4][5] Whole districts exist without a single trained mental health professional. No other medical specialty in India has such a mismatch between need and available human resources.

Padhar Hospital, Mental health scenario in Madhya Pradesh

Padhar Hospital is a 200 bedded multispecialty Lutheran mission hospital located in Betul district of southern Madhya Pradesh. The hospital started a Psychiatry department in June 2014, which is the first and only full-time mental health service in Betul district and in at least three other surrounding districts in a radius of more than 200 kms. The department currently consists of only one psychiatrist, myself. I soon realized that most of the patients who were coming to the psychiatry OPD, as well as our inpatients and consults from other departments were predominantly from urban areas, with hardly any hailing from the surrounding villages. This initially struck me as very odd, as I had a very different experience during my training years at Vellore, where large numbers of local people (even those from rural areas) made use of the mental health facilities. Although it was surprising for me then, I soon realized that most of the available literature, reports very similar situations across Central and Northern India, especially in states like Madhya Pradesh, where mental health facilities are not only inaccessible, but, for the most part, completely non-existent.

The majority of these areas around Padhar are poverty-stricken, primarily agrarian villages, and many are situated in areas with very limited accessibility by road with negligible public transport facilities. The population is multi-ethnic (with tribes such as the Gonds and Korkus besides the local Hindi-speaking population, as well as a sizeable Marathi-speaking population and even ethnic Bengalis – who migrated as refugees during the 1971 Indo-Pak war). There is also considerable religious diversity – although Hindus are a clear majority, there is a large Christian minority centered around Padhar Hospital, and a smaller Muslim minority as well. Many tribals practice a primitive form of religion with strong animistic belief systems and practices.

Mental illnesses and epilepsy are looked at in these remote communities with a mixture of fear and awe. Patients are either revered as incarnate deities or shunned as demon-possessed souls. Diverse magical exorcism rites from potions and local remedies to harsh beatings or branding with hot iron rods are common and are done at great financial cost to
the families. Families of these hapless souls also face social ostracism, often being excluded from public functions. Surprisingly, these beliefs and practices are not confined to patients with dramatic conditions like schizophrenia and epilepsy, but also to people who suffer from common conditions like depression, anxiety and migraine, and face many of the same issues of stigma, ignorance and lack of treatment as those with more severe disorders.

Realizing that very few rural patients were coming to the hospital, I decided to try a different approach. Twelve community field workers of the hospital were initially given some training sessions, to teach them some basics of identifying mental illness in the community. These workers are recruited by the hospital from the local population and are used for a variety of community-based programs in a target area of seventy five villages within a radius of 30 km around Padhar. I started informal visits to some of the target villages once a week along with the respective field workers with the intention to screen patients for mental illnesses and refer them to the hospital. Surprisingly, without any intensive preparation or planning, we found 15 severely ill patients with a variety of diagnoses in the very first village we visited. Subsequent visits resulted in similar numbers. Gradually, the field workers began to screen their areas well in advance to facilitate my efforts.

Screening, however, was not the real problem. Very few of the referred patients actually ended up coming to Padhar, and the few that did, proved to be extremely difficult to follow up. Likely reasons included financial difficulties, lack of accessible public transport, unwillingness of relatives to leave a day’s work to bring patients, and lack of awareness of the effectiveness of treatment. In any case, it appeared that merely screening and referring patients was inadequate to make a difference in this community.

Since December 2014, rather than waiting for the patients to come to the hospital for treatment, we decided instead to take the interventions to the community setting itself. We focused our attention at first on the most severe cases (those with schizophrenia/other psychotic disorders, bipolar disorder, severe depression, epilepsy and mental retardation with treatable co-morbidities), and dispense medications to these patients in the field without payment. All patients and their relatives were educated about their conditions, the treatment strategies, and strategies to cope. Patients with less severe mental health issues (such as addictions, anxiety disorders, adjustment disorders, stress-related disorders etc) and especially those who needed more intensive non-pharmacological treatments like psychotherapy or family interventions were referred to the hospital (but had to pay for their treatment, though consultation and therapy charges could be reduced or waived on a case to case basis.). Where necessary, in very select cases, inpatient stay could be offered. Thus was born the Community Mental Health (CMH) project at Padhar Hospital.

We divided the seventy five target villages into eleven clusters based on geographical proximity, with one field worker in-charge and responsible for each cluster. Each cluster was centered around one or two large villages at central locations, to make planning and accessibility easier. Each Wednesday, a team including myself, the respective field workers, some nursing students (undergoing their psychiatry rotation) and an administrative coordinator visited one cluster of villages. Patients who are screened by the field workers prior to our visits are evaluated and appropriate intervention done, old patients are followed up. A few house visits are made for patients who are too sick or too far to come to the central location chosen. Since there are eleven clusters of villages, each cluster gets reviewed roughly
every three months. In the intervening period, the respective field workers follow up patients in their area, and bring problems encountered to my notice so that they can be addressed as required.

To facilitate screening by the field workers, we have created a new screening questionnaire tool designed to be asked by non-professional workers verbatim to one member of each household to identify potential patients with mental illnesses and epilepsy. We are now simultaneously conducting an evaluation study of this tool to assess its sensitivity and specificity as a screening tool in rural Indian settings.

Every Saturday, all those involved hold a short meeting in which problems encountered are discussed and potential solutions considered. Plans for the next week, and specific issues involving individual patients are also discussed. These sessions also provide an opportunity to have brief workshop-style training for the field workers on specific issues that arise in the field such as managing problems in compliance and violent / suicidal patients in the field.

As of July 2015, 410 patients are registered under the CMH project and have been evaluated. Of these, 187 have received long-term medications in the field and are on follow up, and many others have been referred to the hospital for more intensive treatments (medication / psychotherapy.). The current break up of major diagnoses among those registered under the project is shown in the table below.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia &amp; other psychotic disorders</td>
<td>86</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>9</td>
</tr>
<tr>
<td>Depressive disorders (Major Depression, Dysthymia, Recurrent Depression etc)</td>
<td>65</td>
</tr>
<tr>
<td>Anxiety &amp; other neurotic spectrum disorders</td>
<td>57</td>
</tr>
<tr>
<td>Alcohol use disorders</td>
<td>23</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>99</td>
</tr>
<tr>
<td>Autism/ Autistic spectrum disorders</td>
<td>6</td>
</tr>
<tr>
<td>ADHD</td>
<td>5</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>53</td>
</tr>
<tr>
<td>Headache syndromes (including Migraines, Tension headaches etc)</td>
<td>70</td>
</tr>
<tr>
<td>Other neurological disorders (including stroke, Parkinson's etc)</td>
<td>10</td>
</tr>
</tbody>
</table>

We have also started doing Group Therapy sessions in the field targeting patients with severe mental disorders / epilepsy and their family members once a month in one cluster (along with the outreach clinics). These will focus on issues such as nature of the disorders and their treatment, family burden, stigma and issues of social re-integration of these patients.
In terms of cost, the major expenses ultimately come down to medication and transport costs. Since the entire target area is within a radius of just 30 km, transport costs are minimal. We did not hire any new staff for the project – it is structured entirely with existing resources. We do consultations and Group therapy for free. By using cheap (but effective and trusted) brands of a select few drugs, we have managed to keep medication costs to just between Rs.100 - 200 per month for an average patient with severe mental disorder / epilepsy. This translates into just Rs.3/- to 6/- per day per patient, an incredibly small amount of money considering the tremendous impact the intervention has on the patient, family and community. At present we are running the project with a limited budget entirely based on donations by well-wishers. An effective Community Mental Health program is therefore an astonishingly cost-effective affair, unlike what is often portrayed.

One of the major challenges in any community-based mental health program will always be the re-integration of individuals who have been shunned by family and society for so long, and many of whom have, as part of their symptoms, lost their social and communication skills. In this respect, there are many similarities between leprosy work and work with the mentally ill; however there are some key factors in a rural mental health program such as ours that have played well to our advantage.

First, unlike patients with leprosy or cancer, patients with majority of mental illnesses (barring few congenital syndromes with developmental delays) do not look different from others around them. What stands out is their behaviour. And as behaviour improves, they become less conspicuous and easily merge into their community. A second advantage of rural areas is that the predominant occupations are agricultural work and manual labour, which do not demand a high technical knowledge and skill base. Finally, the strong cohesive joint family system which, despite some significant disadvantages, at least provides a solid support system to supervise and care for mentally ill patients at their homes until they get better (preventing the need for unnecessary hospitalization and labour and time of hospital staff).

Realizing these significant advantages, we have fortunately been quite successful in the community re-integration of several patients with severe mental illnesses and epilepsy in the target area. It is gratifying to see so many of our community patients who once behaved violently and roaming aimlessly through the villages or frequently fell unconscious with seizures now much better and back to work at home or in the fields. Once families understand that their symptoms can be controlled, and once they are encouraged to give them minor tasks at home or in the fields on a regular basis as the major symptoms improve, the patients easily begin to contribute economically and socially to their families and community. And in most instances, that itself diminishes the terrible isolation they have faced in silence for years.

Two stories (continued...)

Goddess in human form – The story of Priya
During one of the CMH outreach visits to the Chiklimal cluster of villages, Priya’s father brought her for evaluation. We evaluated her and recommended that admission in the hospital was necessary. During the two-week hospitalization (in which consultation and therapy charges were waived), the parents were educated about the nature of her condition and effective management strategies. She was started on Carbamazepine for her epilepsy, and on a low dose of Risperidone for her hyperactivity and stereotypical movements and speech. The patient and her parents also underwent intensive behaviour therapy, and techniques like activity scheduling, differential reinforcement and time-outs were employed using appropriate reinforcements.
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Over the course of her stay, her seizures were controlled, her hyperactivity and stereotypical movements decreased significantly. Her aggressive behaviour decreased considerably, meal times were regularized and she was able to remain without soiling her clothes throughout the day.

Priya is one among many such patients with post-encephalitic syndromes we encounter frequently in our target villages. Several of these hapless patients develop their neuropsychiatric symptoms due to improper or delayed treatment (or in many cases non-treatment) of their initial encephalitic illness or seizures due to prevalent beliefs of supernatural causation of mental and neurological illnesses. This represents a group of preventable severe neuropsychiatric conditions, and we hope that through this project we may be able to improve awareness about the need for early and correct intervention in order to prevent or reduce the morbidity of these disabling disorders.

Demon possessed – The story of Dhanush

During a field visit, one of the Project Coordinators (Mr. Achal) found that Dhanush was tied with an iron chain in one of the village temples for magico-religious exorcism rituals for demon possession. He was called to Padhar Hospital for psychiatric intervention a number of times but his family members refused to come. At this temple, his hands were branded with iron rods as part of the exorcism rites (he still bears the scars of these rituals on his palms). He remained in the same condition and was taken back to his home village.

Subsequently, Dhanush was evaluated during one of our outreach visits under the Community Mental Health Project and was diagnosed to be suffering from Schizophrenia. He and his family were educated about the nature of his condition and the treatment required. He was prescribed Olanzapine for free for three months and reviewed at the subsequent review camp in his cluster. His family members started giving him medicines regularly and it transformed his behaviour. Now, he has stopped wandering around aimlessly and hitting people and remains at home. He also started supporting his family in household work as well as in the fields.

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