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Mental Health in Primary Health Care: The Karuna Trust Experience

N.S. Prashanth, V.S. Sridharan, Tanya Seshadri, H. Sudarshan, K.V. Kishore Kumar, and R. Srinivasa Murthy

Arguing that there cannot be physical health without mental health, all World Health Organization (WHO) member states in the 2013 World Health Assembly approved a comprehensive *Mental Health Action Plan 2013–2020* (WHO 2013). The plan is a commitment by all WHO member states to take specific actions to improve mental health and to contribute to the attainment of a set of global targets. Such a global commitment is in line with the comprehensive primary health care approach, which includes the provision and promotion of mental health within its ambit. It is vital that country health systems take into consideration the need to provide mental health care in an accessible manner, while taking into consideration geographical, financial and

N.S. Prashanth (✉)
Institute of Public Health, Girinagar, Bangalore, Karnataka, India

V.S. Sridharan
Swami Vivekananda Youth Movement, Saragur, Karnataka, India

T. Seshadri
The Malki Initiative, Karnataka, India

H. Sudarshan
The Karuna Trust, Bangalore, Karnataka, India

K.V.K. Kumar
The Banyan Academy of Leadership in Mental Health, Chennai, Tamil Nadu, India

R.S. Murthy
The Shankara Cancer Hospital and Research Centre, Bangalore, Karnataka, India

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socio-cultural barriers to deciding to seek mental health care. The provision of good quality and accessible mental health care hence requires a functional primary health care system staffed by trained primary health care workers with appropriate referral systems in place. In such a system, specialist mental health services become only a part of the solution, wherein a responsive primary health care system addresses the majority of mental health problems. Seen in this manner, mental health care requires demystification as well as task shifting from psychiatrists in centrally located tertiary care institutions to health workers in primary and secondary care. Indeed, task shifting is a worldwide phenomenon even in countries with a relatively good numbers of psychiatrists, albeit with a young and growing evidence base (Patel 2009). For example, the UK National Health Service initiative called Improving Access to Psychological Therapies aims to provide accessible evidence-based psychological treatment for anxiety and depression through a large network of well-trained health workers in each locality functioning within a well-supervised system of mental health care (Clark et al. 2009). In the UK, the systematic progression from the publication of national-level guidelines identifying the need for evidence-based psychological therapy (as opposed to only antidepressant medications) at the level of PHC to the funding and deployment of a cadre of therapists at local levels makes for a useful lesson in accessible and evidence-based mental health care (Layard 2006).

In this chapter, we briefly discuss the large unmet need for mental health care in several low- and middle-income countries (LMICs) including India. With this background, we present our experience with integrating mental health services into the primary health care system in one of the districts in the south Indian state of Karnataka. We describe the history of a programme initiated by R. Srinivasa Murthy and K.V. Kishore Kumar of the National Institute of Mental Health and Neurosciences, Bangalore (NIMHANS) in 1995. Both of them were psychiatrists (then at NIMHANS), and have worked closely with non-governmental organisations (NGOs), doctors in primary health care and community health workers to develop decentralised mental health care. The need to develop such a programme was identified by them in order to understand the mental health needs of a tribal and rural population, and explore the feasibility of working with primary health care workers. We illustrate some of the lessons learned using two brief interview-based case studies, and discuss the limitations and challenges of this experience. We hope that such experiences can shape a systemic response by governments and policymakers to make mental health care accessible through the wide network of primary health centres (PHCs).

Use of Non-professionals for Mental Health Care

During the 1960s and 1970s a trend emerged of involving non-professionals for delivering mental health care, known as 'de-professionalisation'. Non-professional workers are often able to provide accessible and patient-centred care because they have better knowledge of the community, language and customs. Patients may also readily identify with them and form therapeutic alliances. However, it is important to ensure that non-professional workers are competent, and that professional staff can be drawn upon, when necessary, to deal with complex cases, provide supervision and consultation-liaison. If non-professional staff are to be trained and employed, consultation with professional staff is needed to avoid the perception that non-professional staff are undermining professional staff, lowering standards of care, and providing service managers with a less costly workforce (WHO 2005).

However, the WHO Mental Health Atlas 2011 points to glaring disparities in the distribution and availability of mental health care across the world (WHO 2011). In many LMICs, there are severe inadequacies in the care provided as well as an inequitable distribution of health workers trained to deliver mental health care, be it psychiatrists or primary care workers who can identify and manage mental health problems in the community or in primary care settings. WHO estimates that nearly half of the world's population live in countries where there is less than one psychiatrist for 200,000 individuals (WHO 2011). In many LMICs, a legislative framework is the first step towards organising and delivering mental health care; only 36% of low-income countries are covered by mental health legislation (WHO Secretariat 2011). There is also a disparity in the type of facilities available for treatment. Sixty-three per cent of inpatient facilities for the mentally ill in LMICs are located in dedicated mental health care institutions with poor linkages to the other health services and systems. At the community level, most LMICs have limited availability of mental health services. Even at primary health centres and secondary hospitals, health workers are not trained to identify, manage or appropriately refer people with mental health care needs. In terms of proportion of country health expenditure on mental health, it is estimated that 67% of health budgets are being spent on tertiary level care in specialist mental health care institutions (WHO 2011).

Over the last several decades, globally, mental health has gradually shifted from being centred on specialist psychiatric hospitals to primary care institutions (WHO 1975). Such a move relies on various underlying principles

ranging from cost-effectiveness and economic arguments to the integration of health and human rights, comprehensive primary health care perspectives and increasing access to care. The push towards *communitisation* (shift of care to the community from specialised institutions) of mental health and grounding it within general health services as well as pushing for greater civil society and community engagement with mental health care is a part of a global trend.

There are many reasons for this integration of mental health with primary health care. Firstly, the widespread reporting of the unaddressed burden of mental health problems in primary health care outpatient settings; secondly, the limited number of psychiatrists and other mental health professionals to provide specialised psychiatric care; and thirdly, the emerging global trend towards integration of all health programmes from a vertical disease-control programme model to a multipurpose and integrated model. Fourthly, there has been a growing international recognition of primary health care as the approach to organise accessible health services. Fifthly, there has emerged a global movement towards strengthening health systems to deal with chronic conditions and a push to early detection wherever possible to prevent chronicity. The latter has guided the global recognition of the concepts of continuity of care and community-based care that are today being embraced as important characteristics for local health systems in order to deal with the challenges of all chronic health problems ranging from tuberculosis and HIV/AIDS to diabetes, hypertension and other cardiovascular conditions. Consequently, integration of mental health into PHC requires systematic capacity building at primary health care level, development of simple interventions, as well as setting up appropriate support mechanisms through referral pathways and feedback systems to ensure that primary care staff feel adequately supported to provide mental health care (WHO & World Organization of Family Doctors 2008).

Mental Health Care in India

In India, the journey of mental health care has a long history, ranging from descriptions of mental health problems in ancient Ayurveda texts to contemporary post-independence efforts at establishing a system of care for mental health through policies and programmes (Agarwal et al. 2004; Nizamie and Goyal 2010). Despite a long history of written discussions of mental health, a comprehensive historical and analytical review of mental health initiatives

by Murthy (2011) reports that at the time of independence, mental health was not considered as part of the general health services but to be delivered by mental hospitals following the establishment of *asylums* under British colonial rule (Murthy 2011). There was a severe dearth of infrastructure for providing mental health care services with as few as one bed per 30,000 people in India at the time (Murthy 2011). The initial two decades after independence were dedicated to significantly increasing the number of beds in mental hospitals and humanising treatment of the mentally ill. The mental hospital beds increased from 10,000 to 20,000 in the first decade after independence. In the 1950s, families in India were involved as part of the treatment process, at a time when institutions in high-income settings routinely separated patients from their families for treatment, seeing the family as contributing to pathology rather than co-opting them into organising care. Introducing psychiatric wards in general hospitals then followed in the 1960s in a significant way. In 1975 for the first time mental health was integrated into general health services under the banner of a community psychiatry initiative echoing a global trend—backed by the WHO—towards de-institutionalising mental health care and introducing community mental health (Agarwal et al. 2004; Anthony 1993). In India, the community psychiatry initiative has been active in 127 of the 626 districts, catering to about 20% of the population (Murthy 2011).

Challenges of Mental Health Care in India

Large 'unmet need' for mental health in the community

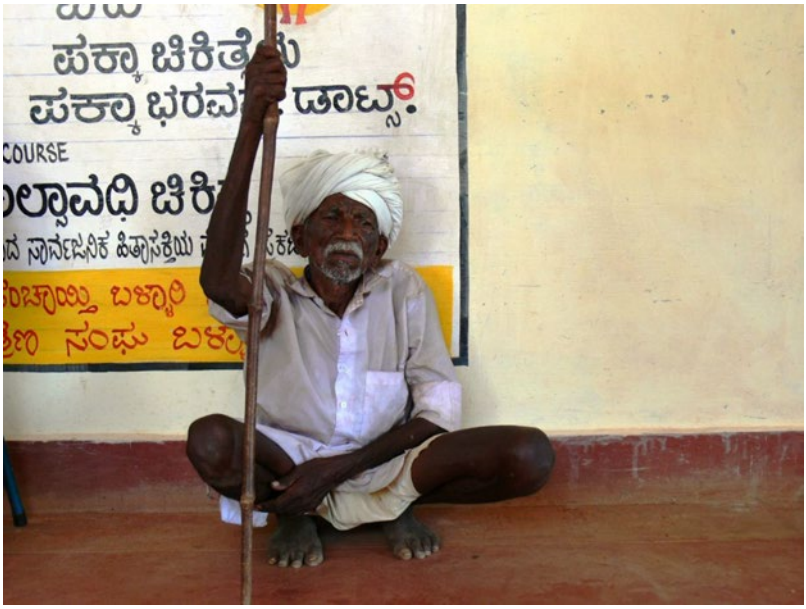
- Lack of awareness that psychological distress requires medical intervention in the general population
- Limited acceptance of modern medical care for mental disorders among the general population
- Limitations in the availability of mental health services (professionals and facilities) in the public health services
- Difficulty in uptake of available services by the mentally ill
- Lack of integration of services in recovery and reintegration of persons with mental illnesses among various actors
- Lack of institutionalized mechanisms for organization of mental health care.

From Murthy (2011), *National Medical Journal of India*

In some respects, India's early efforts in mental health are laudable. In 1982, when the National Mental Health Program (NMHP) was launched, India was one of the first post-colonial countries to have a mental health programme (van Ginneken et al. 2014). There have been several initiatives in the last few decades focusing on outreach services in rural areas, as well as providing community-based mental health care in such areas to supplement the tertiary institutes of mental health. There have also been initiatives focusing on rehabilitation and health promotion (developing appropriate awareness-raising material, improving the community's understanding of mental illness, extended care for caregivers of mentally ill individuals etc.) (Patel and Thara 2003).

However, many challenges persist in achieving a reasonable standard of mental health care in India including poor systematic evaluation of small successes in micro-contexts, poor training capacity, socio-cultural mismatch between programme design and services, a grossly under-financed health system and poor agenda-setting, political will and leadership at various levels (Jacob 2011; Jain and Jadhav 2008; van Ginneken et al. 2014).

Photo 1 An elderly person waits for the doctor at a rural primary health centre in Karnataka, India. Many such centres are not yet equipped to cater to the large unmet mental health care needs of rural populations



Integrating Mental Health into Primary Health Care

By definition, comprehensive primary health care includes curative and preventive care, mental health promotion and psychosocial rehabilitative components of mental health care (Magnussen et al. 2004). In several LMICs, non-specialist health workers are deployed in primary health care settings (including doctors, pharmacists, laboratory technicians, nurses and other health workers, none of whom are specialised in mental health). Management and delivery of a variety of pharmacological and other interventions for mental, neurological and substance abuse disorders has been demonstrated in a variety of community and primary health care settings across the country through systematic capacity building and supportive supervision (Agarwal et al. 2004).

Mental health care in primary care is a logical way forward to address the mental health needs of the population, taking into consideration the resources for mental health available in the country. In a mixed public and private health provider landscape in India, the growth of psychiatry in the private sector has also progressed, albeit catering mainly to the urban population. In most rural areas, large gaps exist in terms of sheer availability of psychiatrists, counsellors and health workers with knowledge and/or skills for providing mental health care. There is a 40–60-fold deficit in the number of clinical psychologists, social workers and nurses (van Ginneken et al. 2014). As for primary mental health care, the District Mental Health Programme (DMHP) is in place in some districts only. DMHP is conceived as a community-based mental health service delivery programme initiated through early pilots in the 1980s and later in 1996 institutionalised under the NMHP and is being extended in a phased manner (Agarwal et al. 2004; Jain and Jadhav 2009). DMHP now operates in 189 out of 652 districts of India. In India currently, there are 43 mental hospitals and 10 centres of excellence in 652 districts altogether generating 30,000 inpatient beds. In addition, mental health services offered at government medical colleges were upgraded in terms of provision of mental health services, and also to increase the number of post-graduate training programmes for doctors (Sinha and Kaur 2011). Nearly all of the psychiatric inpatient beds are in large urban and peri-urban centres, hundreds of kilometres away from most of the rural Indian population. This resource is grossly inadequate in comparison to the need. The scaling up of these systems involves building a comprehensive mental health care service by developing partnerships with the primary health care teams, community-based

organisations, NGOs, service users, family groups and various government departments. However, the availability and treatment of mental health problems in primary care is still not effective. Unfortunately, initiatives targeting mental health, including the DMHP, are specialist driven, and located in the *talukas* or above. *Talukas* are administrative sub-divisions of districts (also called blocks in some states of India). The headquarters of the *taluka* is usually a large town. *Talukas* usually have a population ranging from 100,000 to 400,000 people, and are thus not the ideal location for providing primary mental health care, leaving mental health care inaccessible to a very large rural population.[1]

In Karnataka and possibly in most other Indian states, PHCs have limited capacity to identify or treat mental illness. In 2011, an evaluation across 24 PHCs across Karnataka found that most PHCs see very small numbers of mentally ill people. Many of the PHCs surveyed across Karnataka were seeing 10% or less of the expected number of mentally ill in their catchment area (Prashanth et al. 2011). The PHCs surveyed were involved in a project on integrating mental health care into general health services. Although mental health training has been conducted for several primary health care doctors of Karnataka by NIMHANS, health worker training on mental health in primary health care is not yet routinely organised. The survey found that posters and awareness generation materials and manuals in English and Kannada[2] were available at these PHCs. A questionnaire on the knowledge, attitudes and practices of primary health care workers on mental illness found that their awareness levels were fair, although the assessment was done after a recent training programme. The maintenance of case records of patients seen at PHCs was below average and follow-up of registered cases was also delayed. A robust system of registration and follow-up is crucial to delivering mental health care at PHCs. There was a clear dearth of clinical skills among the doctors. Most doctors were not comfortable working with mentally ill patients or were not used to counselling. Moreover, many doctors trained under the Indian systems of medicine, who are routinely posted in many PHCs in India showed a significant knowledge gap in identifying mental health problems.

[1] Various critiques of the DMHP including several ethnographic approaches at understanding its local effects as well as macro national-level critiques have emerged in the recent years. While some have praised the underlying principles of the DMHP, a lot has been written about its patchy implementation and its dependence on a very weak and under-financed health service, poor leadership and political will and its specialist-driven character. See, for example, Badami (2014) for a particular case of DMHP's limitations in mitigating suicide incidence in the *Paniya* community in Kerala or the need to reconcile possible multiple narratives about the DMHP by Sarin and Jain (2013). For an ethnographic study that discusses the specialist-driven nature of DMHP, see Jain and Jadhav (2009).

[2] Kannada is the local language in the south Indian state of Karnataka.

One of the early experiences at integrating mental health into general health services in Karnataka was by several actors coming together at the Gumballi PHC run by Karuna Trust in the year 1996. Karuna Trust is a NGO that is involved with strengthening primary health care through innovative projects implemented in PHCs that they run in partnership with the government. Karuna Trust (founded in 1986) and its sister organisation Vivekananada Girijana Kalyana Kendra (VGKK), founded in 1981 by Hanumappa Sudarshan, have been recognised for their integrated approach to addressing development issues of indigenous tribal and rural communities in India. The Trust raises resources for its activities mainly from the government but also from various other philanthropic organisations, individuals and funding agencies. In a brief case study below, we describe the nature of activities related to integration of mental health services into primary care in Gumballi PHC, and list various lessons learned and challenges that remain. The Gumballi PHC located in Chamarajanagar district was the first PHC in the state to be handed over to the Karuna Trust under a public–private partnership initiative of the Karnataka Government in 1996. The PHC continues to function within the larger district and state health system, but the daily operations and management are by Karuna Trust. The Gumballi PHC is one of the 2355 PHCs in Karnataka, located in Chamarajanagar district in the southern part of Karnataka. The district is one of the more worse-off districts in terms of various social and development indicators including health, education and socio-economic development (Government of Karnataka 2004, 2005).

Gumballi PHC: A Case for Non-specialist-led Mental Health Care

The Gumballi PHC, although one of the pioneers in initiating mental health within a primary health care setting, is not the first such experience. Early efforts at integrating mental health into primary health care began as small pilot rural mental health programmes in the mid-1970s in Bangalore in southern India and in Chandigarh in north India (Murthy 2010). The programme in Bangalore was led by the community psychiatry department of NIMHANS, a national-level expert centre for psychiatry. The aim of the project was to develop suitable training programmes for the doctors and multipurpose workers from various PHCs in Karnataka so that after their training primary health care personnel could provide basic mental health care (detection and management of epilepsy, neurotic illnesses and psychosis). The team studied the needs of rural population, followed by a pilot project to

integrate mental health with primary health care in a PHC serving a population of 100,000 in the early 1980s. Similarly, the Chandigarh project focused on developing a model for rural psychiatry services with the support of WHO. Subsequently, these projects led to various PHC-level pilot initiatives in and around Bangalore as well as the early district-level pilots in Bellary district in northern Karnataka. A detailed history of the evolution of early pilots in Bangalore and Chandigarh in the 1970s, their subsequent transformation into district-level initiatives such as the DMHP in the 1980s, and the few evaluations of these programmes is provided by Murthy (2010).

The integration of mental health into primary health care at Gumballi PHC is one of the spin-offs of the DMHP and other community mental health initiatives of NIMHANS, Bangalore, in partnership with Karuna Trust. The Gumballi PHC intervention can be divided into three phases. The first phase involved understanding the needs of the population and exploring the feasibility of providing mental healthcare. The second phase was the pilot involvement of the health workers in mental health care. In the final third phase, Karuna Trust tried to extend the care to other PHCs using training programmes, tele-psychiatry and other innovations. The aim of the Gumballi PHC mental health initiative was to train health workers, auxiliary nurse-midwives (ANM) and doctors in PHCs to integrate mental health into general health care. The ANM is a community-based health worker attached to a sub-centre. Sub-centres are the first point of contact between the government health services and the community in India, and currently focus on providing reproductive and child health services. However, the ANM is also the first point of contact for various other disease-control programmes and initiatives including follow-up and referral services for the mentally ill. As part of this activity, all male health workers and ANMs, doctors and community-based social workers associated with the Karuna Trust were trained, and monthly mental health outpatient clinics were organised at the Gumballi PHC on every second Saturday. The training involved classroom training on sensitisation to mental health problems seen in the community, building a referral pathway to the PHC, and skills for listening and engaging with family members and mentally ill patients. The classroom training was reinforced through on-the-job training and supervision by visiting psychiatrists and the medical officer of the PHC. The on-the-job training involved a process of continuous improvement wherein the case management of every patient seen was discussed. During each subsequent consultation, the health worker was involved in the consultation, follow-up and discussions on the patient's response to treatment.

In the first phase, the programme started with the training of the health workers and village visits within the Gumballi PHC catchment area and

around. The health workers administered a 10-point questionnaire in village meetings and focus groups to help improve awareness and detect people with mental illness within the community. During this process, the community's dependence on faith healers for seeking care for mental illness emerged and a conscious effort was made at contacting and building a rapport with these healers. Karuna Trust's earlier demographic work with leprosy, experience with community-based tuberculosis care and especially its work on community-based management of epilepsy initiated in the early 1990s was helpful in providing an impetus to the community-based mental health care work. During this early phase, the programme worked with traditional healers and faith healers from the community to sensitise them about various mental health problems. Over a period of time, the traditional healers and faith healers began to refer people with severe mental illnesses.

The most common problem encountered in the clinics initially was patients with severe mental illnesses who presented long duration of illness. Gradually, patients with shorter duration of illness started utilising the services, indicating patients who began to seek treatment earlier. On average, about 50–60 old patients and 5–10 new patients were seen each month every second Saturday. The patients who came to the clinic were offered a clear case management plan with strategies to educate the families about the nature of the illness, need for medication, side effects that may occur, need to initiate home-based vocational activities, dealing with specific problems like social rejection and crisis intervention (as and when necessary), as well as free medication. For nearly a decade since the establishment of the clinic, K.V. Kishore Kumar, a psychiatrist from NIMHANS, visited the facility every month. The long-term plan was to slowly shift various diagnostic, treatment and follow-up tasks to the local staff through a systematic process of capacity building and reflective discussions at the end of the clinic.

After seeing the patients, health workers, nurses, pharmacists and doctors were involved in discussing the problems seen on the clinic day. In addition to the systematic training provided to the health workers in the classroom, these post-clinic discussions and debriefing sessions served as useful platforms to build the skills for history taking, diagnosis and patient communication. At the end of the clinic day each month, an assessment was also made of those patients who did not turn up for the monthly follow-up visits that day. The community-based health workers and the ANMs were supposed to visit these families in the following days and report about their progress to the doctor in the subsequent visit. In case the patient was found to be very ill, or they had problems in attending the clinic, appropriate help was provided in keeping with the need. Those patients who were very ill were referred to the VGKK tribal hospital in BR Hills (in the same district) for inpatient care, since the nearest inpatient care

for these problems was only available in Mysore (80km by road) or Bangalore (180km by road). They run a hospital for indigenous tribal communities, a school and a vocational training centre at BR Hills in Chamarajanagar district. Over a ten-year period, more than 80 patients were admitted to the VGKK hospital in BR Hills for inpatient care, and discharged to be followed up by the community-level workers associated with the programme.

Most PHCs in India do not maintain medical records. Recently, there have been a number of pilot projects for maintaining immunisation and health records, but ensuring continuity of care for chronic diseases remains a challenge in most settings. In 1996, when the Gumballi mental health clinic started, registration of all patients and provision of PHC-based health records was prioritised in order to ensure continuity of care, a defining component of mental health care. All people with mental health problems who registered in this clinic had a file, which consisted of data on background characteristics, clinical variables and qualitative information about the family, occupational functioning and difficulties experienced by the individual. Over 2500 patients with a nearly equal representation of both genders were registered in this clinic over a period of 14 years.

Even though Chamarajanagar district was one of the DMHP implementation districts, for a large part of its existence, the programme remained on paper only. The growing popularity of the Gumballi clinic attracted a lot of mentally ill patients, not only across the district but also from neighbouring *talukas* of adjoining districts. Eighty-seven per cent of the 2648 patients seen were in fact outside the catchment area of the Gumballi PHC, indicating the severity of mental health care needs in the other primary health care areas of the district. Also, being housed within a PHC was very important as it catered to the most socially vulnerable groups with mental health care needs—85% of patients seen till 2009 were from households below the poverty line and 43% of the patients were from scheduled caste/scheduled tribe communities.[3] Over half of the patients seen (50.3%) were illiterate. Many of these categories of patients may not be able to seek care in distant cities or in for-profit private facilities. Below, we present two case studies prepared from interviews with a health worker and a patient who volunteered to share her experience with the clinic. Subsequently, we summarise the lessons learned in integrating mental health care into PHCs organised according to their relevance to diagnosis, treatment, follow-up, rehabilitation, co-morbidities and the impact.

[3] The Indian Constitution identifies several socially disadvantaged population groups as scheduled caste and scheduled tribe for various types of affirmative action. These population groups are among those facing varying degrees of social disadvantage and exclusion and various schemes and programmes of the government target these groups.

Photo 2 Gumballi PHC maintains medical records of all patients seen in the programme

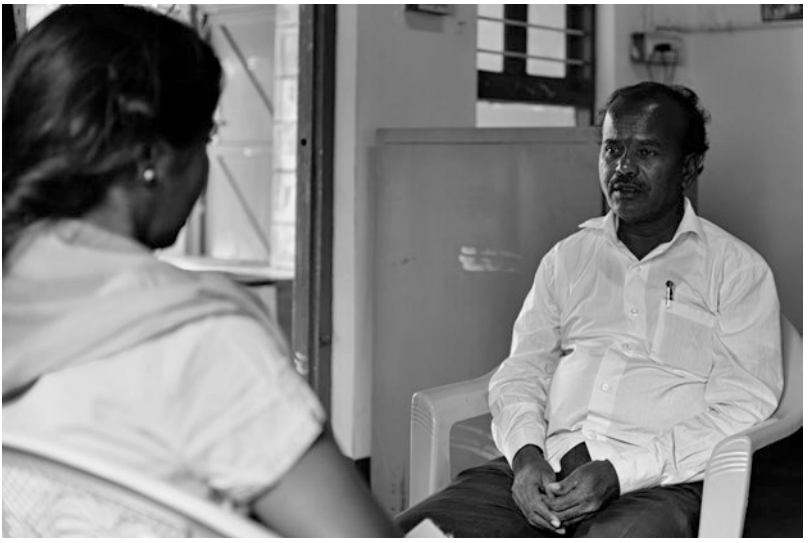
Photo 3 The clinic continues every second Saturday. It is managed by a PHC doctor trained and supervised in providing basic mental health care

Case Study 1: PHC Workers Can Play a Major Role in Providing Mental Health Care

Mahadeva Murthy grew up in Komaranapura, one of the sub-centres within the area covered by the Gumballi PHC. His father worked for daily wages and often was not able to find work every day. With six children to feed and raise and with no land of his own in a largely agrarian part of Karnataka, Murthy's father's struggled to make ends meet. After a degree in arts in the early 1980s, there was a lot of pressure on Murthy to not continue with his studies, but contribute to the family's meagre income. Introduced to Karuna Trust by a social worker, he was initially involved in their community-based leprosy elimination programme. He participated in door-to-door surveys, conducting community awareness generation meetings and using flip-charts, posters and awareness generation materials. Subsequently, as Karuna Trust expanded its activities to tuberculosis, he also began to participate in that programme. When the NIMHANS team and the medical officer at VGKK hospital were looking for health workers who could join their effort at detecting mental illnesses in the community, increase awareness on treatment of mental illnesses and refer such patients to the PHC, Murthy (among several other such non-professional health workers) was a natural choice. He attended a ten-day training at NIMHANS where he participated in lectures, watched patient education material and was shown several signs and symptoms of mental illnesses by the psychiatrists there. Subsequently, under the supervision of the medical officer at VGKK hospital, Murthy and several other health workers like him improved their listening skills and were able to help people in the community identify mental illnesses and take them to the PHC clinic for treatment. At the clinic, Murthy would talk to all the patients, make notes about the improvement/deterioration of various symptoms, chat with patient's family members about their attitudes towards care for mentally ill, assess compliance to treatment and organise appointments for home visits and follow-up visits in cases where the medical officer identified such a need. Under the supervision provided by the psychiatrist (initially) and later taken over by the local doctor, Murthy today feels confident of being able to help people with mental illnesses. He looks back at his stint in various disease-control programmes including leprosy, tuberculosis, epilepsy and mental health and observes that mental health is the only one which really helped him form lasting relationships with patients

and helped him improve his communication skills in general. He feels a sense of purpose today and is very satisfied with his decades of work in mental health. Not much has changed in terms of referral and availability of mental health care in most of the government PHCs, he notes as he has a lot of experience with patients from neighbouring PHC areas who were referred to their own PHCs for medicines returning to Gumballi citing non-availability of these medicines and/or erratic supply. He also laments on the lack of a programme for mental health such as the ones for tuberculosis and leprosy, attributing the decrease in the prevalence of these diseases to the existence of national programmes specifically providing health workers for these purposes at PHCs.

Photo 4 Mahadeva Murthy



Case Study 2: Huge Unmet Need for Mental Health Care in Rural India

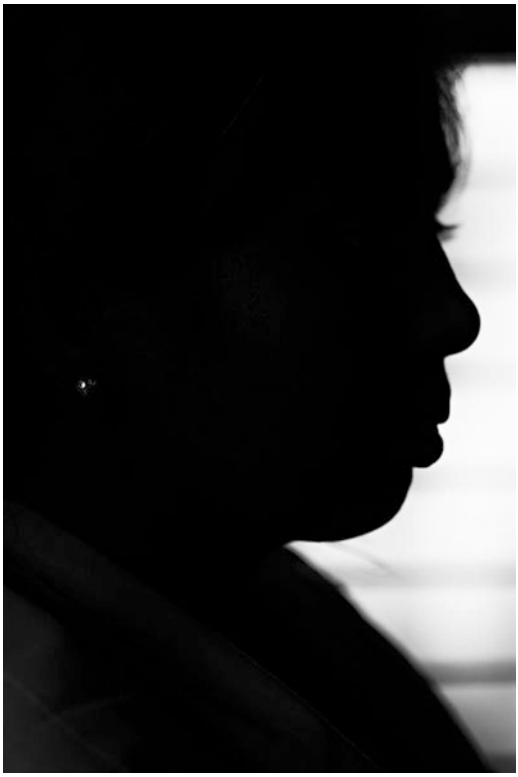
Indira (name changed) is today in her late 30s. In her late teens, her aunt and parents noticed a distinct change in her behaviour. She began to talk a lot and easily picked fights with people at home. She would sometimes suddenly

break into song and dance. Initially, these symptoms would eventually decrease in a matter of weeks. For some years, the family members attributed this to her age and growing up. When this became more severe, they were confused as to what to do. In 1997, one of her parents' neighbours informed her aunt that there is a visiting doctor from NIMHANS, Bangalore, who comes to a government PHC eight kilometres from their village. The aunt shared that, in their village (which was within the area covered by Gumballi PHC), health workers had visited home to home inquiring if there were people in their village with some of the symptoms that Indira had. She also informed Indira's aunt that these were treatable with medicines and counselling at the PHC. Ever since that visit to Gumballi PHC in 1997, Indira has been on treatment with medicines for bipolar affective disorder and attends monthly follow-up visits. She notes that in 2007 the doctor informed her that the government is now extending the mental health programme to all PHCs and the Gumballi doctor referred her to continue further treatment at a PHC in her own village. She describes this as a difficult experience. She notes:

> Our PHC is nearby but for my kind of problems, they don't keep medicines. They did give me CPZ tablets [chlorpromazine, an anti-psychotic medication] for some weeks, but the supply was so erratic. They also don't have a system of writing in records or helping me with my problems. Finally, I decided to go back to Gumballi itself.

She is glad that she is able to discuss her problems on a monthly basis with a doctor and obtain medicines every month. Indira's family, over time, has understood her needs and takes care of her. She takes care of a lot of household chores and lives most of the time with her sister's family. Indira was born into a family recognised as a scheduled caste. After several years of facing structural discrimination and being socially disadvantaged, scheduled caste and scheduled tribes are recognised by several affirmative action policies. Indira's family is somewhat atypical in being economically better off than most of the scheduled caste families. Her family also supports her with a moderate monthly allowance and takes care of her cost of medicines (already subsidised at Gumballi PHC). She accompanies them to family events and gatherings. Today, Indira appears confident that she will overcome occasional episodes of increased anxiety and suspicion with the support of family members and continuing treatment at the nearby Gumballi PHC.

Photo 5 Indira



Lessons Learned

Below, we have summarised the lessons learned in integrating mental health care into PHCs organised according to their relevance to diagnosis, treatment, follow-up, rehabilitation, co-morbidities and the impact.

1. Diagnosis

   (a) The administration of a screening tool in the form of a questionnaire, administered systematically at the village level (in focus groups with village heads and self-help groups) to identify people with mental illnesses was very useful in improving awareness on identifying mental health problems in the community as well as extending care to the *invisible* mentally ill.

(b) Initially, patients often presented to the clinic several years after onset of the illness. This trend slowly shifted to patients with recent onset of symptoms visiting the clinic. Patients with depression often presenting with multiple somatic symptoms were diagnosed and initiated on treatment. As the programme progressed, we began receiving referrals from community members, often households or neighbours who could identify patients with symptoms of mental illness and refer them to the monthly clinic.

2. Treatment

(a) Most of the patients with psychosis received only conventional neuroleptics like Fluphenazine and Chlorpromazine as they worked out to be more economical. Yet, it was found that they were very effective and safe without many side effects at the doses in which they were used. Atypical antipsychotics were used only in exceptional cases.
(b) Registration at the clinic entitled patients to routine follow-up, monthly medication and health worker visits to homes wherever necessary. Good quality generic medicines were procured in bulk and were given at cost price to patients. Average cost of treatment (including registration, consultation and medicines) for a typical patient undergoing treatment with antipsychotic medication was less than $5 per month (about INR 200 per month). During the last few years, the Karnataka government improved the availability of free medicines for mental health problems in primary care and even this component of the cost was therefore removed.
(c) Lithium, as a mood stabilising agent, was used in people with bipolar affective disorders. This was followed even though there was no facility to check blood levels and patients, though advised, would often not be able to afford monitoring lithium levels at laboratories located in faraway cities. It was always used at lower doses than that used in tertiary mental health establishments and again it was found that it was effective without side effects in the doses in which it was used.
(d) Such experiences gave us the confidence to use them in cost-constraint situations with good success. Based on the Gumballi experience, it was possible to help various other community-based mental health initiatives in costing medicines and care.[4]

[4] The second author V.S. Sridharan was an external evaluator for a few community-based mental health initiatives across the country. He could share his insights with these projects based on his experience in

(e) The project focused on treatment of severe mental illnesses such as major affective disorders and psychosis. In view of the nature of staff involved and their training, there was a relative neglect of psychosocial interventions to supplement the medicines. Also, the clinic did not explicitly focus on substance abuse or alcohol addiction, although patients with these problems also began to present themselves at the clinic over the years.

3. Follow-up

(a) It was found that some patients could not come to the clinic for follow-up due to practical difficulties like bringing an acutely psychotic patient by public transport, an elderly caregiver and economic difficulties. The clinic team led by the doctor and sometimes the visiting psychiatrist visited the house of the patient on a regular basis to provide treatment. Such involvement and sustained effort from the clinic and the positive outcome it brought out reinforced the faith of the community in treatment.
(b) Some very severe cases, which could not be managed at the clinic, were even referred or even transported to NIMHANS for further management.

4. Rehabilitation efforts

(a) Rehabilitation was the most challenging component of the care provided even though it is an integral part of mental health care. Community-based rehabilitation requires convergence and intersectoral coordination between a variety of actors at the village, *taluka* and district level. In a limited way, rehabilitation opportunities were explored and provided for some patients within Karuna Trust.
(b) Families were helped and empowered in getting linkages with existing social welfare schemes of the government to mitigate distress secondary to dysfunction in the individual leading to economic difficulties. Although the schemes are limited in their scope and difficult to access

anchoring the mental health programme at Gumballi. The projects that benefited from these insights include Association for Health and Welfare in the Nilgiris (ASHWINI), Tamil Nadu, The Banyan, a voluntary organization working for homeless mentally ill women in Chennai as well as its initiative for the Tsunami-affected community in costal Tamil Nadu, Paripurnata, a voluntary organization established in the year 1991 with the vision of bringing hope and wholeness in the lives of mentally ill women, and The Richmond Fellowship Society (India) Bangalore which has developed a community-care model in rural Karnataka.

for the most affected and vulnerable, they are often the only available source of support for many families that are severely affected socio-economically by a member suffering from mental illness.

(c) Volunteers were identified in some of the villages in the catchment area and trained to support the families caring for persons with severe mental health problems. They often discussed with the health worker many issues like discontinuation of medication, not keeping follow-up contacts, specific difficulties encountered by the families and crisis situations. Many of the volunteers advocated for employment for the affected person in the village or with any other potential employers in the neighbourhood.

(d) Support groups of people and families with mental illness were also initiated to share their experiences every month. This activity typically lasted for about 45 minutes before the consultation or reviews occurred.

5. Co-morbidities

(a) Co-morbidities like tuberculosis, severe anaemia requiring blood transfusion, diabetes mellitus and hypertension were also addressed when identified. This was especially possible because the clinic was housed within a primary healthcare facility.

(b) Through their participation in a primary care facility that provides mental health care, over time, caregivers' attitudes towards addressing mental health components of other diseases also improved. There is anecdotal evidence to suggest that patient-centered care provided by doctors and health workers participating in the clinic improved due to their becoming sensitive to mental health care needs of patients.

6. Impact in the community

(a) Over time, the community developed an insight into the treatable nature of mental illnesses and it gave a new hope and help to the silently suffering family.

(b) Many opinion leaders and people of prominence in villages and towns began to talk openly about seeking care for mental illnesses at the health centre and this helped address social barriers to seeking care for mental health problems.

(c) Though we could not document evidence of reduction in deliberate self-harm in the mentally ill, the availability of care at the level of primary care contributes to decreasing such instances. The availability

and responsiveness of PHC staff to mental health emergencies and follow-up visits improved the confidence among patients and family members.

7. Other impacts

(a) The PHC health workers were trained and sensitised to identify different types of mental illnesses like schizophrenia, depression and bipolar affective disorders. We found that this skill was dependent on observation, careful history taking and patient communication and was often neglected in medical training and lacking among professionals in several other primary health centres.
(b) Involvement in caring for the mentally ill also enriched the soft skills of the medical and para-medical staff to address other programmes for chronic diseases like diabetes, hypertension, epilepsy and tuberculosis.
(c) The experience also made us aware of the need for and feasibility of running an alcohol de-addiction programme at the community level.

As there are only about 3500 psychiatrists for over a billion people in India, they are better involved as trainers and not as the primary caregiver for the mentally ill. However, the presence of strong alliances between psychiatrists and PHC teams in the form of formal referral networks or through strategic linkages with NGOs and private practitioners is needed. The role of psychiatrist in providing a higher level of care as well as providing expert input on treatment plans for existing patients is crucial to the success of an integrated PHC-level mental health care programme. The psychiatrist may review the programme periodically and give on-site training and plan psychosocial rehabilitation facilities within local settings.

As the programme evolved, and access to mental health services increased in the local area, patients who were using the Gumballi services were subsequently referred to facilities closer to where they lived. Today, the availability of medicines in several PHCs across the state has improved and whenever possible patients are referred for care to their respective PHCs. Although there are still many challenges in the scale of human resources and capacity gaps for delivering mental healthcare in PHCs in Karnataka, there is no doubt that it is possible to do this cost-effectively when there is a local vision to provide mental health care within PHCs, a committed team led by a doctor as well as key linkages with tertiary mental health care facilities (medical colleges or specialty hospitals with psychiatry departments).

Broadly, the lessons learned may be summarised as follows:

1. There is a wide range of unmet mental health care needs in the community, especially in the rural areas of India. The challenge of reaching services is accessibility, acceptability of the offered services and the affordability of care.
2. It was possible to provide inclusive mental health care within primary care settings in a relatively deprived and largely rural south Indian district.
3. A large number of people benefitted from decentralised mental health care, which was a specialist-assisted, but eventually non-specialist-driven programme.
4. Our intervention increased the number of people who sought medical treatment for mental illness in addition to traditional healers and faith healers over a period of time, as evidenced by the fact that number of registrations for acute psychosis increased in the clinics. In view of early involvement and negotiations with these actors, it was also possible to establish an informal referral system from traditional providers to mental health services, especially for severe mental illnesses.
5. People and their families exhibited a great degree of comfort using these services.
6. It was gratifying to note that non-specialist primary care doctors associated with Karuna Trust and BR Hills were able to gain knowledge and skills to manage both acute and chronic mental health problems, substance use disorders, intellectual disability and seizure disorders.
7. The programme appears to have reduced mortality and morbidity associated with mental health problems.
8. The success of this programme resulted in up scaling of mental health into primary care in other PHCs run by Karuna Trust.[5]
9. Many people with severe psychotic illness remained untreated despite the above-mentioned resources in the catchment area. Services for these people will require higher resources, better convergence and coordination with social and legal services.

[5] With the support of The Banyan, Chennai and Sir Ratan Tata Trust, the Karuna Trust has begun integrating mental health care into primary care settings in all its other PHCs in Karnataka, run under public private partnership with the government. However, several challenges remain in doing this in other PHC settings due to difficulty in establishing a systematic two-way referral system for mental illnesses as well as the challenges in linking with psychiatrists for building capacity of doctors and health workers.

Conclusion

Many LMICs including India suffer from very scarce systematic evaluation of public health programmes, schemes and interventions; in the lack of this, policymaking tends to rely heavily on single success stories. On one hand, there is poor public health capacity and hence poor research outputs in this field, while on the other hand, very limited evidence for scaling up small successes mostly demonstrated by NGOs in very particular contextual conditions (Dandona et al. 2009). For example, an increasing body of literature critically looking at public–private partnerships and the role of NGOs vis-à-vis sustainability and permanence of innovative civil society/NGO-based approaches are advocating for cautious interpretation of success stories (Prashanth 2011). The descriptive case study of the Gumballi experience that we present needs to be read in that background. A scientific evaluation using health systems research methodologies are required for a systematic understanding larger lessons from the Gumballi experience (Prashanth et al. 2013; Rao et al. 2014). However, the long-term nature of engagement at Gumballi and the urgency of action on mental health at a very large scale are both important considerations underlying a descriptive approach followed here. It is possible to draw lessons on particular aspects of the Gumballi experience to strengthen the response of public health systems to the increasing unmet need for mental health care and support in the community. However, several challenges remain and need to be addressed within the larger health systems:

1. Strengthening health systems: Mental health care is an indicator of strong health systems. Care for mental health problems require patient-centred approaches as well as a good system of referral to ensure continuity of care. Given the lack of a district-level health system that is well resourced in terms of infrastructure, human resources, medicines and a system of good governance, mental health care in primary care will remain contingent on health systems strengthening initiatives.
2. Sustainability: Experiences of NGOs in showcasing good practices need to be integrated into the general health planning at the state level in order to ensure that such initiatives are sustainable and long lasting.
3. Medical records and continuity of care: Building a system in primary care based on health centre-held medical records for households or individuals is an important challenge in a country like India, where there is hardly any investment to date on building health information systems.

4. Referral and patient follow-up: Very poor follow-up on cases due to poor tracking system, rehabilitation and reintegration of the patients.
5. Limited human resources for mental health: Not only psychiatrists but also counsellors, other health workers and nurses are few and far between in India. This imposes limitations on scaling up such initiatives to *talukas* and PHCs across the country.
6. Rehabilitation and convergence: Within a system with weak investments in social welfare and social protection and poor convergence at district level between health and various other social services, organising rehabilitation for those who have been treated for mental illness is a difficult enterprise.

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