

Strengthening mental health systems in fragile setting



Opportunities and challenges for strengthening mental health systems in low and middle income countries: A case example from Nepal

Nawaraj Upadhaya, 2020

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Strengthening mental health systems in fragile settings

Opportunities and challenges for strengthening mental health systems in low and middle income countries: A case example from Nepal

Versterking van het geestelijke gezondheidszorg systeem in een fragiele staat

Kansen en uitdagingen voor het versterken van het geestelijke gezondheidszorg systeem in lage- en middeninkomenslanden: een voorbeeld uit Nepal

(met een samenvatting in het Nederlands)

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CHAPTER 1

Problem statement and dissertation structure

Introduction and dissertation structure

The main focus of the dissertation is to explore the challenges, opportunities and barriers for mental health system strengthening in the context of a low-resource setting like Nepal. The dissertation also aims to examine the interplay between research, policy and practice and identify the underlying reasons why policies developed at the national level are not followed up at the implementation level. This introduction chapter provides a brief description of the situation of global mental health (and specifically in Nepal), important developments in global mental health in the past two decades and a summary of literature on mental health systems. This chapter (and the overall dissertation), is structured around the World Health Organization (WHO) Health System Strengthening building block framework. In this framework, a health system is organized in six building blocks including financing; information; service delivery; medical products, vaccines and technologies; health workforce; and leadership and governance. The framework assumes that inputs in the six building blocks will improve access, coverage, quality and safety and thereby yield better health, responsiveness, financial risk protection and improved efficiency. The introduction chapter also includes a description of the setting/context where the research was conducted, research objectives/themes, the study's conceptual framework, and the inter-connectedness/relationship of the dissertation chapters.

Global mental health situation

The Global Burden of Disease Study 2010 reported that mental, neurological and substance use (MNS) disorders accounted for 10.4% of global disability adjusted life years, 2.3% of global years lost to premature mortality and, 28.5% of global years lived with disability. [1]. Thus, MNS disorders were the leading cause of years lived with disability. Vigo and colleagues argued that this was an underestimate of global burden of MNS disorders because suicide and self-injury are categorized separately and personality disorders were not included in the MNS-disease burden calculations [2]. According to a WHO global health estimates report about 800,000 people die by suicide every year, making it among the top 20 leading causes of death worldwide. Among youths aged 15-29 years suicide was the second leading causes of death for both sexes. The majority of deaths by suicide (79%) most recently, have occurred in low- and middle-income countries (LMICs) [3]. The Global Burden of Disease Study 2015 reported that the depression and anxiety were the third and ninth leading causes of disability, respectively [4].

Despite the high disease burden, many people with MNS disorders do not receive the treatment they need, thereby creating a treatment gap. Globally, over 70% of young people and adults with MNS disorders do not receive treatment from a health facility [5], whereas in LMICs this treatment gap has reached nearly 90% [6]. Health systems in LMICs have still not been able to meet the mental health and psychosocial needs of their population.

Fortunately, in the past two decades, several positive initiatives have addressed the high treatment gap for MNS disorders. For example, for the first time, the WHO World Health Report focused on providing public health perspectives of mental health (2001) and a Lancet series on global mental health (2007) published several papers and highlighted the dire treatment gap. The Inter-Agency Standing Committee (IASC) guidelines on Mental Health and Psychosocial Support in Emergency Setting (2007) created a set of common guidelines on how to provide mental health and psychosocial support during emergencies. The establishment of “The Movement for Global Mental Health (the Movement, www.globalmentalhealth.org)” in 2008 was another important milestone in global mental health that aimed to close the treatment gap for people living with mental disorders worldwide. The Movement focuses on populations where the gaps are the largest—people living in LMICs. The Movement seeks to promote actions based on two fundamental principles: evidence on effective treatments and the human rights of people with mental disorders. The Movement is the follow-up strategy to the call for scaling up services for people with mental disorders (Lancet Global Mental Health Group, 2007). A core principle of the Movement is to strengthen the platform on which all global mental health communities can build a partnership to take collective action for global mental health.

Given the significant unmet needs and lack of specialist human resources in the mental health sector, WHO launched the mental

health gap action programme (mhGAP) guideline in 2008, with the aim to facilitate delivery of evidence-based interventions by non-specialised health workers in primary health care (PHC) settings [7]. To make integration of mental health in PHC a success, there have been global efforts to change the role of mental health specialists (such as psychiatrists and psychologists) to also include training and clinical supervision support to PHC workers, an approach known as task-shifting or task-sharing [8].

These initiatives led to the WHO mental health action plan (2013), which aimed to promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders [9]. The action plan relies on six cross-cutting principles and approaches: 1) universal health coverage for persons with mental disorders, 2) mental health policy, strategies, actions and interventions compliant with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments and declarations, 3) mental health strategies and interventions based on scientific evidence/best practices while considering social and cultural contexts, 4) strategies and interventions for mental health use a life-course approach to ensure that mental health and social needs at all life stages are addressed, 5) a multi-sectoral approach for mental health services strengthening both the public and private sector capacity to provide services, and 6) persons with mental disorders and psychosocial disabilities empowered and involved in mental health advocacy, policy,

planning, legislation, service provision, monitoring, research and evaluation.

All these efforts over the past years have brought mental health to global attention and as a result, mental health indicators were included in the UN Sustainable Development Goals (SDGs) when ratified in 2015. In 2016, the World Bank and WHO recognized mental health not only as a global health priority, but also as a global development priority. The 2018 Lancet Commission on Global Mental Health suggested reframing mental health to concurrently address prevention and quality gaps alongside treatment gaps [10].

Although all the above-mentioned important initiatives have helped to promote mental health agenda globally, mental health is still neglected in many LMICs. For LMICs the mhGAP intervention is a strategy to reduce this large treatment gap. For mhGAP-based interventions to be successful, the health system-level interventions need to be implemented hand in hand. Currently, this is not the case, due to mental health's low priority worldwide, and the lack of research on mental health systems; thus, there is little knowledge about the successes and challenges of mental health system-strengthening efforts in LMICs. For physical health problems, the WHO's health system building block approach has been widely used and researched, but for mental health, this framework has rarely been utilized to develop and assess a sustainable mental health system-strengthening approach. Therefore, a better understanding of mental health systems and sustainable approaches to mental health system

strengthening is needed in order to address the treatment gap described above. With the aim to contribute to mental health integration into existing public health systems, I summarize mental health literature from LMICs using the WHO health system strengthening building-blocks framework.

Conceptual framework:

The WHO Health System Strengthening building-blocks framework (Figure 1) is one of the most frequently used frameworks for health system intervention and research. In this framework, a health system is organized in six building blocks including financing; information; service delivery; medical products, vaccine and technologies; health workforce; and leadership and governance.

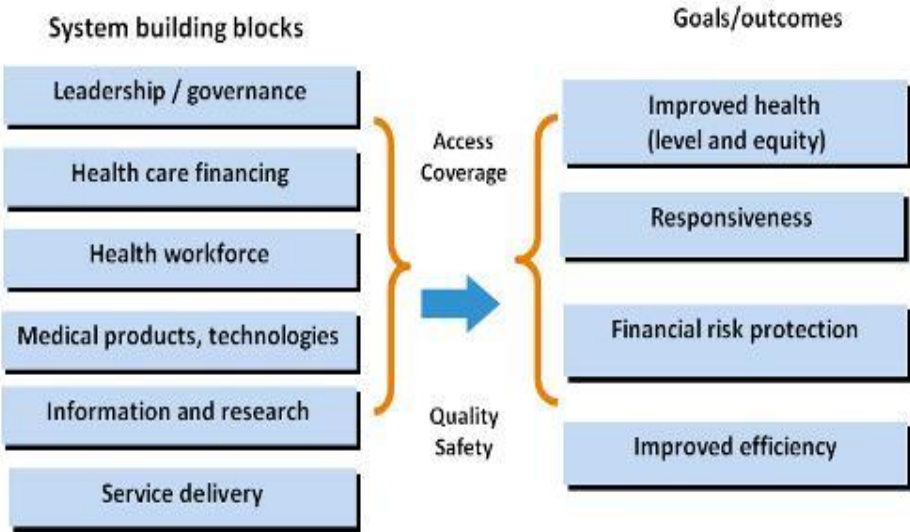


Figure 1: WHO Health System Strengthening Building Blocks Framework

The building blocks are associated with the process elements (access, coverage, quality and safety) and outcome elements (improved health and health equity, responsiveness, social and financial risk protection, and improved efficiency). It is assumed that inputs in building blocks will contribute to achieve outcomes by improving access, coverage, quality and safety.

I used this framework to explain how interventions implemented in several health system building blocks increase the coverage, access and quality of health care delivery. To reduce a mental health treatment gap, the focus should not only be in service delivery (mhGAP-based interventions), but also on the required health systems (as pre-requisites) to strengthen the delivery of mhGAP-based interventions. Hence, there is a need for mental health research through a system lens and for that purpose, the WHO Health System Strengthening building blocks framework was most appropriate.

Leadership/governance

Health system governance (HSG) is a framework for improving access to quality care by increasing shared learning, transparency and accountability [11]. However, health system governance is under-researched and least understood. Therefore, assessing HSG is a priority because it provides the opportunity to debate subjects that are often ‘pushed under the carpet’[12]. Mental health is one such subject and is often neglected in major public health policies and plans.

Poor governance (e.g. lack of policy, legislative framework, and health system design to facilitate optimal policy implementation) is a barrier to effective integration of mental health in PHC in LMICs [13]. Similarly, inadequate financing and insufficient human resources and infrastructures are the causes of poor mental health system performance [14]. To address the challenges of poorly performing mental health systems, Petersen and colleagues (2017) suggested a set of key governance strategies including: (1) strengthening manager capacity at district or health facility levels; (2) strengthening health system building blocks to promote efficiency, responsiveness and effectiveness of PHC facilities; (3) engaging community and service users and caregivers in mental health awareness raising and advocacy initiatives; and (4) developing innovative approaches to reduce social stigma associated with mental illness. A model of mental health governance based on rights, risks and recovery proposed by Sugarman and Kakabadse (2008) could help address mental health system challenges. The model includes an integrated healthcare governance strategy with elements such as staff training, protection of patients' rights and service audits [15]. However, a model of mental HSG structures should be developed after exploring the local health system context, such as challenges, opportunities and barriers affecting the development of targeted activities and procedures to enable health system strengthening [16]. These governance structures and mechanisms need to strengthen coordination, leadership and ability to plan and implement mental health care at the national and sub-

national levels [17]. The governance framework should consider the role of the government as well as all other non-state actors involved in health service delivery (private hospitals, medical colleges and health programmes run by civil society organizations). One useful framework is described by Abimbola and colleagues (2014) and presents three levels of governance including government-run constitutional governance, community-run collective governance and provider-customer-run operational governance [18].

Health care financing

MNS disorders account for a significant and growing proportion of the global burden of disease (10.4%) and yet remain a low priority for public financing in health systems. In most LMICs, the percentage of health budget for mental health services is approximately 1% or less [19]. This small budget in LMICs is generally allocated to running mental hospitals, thus leaving no resources for community-based mental health integration in PHC and social platforms [10]. This increases patient and family out-of-pocket payments for mental health services [20]. Out-of-pocket expenditures for mental health services contribute to a household's economic burden and reinforce poverty. Past studies have shown that mental ill health and poverty are linked and negatively affect one another [21]. Therefore, barriers to mental health financing need to be identified and addressed. The main barriers related to resources, such as insufficient resources, mal-distribution of resources, lack of information about resources and inappropriate use of existing

resources could be overcome by improving mental health literacy among policy makers and planners, improving financing mechanisms for the appropriate use of existing resources and exploring new approaches for financing mental health services [22]. The key strategy for equitable and sustainable mental health financing in LMICs is the inclusion of mental health in existing or planned national health insurance schemes [23].

One of the barriers for lack of mental health financing, is that policy makers and planners are not aware of cost-effective mental health interventions. For example, one study using an MNS component of the UN One Health Tool showed that an estimated USD 0.06-0.33 per capita of the total population per year was needed to deliver key interventions for psychosis, depression and epilepsy in four of the study countries: Ethiopia, India, Nepal and Uganda [24]. The One Health Tool is an integrated health planning tool used to assess a country's resources for pre-defined key strategic activities and associated costs. Likewise, the cost of implementing a district mental health care package (developed through the PRIME project) with target coverage, ranged from USD 0.21 to 0.56 per head for the population in Ethiopia, India, Nepal and Uganda [25]. These results show that cost-effective mental health interventions exist and can be implemented in LMICs, but to do so requires strong lobbying and advocacy with policy makers and planners to include mental health in national health insurance schemes and initiate a provision of private health insurance (PHI) plans for people with MNS disorders.

A study in Kenya evaluated the effects of PHI on access and utilization of mental health services and found that insurance paid in full for 28.8% of patients [26]. Patients with PHI could afford their care and stayed in hospital 36% longer than those paying out of pocket. The readmission rate was 2.5 times higher among patients with PHI compared to patients paying out of pocket. However, Dixon et al. (2006) identified three main problems with PHI for mental health service users in LMICs: (1) mental health was not included in benefit packages, (2) people without employment had very limited access, and (3) public insurance providers refused to insure pre-existing conditions. The authors also identified problems with social health insurance since in many LMICs, this insurance is based on contributions and limited to those in formal employment; therefore, many people with MNS disorders are excluded [20]. There is a need to advocate for insurance policies that include financial risk protection for people with MNS disorders and their family members.

Medicine and technologies

Prescription of psychotropic drugs in many cases is accepted as an adequate approach for the treatment of MNS disorders. Hence, anti-psychotic, anti-depressant, and antiepileptic drugs are prescribed and used in LMICs [27]. For example, a study from India showed that Fluoxetine and Escitalopram were the most commonly prescribed drugs for depression, Alprazolam and Lorazepam (benzodiazepines) for anxiety and panic disorders, and olanzapine and risperidone for psychosis [28]. In Nepal, Fluoxetine was also the commonest

antidepressant prescribed followed by Amitriptyline and Trazodone [29]. Among anxiolytics, the commonest drug prescribed was Alprazolam, followed by Clonazepam, Chlordiazepoxide and Lorazepam [30]. However, atypical antipsychotics, such as Olanzapine, were used more commonly than typical antipsychotics [31].

A variety of factors such as patient characteristics, the physician, or the patient/physician interaction may affect prescriptions and the effects of psychotropic medications in primary care [32]. But, it is widely believed that Nepalese health professionals' decisions on psychotropic drug prescriptions are influenced by the benefits they are offered by the pharmaceuticals companies to prescribe drugs according to specific brands [33]. The higher number of prescriptions for brand name medications (as opposed to generics) raises questions and erodes patient and stakeholder trust. Restoring trust among stakeholders in pharmaceutical supply chains is a challenging task [34].

Another challenging task is the social stigma associated with the use of psychotropic drugs. Psychotropic drugs act as socializing agents and their use determines social positioning, thus having effects on a person's self-esteem, personality and psychological development [35]. Use and access to psychotropic drugs are determined by the patient's socio-economic situation. For example, patients who are able to pay out of pocket have a wide range of available options

compared to those who rely entirely upon public sector health care [36].

Due to poverty, many people with MNS disorders in LMICs cannot afford to buy psychotropic drugs, so strengthening mental health systems features would potentially facilitate access to psychotropic drugs [37]. The implementation of a Drug Revolving Fund could be a sustainable and alternative approach for managing drugs for those who cannot afford to buy their medications [27].

Service delivery

In LMICs, mental health service delivery has largely been through institutions (mental hospitals and private residential clinics). However, compared to institutional treatment, community care has a more realistic treatment outcome and better quality of life for individuals with MNS disorders [38]. Therefore, large mental hospitals and institutions are increasingly being replaced by psychiatric beds in general hospitals and the integration of mental health in PHC and community-based structures [10]. This school of thought has led to a global ambition to improve access to mental health care in LMICs by scaling up integrated mental health care in PHC facilities [39]. However, to improve mental health service delivery in PHC settings, there is a need to overcome the barriers, especially the lack of human and financial resources and systems and procedures for delivering and documenting mental health services [40]. Similarly, achieving sustainable scale-up of primary mental

health care requires a sufficient allocation of resources into PHC settings and appropriate use of existing resources [41].

Given PHC workers' lack of mental health training in LMICs, WHO launched the mhGAP guideline in 2008, to facilitate the delivery of evidence-based interventions by non-specialised health workers in PHC settings. The mhGAP Intervention Guide is a potentially useful tool for scaling up mental health services in LMICs where there are very few mental health specialists [42]. But, mental health training for PHC workers alone is not adequate for scaling up integrated mental health care in PHC, since health care system building blocks also need to be strengthened to provide a more enabling context for mental health service integration and scale-up [39].

One of the critical components of mental health service delivery is the involvement of service users and caregivers. Service user and caregiver involvement in mental health system strengthening can improve the acceptability, quality, relevance and responsiveness of mental health care. Potential benefits of service users and caregiver involvement include: (i) implementation of more appropriate service user-centred quality mental health services and (ii) greater protection and improved respect for service users [43]. But, there is limited involvement of service users and caregivers in mental health policy-making, planning and developing or monitoring mental health services [44].

Health workforce

Building human resources capacity in mental health system strengthening and provision of care will support scale up of integrated mental health care in LMICs [45]. However, compared to high-income and middle-income countries, the mental health human resources in low-income countries are scarce (median 0.06 psychiatrists and median 0.16 psychiatric nurses per 100,000 people) [38]. Similarly, a study by Buckner and colleagues (2011) found that all low-income countries and 59% of middle-income countries had significantly fewer mental health human resources compared to what they needed to deliver a set of mental health interventions [46].

Evidence suggests that using task-shifting approach (accompanied with training and supervision) mental health care can be delivered effectively in PHC settings by non-specialist health professionals, PHC workers, lay community workers, caregivers and service users [47]. However, for this to be sustainable, a proper strategy of involvement and engagement of these workforces is needed. Some of the strategies may include: shared competencies and task-shifting between health professionals [46], and provision of structured training, coaching, and onsite supervision by specialist mental health professionals. Training and supervision are not enough, and financial and non-financial motivations are crucial to ensure continuity of health workers providing mental health care. Improvement in working and living conditions, provision of financial and social incentives and availability of career development opportunities could motivate health workers' availability and performance [48]. In

the absence of such incentives and career development support, the task shifting approach is unlikely to succeed and may even lead to health worker burnout [49]. Therefore, capacity-building interventions should take into account the local context in which health workers function, and ensure it is tailored to suit the specific needs of individual countries [50] and evaluated to determine local indicators of success [45].

Success indicators should also include health workers' performance compared to their job descriptions and in consideration of their working conditions. This is important because the performance of health workers in relation to performance-based incentives is under-researched [51]. Therefore, further research exploring the link between the health workforce and governance and its impact on the effectiveness of specific interventions is needed [52].

Health Information

Along with a treatment gap for mental health care, there is also a large information gap in mental health. In LMICs, there is a lack of reliable information on the need for mental health services, access and coverage for mental health treatment and the quality of existing mental health services [53]. The dearth of evidence-based information is an important barrier to the implementation of effective policy or practice [22]. One of the reasons decision makers in many LMICs lack required data for evidence-based planning and health management is that routine national health management information systems (HMIS) do not capture community health

events [54]. Therefore, there is a need to close the mental health information gap, which will contribute to reducing the mental health treatment gap as a consequence. The WHO mental health action plan of 2013 had a target that by 2020, approximately 80% of member states would report on a core set of indicators every two years through their HMIS [9]. This target now appears to have been too ambitious because in many LMICs, mental health does not receive the priority it deserves, so mental health information systems are either not developed or inadequate. Second, the current mental health information systems in low-resource settings have not been optimally used due to limited training, poor staff involvement, increased health worker workload and lack of logistical support to maintain the systems [55]. Mental health information systems can only provide evidence-based information for policy, planning and service delivery when there is a proper system for collecting, processing, analysing and reporting mental health-related information [56]. To improve the use and effectiveness of mental health information systems, we need to have sound mental health indicators. Second, routine monitoring of key mental health programme performance indicators is needed to assess whether or not the integration and scale up of mental health services in PHC are successful [57]. To address this challenge in LMICs, Jordans and colleagues (2016) designed mental health indicators to allow for monitoring of effective coverage of mental health care in PHC settings [58]. Jordans and colleagues [59] conducted another study to evaluate newly designed indicators that showed high levels of

performance and perceived utility when implemented by PHC workers. Hence, the authors recommended incorporating these indicators into existing HMIS and mhGAP-based mental health interventions. Likewise, a study by Ahuja and colleagues (2019) in six countries in Asia and Africa showed that mental health indicators (except for severity, functionality and cost) were acceptable to the PHC workers because of the indicators relevance and usefulness for improving mental health care provisions [57]. Available literature and field experiences suggest that greater technical and financial inputs are needed to strengthen routine HMIS and facilitate the implementation of the mhGAP-based mental health interventions and targets set by the WHO mental health action plan 2013–2020 [53].

Dissertation Research Themes

In LMICs, there are challenges in terms of health system strengthening due to weak governance and leadership. It is even more challenging to strengthen mental health systems since mental health is neglected in government, civil society and community structures. In this context, the central theme of this dissertation is how to strengthen mental health systems in a setting confronted by many constraints (e.g. lack of trained mental health human resources, finances, drug supply and other infrastructure weaknesses) in order to promote community-based mental health care and integration of mental health into PHC. Throughout this dissertation, the main research question is considered, “What are the

challenges and opportunities for mental health system strengthening in the context of a low-resource setting like Nepal?” by answering the following sub-questions.

- What is the current state-of-the-art of mental health system strengthening efforts?
- What system-level factors facilitate or impede mental health system strengthening in low-resource settings?
- What are the perspectives of stakeholders on mental health governance, supply chain management of psychotropic drug and task-sharing for community-based mental health interventions?
- What are the key actions to be undertaken for the strengthening of mental health systems in LMICs?

Setting

Nepal is a South Asian, multi-ethnic, and mountainous country, and is one of the poorest in the world. According to UNDP Human Development Report 2019 Nepal ranks 147th of 189 countries and has a low human development index (0.579; range 0.954-0.354). The Gross National Income (GNI) per capita is USD 2748. Approximately, 25.2% of the people live below the national poverty line and 15% earn less than USD1.90 per day. The average life expectancy is 69 years for males and 71.9 years for females, and the maternal mortality ratio is 258 per 100,000 live births. There are three hospital beds per 10,000 people; 89% of the population use at least basic drinking water and 62% of the population use at least

basic sanitation facilities. Gender inequality rank for Nepal is 115 of 189 countries and 33.5% of seats in parliament are held by women. A total of 42.2% of males and 29% of females have at least secondary level education [60].

Nepal is a post-conflict country. Political instability, long-lasting injustice and structural violence have given rise to conflicts in Nepal; the most prolonged conflict was the Maoist conflict which lasted for 10 years (1996-2006) and claimed the lives of more than 13,000 people [61]. In addition to this human-made disaster (conflict), Nepal is also affected by natural disasters such as landslides, inundation and earthquakes. The latest earthquake in 2015, was 7.6 magnitude and claimed the lives of 8,659 people, injuring more than 100,000, and demolishing more than 500,000 houses [62].

Situation of mental health in Nepal

There is very little known about the national mental health situation in Nepal due to the lack of a national-level prevalence study or large-scale research with national coverage. This situation is changing because the Nepal Health Research Council (NHRC) is undertaking a national mental health survey expected to be complete by January 2021 (<http://nhrc.gov.np/projects/nepal-mental-health-survey-2017-2018/>). It is anticipated that this study will provide a baseline for the mental health disease burden and subsequently inform policy for greater mental health investment in Nepal.

Currently, mental health is a neglected area in Nepal, since less than 1% of health budget is directed to mental health [63]. A mental health policy developed in 1996, is not yet fully implemented [64] and mental health legislation drafted in 2006, is not yet endorsed by the government.

Though not fully implemented, mental health policy documents have good provisions for promoting the prevention and treatment of mental health problems. For example, the mental health policy of 1996, aimed to integrate mental health care into the existing health care system to provide mental health services to people in an effective and efficient manner. This policy included key aspects such as ensuring mental health services for all, preparing human resources, protecting the fundamental human rights and improving community awareness. The policy proposes establishing a separate mental health division in the Ministry of Health and Population, however, to date this has not occurred. Mental health is also included under disability in Nepal and ensures disability benefits for people with severe mental illnesses. Unfortunately, not many people with mental illness have requested these benefits due to their lack of information and fear of being stigmatized. Mental health is included under essential care services in the government's second long-term health plan (1997-2017 and National Health Sector Support Program (NHSSP) II: 2010-2015 and NHSSP III: 2016-2020).

Mental health services (mainly pharmacological treatment) are available in Kathmandu valley and major cities in mental hospital

and the psychiatric wards of regional hospitals. Some private medical colleges also have psychiatric wards with mental health services, but such services are mainly in large cities [65]. The country has only 440 in-patient beds for people with mental illnesses in both governmental and private hospital facilities, which means 1.5 beds per 100,000 population. Mental health services are supposed to be included among the basic health services expected to be delivered in PHC; however, there is limited data indicating that this occurs. That said, the Management Division, part of the Department of Health Services (DoHS), mental hospital and some non-governmental organizations (NGOs) have taken the initiative to train PHC workers in a few districts [66].

Due to the lack of central coordination mechanisms, there is no clear data on the budget allocated to mental health and how this money is being spent, since expenditures occur in several ministries including the Ministry of Health and Population and the Ministry of Education, Ministry of Women, Children and Social Welfare. Available data, however, indicates that the budget allocated to mental health remains quite small, i.e. according to the most recent data available, less than 1% of the total health budget is spent in mental health [63].

Information on a few indicators (such as morbidity and mortality) is being collected from mental hospital and psychiatric units of regional hospitals, but the data from district hospitals and PHC facilities do not appear in government's HMIS because no mental

health service is available in most district hospitals and PHC facilities [53].

The national list of essential medicines (2011) includes 15 psychotropic drugs and the free drug list approved by Ministry of Health in 2014, includes five psychotropic drugs. However, the availability of these drugs is limited to the capital and large cities [33]. In the absence of government investment, NGOs have been instrumental in initiating community-based mental health care and psychosocial counselling and support services [67]. Most NGOs provide mental health and psychosocial support services to refugees and people affected by conflicts and natural disasters. However, a few have been implementing a mhGAP-based mental health intervention through PHC centres.

Major events for mental health in Nepal relevant to this dissertation

Before 1990, only hospital-based psychiatric care was available, and only in a few hospitals in Kathmandu. In the 1990s, due to the Bhutanese refugee crisis, the mental health issue was taken up as human rights issue and some funding for torture survivors was made available and limited psychosocial support for tortured Bhutanese refugees was implemented. The 1996 Maoist conflict, which first affected many rural areas of Nepal, created the need for community-based psychosocial support. Hence, school- and community-based psychosocial support and counselling services were initiated. The NGOs working in this sector formed the Kathmandu Psychosocial Forum for the coordination of psychosocial support activities among

NGOs and other stakeholders. Between 2006 and 2008, mental health service users and caregiver organizations arose and started advocating for their rights. In 2009, a National Mental Health Network was established and had representation from government, NGOs, service users and caregivers. The Koshi river flood of 2008-2009, provided an opportunity to pilot the Inter-Agency Standing Committee guidelines in Nepal and develop a Nepali version of the guidelines. In 2010, formal NGO collaboration with international academic institutions for mental health research in Nepal started and since then, NGOs have been actively participating in multi-country mental health research projects. From 2010-2011, the integration of mental health into PHC was suggested and implemented in a few districts with a formal memorandum of understanding with the Ministry of Health. Then in 2013, the mental health system strengthening efforts started. The cumulative effect of all these initiatives by several stakeholders influenced the inclusion of mental health in a multi-stakeholder action plan for non-communicable diseases in 2014. From 2014-2018, due to joint advocacy, six psychotropic drugs were included in the free drug list, the essential drug list was revised to include new-generation psychotropic drugs with less side effects compared to old-generation psychotropic drugs and mental health training manuals and treatment protocols were developed with stakeholder consultation for the delivery of mental health services by PHC workers. In 2016, a set of mental health indicators were developed through a Delphi study, revised through stakeholders' consultation and piloted in PHC facilities of the

Chitwan district in collaboration with the HMIS section of the DoHS. Around the same time (2015-2016), a training manual on the involvement of service users and caregivers in mental health system strengthening was developed and piloted through workshops among service users and caregivers in Kathmandu and Chitwan districts.

The earthquake of 2015, also provided an opportunity for policy makers to realize the importance of psychosocial support. Based on the WHO “building back better” approach the mental health stakeholders grasped this opportunity to orient policy makers and donor representatives about the importance of psychosocial and mental health support in a post-disaster setting. The Nepalese government was supportive and provided funding for post-earthquake psychosocial programmes.

The Emerald and PRIME programmes

This dissertation is based on two large multi-country research projects implemented in Nepal and other LMICs. The Emerging Mental Health Systems in Low- and Middle-Income Countries (Emerald) programme aimed to strengthen health system capacity to provide better mental health care. The Emerald project had several thematic work packages: 1) coordination and collaboration, 2) mental health capacity building of PHC workers, service users/caregivers, policy makers, planners and mental health researchers, 3) identifying health system resources and financial mechanisms to support universal coverage for persons with mental health disorders, 4) identifying policy- and system-level barriers for

mental health integration in PHC, 5) development and implementation of information system for mental health within the government HMIS and 6) dissemination and publication of study results to relevant stakeholders at the community, district, national and international level.

The same international consortium was involved in another mental health project called Program for Improving Mental Health Care (PRIME) to implement an mhGAP-based mental health care package (MHCP). The MHCP included pharmacological treatment, psychosocial counselling support, protocolized psychosocial interventions, and home-based care and community awareness. Three types of PHC workers (prescribers, non-prescribers and female community health volunteers) were trained to implement the MHCP. Prescribers were trained to provide pharmacological treatment, and non-prescribers were trained to provide basic counselling and protocolized interventions. Female community health volunteers were trained to conduct community awareness, identification, referral and home-based follow-up care.

Structure of the dissertation

The dissertation chapters are structured based on the conceptual framework of the WHO Health System Strengthening Building Blocks. First, the dissertation provides the global and national state-of-the-art in mental health system strengthening and roles of non-governmental organizations in mental health and psychosocial support (Chapters 1 and 2). Then, it presents research papers

representing several building blocks of health system strengthening (Chapters 3-7). Chapter 8 explains the level of service user and caregiver involvement in mental health system strengthening in Nepal. Finally, Chapter 9 provides reflections and presents key actions for strengthening mental health systems in LMICs.

Chapter 2 provides the situation of mental health and psychosocial support in Nepal using a four Ws (who is doing what, where, and when) methodology and describes the role of NGOs in mental health system strengthening and service delivery, especially during conflict. Chapter 3 includes the findings of a qualitative study among policy makers and planners in Nepal. It presents the mental health system governance matrix based on Siddiqui's Health System Governance Framework and explores policy-level challenges and facilitating factors for mental health system strengthening in Nepal. Chapter 4 provides a situation analysis of mental health data collection, compilation, analysis and use for policy and practice in six LMICs including Nepal. Chapter 5 provides the result of a qualitative study among Nepalese stakeholders involved in the supply chain management of psychotropic drugs, including people involved in the production, manufacturing, procurement, import, transport, storage, prescription, administration and uses. Chapter 6 presents the findings of a controlled pre-post study of a mental health intervention among PHC workers in Nepal. It explains how regular mental health support training and supervision of PHC workers contributed in strengthening the integration of chronic care elements into PHC. Chapter 7 explores the real-life challenges faced by PHC

workers in providing mental health services through PHC facilities determined by a qualitative study among three cadres of PHC workers (prescribers, non-prescribers and female community health volunteers). In particular, system-level facilitating factors and barriers for scaling up mhGAP-based district mental health care packages are addressed. Chapter 8 considers a qualitative study among mental health service users and their caregivers and provides the perspectives of the participants on their level of involvement in mental health system strengthening in Nepal. Chapter 9 reflects on how mental health systems can be strengthened in low-resource settings like Nepal and provides key actions for policy and practice relevance.

Personal trajectory

When I was working with the Transcultural Psychosocial Organization Nepal (TPO Nepal), as the head of the organization, I had opportunity to interact with Nepal government officials, donor community and civil society representatives. While advocating for integration of mental health in public health system, I faced many system-level challenges while interacting with these groups since I did not have sufficient mental health system-related information and documents. This increased my interest in system-level research, which intensified when I was working in Afghanistan as a Public Health Advisor supporting the implementation of hospital services as well as PHC services. Though these services were being provided in Afghanistan, I believed there was a disjuncture in several health

system components, and they were working individually rather than in system-thinking approach.

At that time, I was offered the opportunity to work in Nepal for a multi-country mental health system-related project called Emerald (described above). The Emerald project introduced me to many experts in the field of mental health, and my regular interaction with the experts shaped my understanding of mental health systems research. The Emerald project also gave me the means to pilot mental health system-related interventions and research. The PRIME project was being implemented at the same time in Nepal, and afforded me the field realities of system-level challenges and opportunities for mental health integration in PHC. These two projects complemented each other and provided me the opportunity to link policy, practice and research agendas for mental health in Nepal.

Though the dissertation is based on the Emerald project in Nepal, the findings from Nepal are relevant to other LMICs, since it was applicable for five other Emerald project countries (Ethiopia, India, Nigeria, South Africa and Uganda). In addition to the Emerald project and other mental health initiatives in Nepal, this dissertation is also influenced by the knowledge and experiences acquired by the PhD candidate in Afghanistan and South Sudan.

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CHAPTER 2

The role of mental health and psychosocial support non-governmental organizations: Reflection from post-conflict Nepal

*This chapter is based on: **Upadhaya, N.**, Luitel, N. P., Koirala, S., Adhikari, R. P., Gurung, D., Shrestha, P., Tol, W.A., Kohrt, B.A., Jordans, M. D. (2014). The role of mental health and psychosocial support nongovernmental organisations: reflections from post conflict Nepal. *Intervention*, 12(Supplement 1), 113-128.*

Abstract

Background: Armed conflicts and other humanitarian crises impact mental health and psycho-social well-being. In contexts of overwhelming need and overstretched government health systems, non-governmental organisations (NGOs) may play an important role in this regard. In this paper, we reflect on the role of Nepali NGOs in providing mental health and psycho-social support services. In Nepal, NGOs have provided a range of trainings, implemented interventions, organised awareness-raising campaigns, and conducted research on mental health and psycho-social issues in the context of political violence and natural disasters.

Methods: We compiled data from a 4Ws (who is where, when doing what) mapping tool developed in MS Excel format which documents mental health training, services, and research activities of several stakeholders in the aftermath of emergencies. The tool was completed by interviewing NGO staffs. We also collected information available in the websites of Nepali mental health and psycho-social support (MHPSS) NGOs.

Results: Some NGOs were able to capitalise on the emerging interest of humanitarian donors in mental health to strengthen the platform for sustainable mental health reforms. NGOs taking on such tasks have demonstrated strengths as well as presented challenges. Strengths included easy access to local communities, better understanding of local contexts, quick and flexible response

mechanism, and access to marginalised populations and underserved areas. Challenges have included a lack of programme sustainability, weak collaboration, and high staff turnover. Similarly, due to a lack of accreditation of training courses and rigorous monitoring of services, it has been difficult to independently verify the quality of services provided by NGOs.

Conclusions: Based on our observations, we highlight the importance of integration of mental health in broader humanitarian, health, and social systems; strong partnerships with governments; strong alliances between NGOs for more effective advocacy with policy-makers; a focus on monitoring, evaluation and research; standardisation of training curriculums and clinical services; and a focus on anti-stigma interventions.

Key words: Mental health NGOs, role, Nepal

Introduction

Non-governmental organisations (NGOs) globally support government initiatives and social development by assuming the role of advocates, service providers, activists, and researchers on a variety of issues affecting the lives of people [1]. In addition, NGOs play an important role in delivering and developing models for more innovative services than those delivered by governments[2]. Alongside the more familiar roles of service delivery and campaigning, NGOs are active in a complex range of broader development activities that include promotion of

democracy, peace-building, conflict resolution, human rights protection, and policy analysis [3].

NGOs play a crucial role in all settings, but during conflict and disasters, they commonly take on a greater role as such humanitarian crises overwhelm often-already overstretched government health systems [4, 5]. The increased mortality and morbidity associated with mental health and psycho-social problems during and after natural or human-made disaster receives greater media attention and public interest, which may convince policy-makers to more seriously consider the suffering associated with mental health and psycho-social problems[5]. As described by the World Health Organisation, these crises thereby provide opportunities in terms of increased funding and political will to support mental health and psycho-social well-being beyond the humanitarian crisis[6]. Opportunities include creating new leadership, new ways of thinking, and redefining existing service delivery models [7]. For example, Sri Lanka and Indonesia after the 2004 tsunami made rapid progress in the development of basic mental health services, extending beyond tsunami-affected zones to most parts of the country. Similarly, Burundi, Kosovo, Iraq, and Afghanistan have used the opportunity of greater support for mental health during conflict[6].

Given that NGOs may contribute to creating healthcare systems with increased efficiency, more equity, and good governance [4], it is worthwhile reflecting on the role of NGOs in specific

humanitarian settings, discussing the pros and cons of their involvement, and setting future strategies. This paper, based on the authors' work-experiences and grey literature, documents the contributions made by mental health and psycho-social support NGOs in the conflict/post-conflict context, analyses their strengths and limitations, and discusses their future role for strengthening mental health system in Nepal.

Background

Nepal, a home for 26.5 million people [8], is a small, mountainous, multi-ethnic country located in South Asia. It has poor development indicators including the Human Development Index [157 out of 186] [9], low literacy rate [65.9 percent] [8] and relatively low GDP per capita at purchasing power parity [US\$ 1102] [9] among others. Nepal suffered a violent conflict that claimed the lives of more than 13,000, while many more were subjected to torture, intimidation, extortion, and abduction [10]. The fragile health system of Nepal became even weaker during the period of Maoist insurgency as health staffs were often intimidated and tortured by both the government soldiers and the insurgents, and delivery of essential commodities disrupted [11].

Although formal registration of NGOs in Nepal began in 1977, the emergence of mental health NGOs started only after the 1990 people's movement, with the numbers increasing during the 10 years of Maoist conflict (1996-2006). Currently, an estimated 20 out of over 37,000 nationally registered NGOs work specifically

in the field of mental health and psycho-social support. Previously, Nepali NGOs commonly supported government initiatives in delivering quality health services. However, during and after the Maoist conflict, they played increasingly important roles in providing health services to conflict-affected areas and marginalised populations. In our observation, increased funding during the conflict period helped NGOs to develop and strengthen their work in the mental health field in Nepal. Learning from the programmes implemented during conflict period, NGOs have become successful advocates for, and partners in, policy revision and integration of mental health into primary healthcare (PHC).

Key Strengths

We compiled data from a 4Ws (who is where, when doing what) mapping tool developed in MS Excel format [12], which documents mental health training, services, and research activities of several stakeholders in the aftermath of emergencies. The tool was completed by interviewing NGO staffs. We also collected information available in the websites of Nepali mental health and psycho-social support (MHPSS) NGOs. Data are summarised in Table 1, which highlights the contribution of NGOs in developing human resources, raising awareness, conducting rigorous research, and delivering services in the field of MHPSS care. These key strengths of NGOs are described below. *Table 1: NGOs activities in mental health and psychosocial support in Nepal*

Training	Service delivery	Awareness raising and Advocacy	Research
<ul style="list-style-type: none"> - Two weeks basic psychosocial care training for community psychosocial workers - Six months para-professional counseling training - Training on psychological first aid (PFA) - mhGAP training to PHC workers - Non-violent communication training - Training on Inter-Agency Standing Committee (IASC) guidelines for mental health and psychosocial support in emergencies - Care for care givers' training 	<ul style="list-style-type: none"> - Psycho-education - Psychological first aid - Counseling (individual, group and family) - Psychotherapies (cognitive behavior therapy, child parent relationship therapy, creative movement therapy, art therapy, Gestalt therapy, play therapy, sand play therapy, Eye Movement Desensitization Reprocessing (EMDR), Emotional Freedom Technique (EFT) and hypnotherapy) 	<ul style="list-style-type: none"> - Radio program - Street drama - Information dissemination through pamphlets, cultural programs, dance and sports - Community orientation programs - Press meetings - Newspaper 	<ul style="list-style-type: none"> - Need assessments - Process evaluation - Effectiveness evaluation of interventions - Cross-sectional studies and longitudinal studies - Qualitative studies - Cohort studies - Delphi studies - Validation studies of western psychological instruments - Development of ethical guidelines

<ul style="list-style-type: none"> - Training on stigma reduction - Peace building training - Vocational training - Life skills training - Effective parenting training - Classroom based intervention training - Healthy Activity Program Training for depression based on behavioral activation - Counseling for alcohol problems training based on motivational interviewing - Family intervention training for psychosis, bipolar disorder and epilepsy 	<ul style="list-style-type: none"> - Psychiatric consultation and medication - Legal support/legal counseling - Case management, documentation, referral, networking and follow-up - Emotional support, problem management, relaxation and meditation - Rehabilitation services - Residential and day care services - Sports and recreational activities - Livelihood assistance 	<ul style="list-style-type: none"> - Workshop and seminars - Street rallies and silent march pass 	<ul style="list-style-type: none"> - articles
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Capacity building

Training para-professional counsellors: Very few mental health human resources are trained by government institutions. Those who are commonly prefer a more bio-medical orientation and are frequently based in the major city centres [13]. Thus mobilisation and retention of mental health workers in rural areas has been a challenge [14]. Recognising this gap, Nepalese NGOs started developing para-professionals by training community members in psychosocial and mental health issues [15-18]. These trainings range from a few days ‘orientation’ to six-month psychosocial counselling training programmes. They, in addition to classroom-based teaching, focus heavily on field practicum, introducing trainees to the challenges of real-life settings, reflecting upon how psychosocial support and counselling services can address the needs of the population [15]. Based on the training materials available, para-professionals have been trained to play roles in promotion, prevention, detection, referral, and follow-up in psycho-social and mental healthcare.

Other training programs: At the community level, a 2 to 4-week training is provided to develop community psycho-social workers (CPSW) whose main function is raising awareness about mental health and identifying and referring people with mental health problems to nearby mental health service providers [19]. Additionally, female community health volunteers (FCHVs) have been trained in a community informant detection tool, which

assists in identifying people with mental health problems and promotes referral to health service providers at PHC. In addition, a 1- to 2-week training is conducted for PHC workers to help them deal with psycho-social and mental health aspects of PHC attendees[13, 20]. More recently, training through district-level government mechanisms on the mental health gap action programme (mhGAP), which promotes integration of mental health in primary healthcare[21], has been introduced. Counsellors are developed to provide individual, group, and family counselling [15] and support community psycho-social workers, female community health volunteers, and primary healthcare workers [22] at the community level.

Several tailor-made training packages have also been developed and delivered by different organisations. Some NGOs have integrated psycho-social concepts in training packages for teachers, health workers, children affected by conflict[19] and HIV/AIDS[16, 23], frontline workers during emergencies[24] for members of the Nepal Police force, staff working in the nutrition sector, protection workers at Bhutanese refugee camps [25], staff working in gender-based violence and trafficking[26], and outreach workers in the entertainment sector. Training on psycho-social aspects of conflict mediation, peace-building, legal protection, and human rights are also being provided.

Post-training follow-up and clinical supervision: One of the strengths of NGO trainings is that they have had mechanisms for

on-site clinical supervision, group case conferences, and follow-up during refresher trainings. These mechanisms encourage trainees to practice skills learnt and provide opportunities to express difficulties and get suggestions for improvement.

Service delivery

Our observations suggest NGOs have commonly taken on mental health and psycho-social care that does not focus on strict diagnostic categories but rather on more broadly defined distress.

Community-based service delivery model: In line with the global focus towards community mental health services, Nepali NGOs appear to have adopted a community-based model of mental health care. Psychiatric consultation during mobile health camps, integration of mental health into primary healthcare [22], and rehabilitation and family support through home visits[27] are some examples of community-based service delivery models. Other examples include school-based mental health services[28]and conflict resolution and community mediation programmes. In our observation, residential rehabilitation centers contribute to this model by working as a bridge between the medical and social model by conducting recreational activities, providing day-care services with strong family engagement alongside medication.

Culturally relevant intervention designs: NGOs are making efforts to design culturally relevant interventions. Examples of culturally relevant interventions implemented by research based mental

health NGOs include classroom-based psycho-social intervention (Jordans et al., 2010), child-led indicator programme [29], alternative to violence, effective parenting, community mental health promotion programmes [30], women empowerment group intervention [25], and tree of life intervention [31]. Formation of self-help groups for peer support between people experiencing mental health problems is another commonly used intervention, with group members connected to community resources and provided livelihood support through vocational training and grants for setting up small businesses [27]. Although there remain strong debates in the literature on the relevance and sustainability of activities by ‘external’ actors in humanitarian crises, many NGOs have taken a participatory approach, combining service delivery with efforts to better understand local priorities and resources [32], and adapting ‘western’ interventions to make them culturally sensitive to local contexts [15, 33].

Multi-disciplinary team of service providers: Mental health service provision is a multi-sectoral affair [20]. NGOs have tried to combine the medical and social models of mental healthcare [27] and often promote a multi-disciplinary team approach of service delivery [1, 34]. In our observation, NGOs working in mental health are gradually involving service providers from different backgrounds (medical, social, and legal) and are more aware of the need for client’s privacy and confidentiality. The direct interaction between PHC workers and psychiatrists [20,

22],the inclusion of psycho-social counsellors in mobile mental health camps, and the involvement of nurses, counsellors and social workers in community rehabilitation programmes are some examples of a multi-disciplinary team approach.

Awareness and Advocacy

Another key strength of NGOs is that they are good at mental health promotion (e.g., through popular interventions aimed at strengthening psycho-social well-being such as child-friendly spaces, recreational activities), mental health advocacy, and awareness-raising programmes[13, 15]. Because of their knowledge of local context and quick access to and acceptance by the local community, NGOs have been able to sensitise the population either through direct community-orientation sessions or through street plays, radio programmes, cultural programmes, newsletters, and short films [1].In our experience, continued NGO lobbying and advocacy has made stakeholders more sensitive and responsive, resulting in increased coverage of mental health in government policies and programmes, and in the national media.

Strong focus on stigma reduction: In Nepali society, mental illness is highly stigmatised as it is a “mark of shame, disgrace and disapproval”[35]. An important aspect of NGOs’ awareness-raising programmes is the focus on stigma reduction in society [15, 16] and education of people with mental health problems and their family members[22]. In our opinion these efforts have produced

some positive results, including greater acceptance of service-user involvement in programme planning and policy development.

Policy advocacy: NGOs can play a vital role in mental health advocacy [36]. Since 2009, NGOs have joined hands for policy advocacy by establishing a loose network named National Mental Health Network. Advocacy efforts of NGOs have yielded positive outcomes such as endorsement of national minimum standards for shelter homes[37], promulgation of psycho-social guidelines for HIV/AIDS affected-children [23], and integration of psycho-social issues in other sectors such as education, sexual and gender-based violence, trafficking[37], child protection, reproductive health, nutrition, disaster preparedness and response[38], conflict and peace-building. Other examples of positive results of NGO advocacy are provision of social benefits under a disability allowance provided by the Ministry of Women, Children and Social Welfare and establishment of a One-Step Crisis Center under the Ministry of Health and Population [39]. In the authors' observation, NGOs are increasingly involved in national-level policy discussion forums. For example, they have contributed to the multi-stakeholder action plan for mental health (2013-2020) and a chapter on mental health to be included in the proposed integrated Nepal Health Act.

Research

Due to the lack of national-level prevalence studies and large-scale research[35, 40], little is known about the mental health burden in the general population. Though NGOs have not been able to address this gap at the national level, they have provided rich information about mental health and psycho-social situations in specific geographic locations and for sub-populations [41], including torture survivors[42], internally displaced persons[43], refugees [25], people affected by natural disasters [44], girls/women working in the entertainment sector, and children associated with armed forces and armed groups [45]. To ensure that research is conducted in an ethical manner, guidelines such as the C4P model: Four Principles for Ethical Research with Child Soldiers [32] have been developed. Similarly, Western instruments such as Beck Depression Inventory[46], PTSD Checklist [Civilian Version][43], and child mental health and psycho-social research instruments [47] have been validated in Nepal.

Research collaboration and publications: A few NGOs have focused their efforts on conducting psycho-social and mental health research, results of which have been published in academic journals. Publication of research findings on community mental healthcare [48], impact of torture on refugees[49], psycho-social care for conflict-affected children [50], and prevalence of mental disorders [41, 51] are some of the examples of NGO's contributions to research and publication. NGOs have also collaborated with

foreign academic institutions such as McGill University, Canada; King's College London; University of Cape Town, South Africa; and Makerere University, Uganda, to conduct psycho-social and mental health research in Nepal. In our opinion, these collaborations have contributed to develop local research capacity and dissemination of research findings to larger international audiences. This includes research publication and dissemination via collaborative article writing, where the practice of incorporating the strengths of experts from high-income countries with both senior and junior Nepali researchers has been developed [52].

Translation of research knowledge: Findings from mental health research conducted by NGOs have been used by government and UN agencies to design rehabilitation packages for former child soldiers and other programmes for specific sub-populations. Research results have also been used to develop new interventions or modify the existing ones. The revision of classroom-based intervention (CBI) by TPO Nepal, after the results of randomised control trial, is one such example [28]. Information collected by NGOs has also been used by others in various forms. For example, the process of documentation of disaster during Koshi river flood was used for the adaptation and contextualisation of Inter Agency Standing Committee (IASC) guidelines on mental health and psychosocial support in emergency settings in Nepal [38]. Research findings have provided strong advocacy tools to lobby the government for policy changes such as the inclusion of mental

health in Nepal Health Sector Support Program (NHSP-II) and non-communicable disease multi-stakeholder action plan (2014-2020).

Key Challenges

Despite the identified strengths, NGOs have equally displayed several challenges in terms of coordination, sustainability, accreditation and licensing described below.

Coordination and collaboration

Between mental health and psycho-social support NGOs: In our opinion, coordination and collaboration among mental health NGOs in Nepal has been a challenge. Since 2000, several networking efforts among mental health and psycho-social organisations have been made. Groups were formed, often with strong participation in the beginning, but after cooperating successfully for some time, these groups often collapse, possibly due to the lack of a shared vision. Secondly, there are differences of opinions between stakeholder groups regarding mental health treatment and mechanisms for service provision. Due to this, several policy-level consultation workshops have not been able to produce consensus policy documents. Third, due to a lack of clarity and shared vision for mental health and programmatic directions, duplication of NGOs activities has been observed – as has been in other countries [53]. Overall, there appears to be a reticence

towards sharing and learning from each other's best practices and challenges.

Among the government and mental health and psycho-social support NGOs: In our observation a similar lack of collaboration has plagued relations between the government and NGOs. NGOs are free to run their projects in isolation if they so wish, with little government oversight and internal coordination. While NGOs that are working closely with government institutions face red-tape and unnecessary delays. Second, during the armed conflict the government was party to the conflict, so NGOs distanced themselves from the government institutions to retain a neutral position. Though this approach facilitated service delivery during peak time of conflict, it appears to have prevented strong alliances with government and opportunities for public private partnerships.

Between government institutions: In our observation, coordination among government institutions for mental health has also been scant. Currently, the mental hospital, Primary HealthCare Revitalisation Department, Management Division, and National Health Training Centre are involved in mental health, but due to lack of clear policies guiding their relationships, activities of these government institutions do not appear to be well-coordinated. There similarly does not seem to be any clarity about which institution is the official focal point for mental health, with the Ministry of Health and Population to date unable to clearly instruct NGOs to coordinate with a particular division within the ministry.

Low priority of mental health in Nepal

Neither the government nor civil society organisations have prioritised mental health as one of their core areas of focus.

Lack of government attention to mental health: The mental health policy formulated in 1996 is not yet implemented[35]and three rounds of efforts to endorse mental health legislation went in vain[20]. The policy proposes establishing a separate mental health division in the Ministry of Health and Population, but there is still no one to oversee mental health within the ministry. There is one central mental hospital and a few regional hospitals with limited psychiatric services. Thus, in our opinion, mental healthcare is largely institutionalised with limited community mental health activities in the government health system. The lack of law, regulation, government systems and procedures for mental health and non-implementation of mental health policy clearly demonstrate the government's lack of attention to mental health.

This lack of government priority in mental health[20] is a challenge for NGOs because low priority means inadequate funding, weak government mechanisms, and a lack of systems, procedures, and infrastructure. In the absence of these factors, the grassroots successes of NGOs may not be sustainable and opportunities to translate experiences gained by NGOs into lasting policy changes are missed. Secondly, continuation of pharmacological treatments

through institutional-based psychiatric care is a challenge for NGOs that often advocate a socio-medical model of mental health service provision. Thirdly, lack of government initiatives towards the integration of mental health into primary healthcare despite commitments in the 1996 policy is another obstacle for mental health.

Due to lack of government priority in mental health [35], many bilateral and multilateral donors supporting health sector development in Nepal are not providing sufficient funding to mental health NGOs. The government allocates only less than 1 percent of total health budget [35] to mental health and among that a large portion is allocated for the operation of psychiatric facilities. There is almost no budget for community mental health activities in which NGOs have mastery.

Lack of civil society organisations' attention to mental health: Although psycho-social and mental health is a cross-cutting issue and should be addressed by NGOs active in other sectors such as education, protection, livelihood and shelter and site planning, many NGOs have not prioritised integration of mental health and psycho-social issues into their existing programmes.

Sustainability

In our observation, almost all the mental health NGOs in Nepal depend upon external funding, normally of short duration. Due to

these short-term projects, NGOs cannot commit to long-term treatment services. Likewise, NGOs don't have an influence over the structures and mechanisms to continue services. Apart from these external limitations NGOs also have a weakness that they are in competition with each other for scarce resources and move quickly from one location or theme to another for funding without properly addressing the ethical issues of phasing out. The discontinuation of services after phase out of the project makes people even more vulnerable and frustrated towards NGO work. Whilst there are exceptions, most NGOs are running activities in isolation without formal collaboration with government entities, as a result, the services end when the project is phased out. Consequently, there are issues both of the sustainability of the NGOs themselves and the sustainability of services initiated by them.

Discussion

This paper touched upon the strengths and limitations of the role of NGOs in mental health and psycho-social support in Nepal. Below, we discuss these key issues in relation to a) the important role NGOs play in strengthening mental health systems; b) the need for partnerships with the government; c) the standardisation of training programmes and services; and d) the need for a central coordinating body for mental health within the Nepal government.

NGOs can play an important role in strengthening the mental health system. The efforts of mental health NGOs in Nepal appear to have mainly focused on three of WHO health systems building blocks: namely, human workforce development, information, and service delivery[54]. Service delivery by NGOs, especially following conflict and natural disasters [2], is a contribution to health system strengthening as NGOs' work helps in achieving increased health coverage. NGOs' potential contribution to mental health system strengthening has been well-demonstrated in other settings. For example, in Afghanistan due to NGOs' contributions, the capacity of service providers improved, service utilisation increased, and donors finally agreed to fund mental healthcare [55]. Pakistan has benefitted substantially through "health education, health promotion, social marketing and advocacy by the not-for-profit private sector"[4]. Similarly, mental health sectors in Uganda and Burundi were largely supported by NGO initiatives [56, 57]. Likewise, Basic Needs, (an NGO)has introduced a mental health and development model in Nepal, which focuses on concepts like user empowerment, community development, and health system strengthening, offering a feasible method of integrating mental health into existing community-based interventions [27].

Second, although NGOs have several strengths such as easy access to the local community, and arguably better understanding of the local context, quick and flexible response mechanisms [58] and access to the marginalised and underserved areas, they also have a

number of challenges including the limited sustainability of donor-driven programmes, weak collaboration and high staff turnover. NGOs' direct action in humanitarian settings may result into laudable gains in the short terms but without sustained networking and advocacy strategies, NGOs are unlikely to have any significant long-term national impact [59].

Experiences of conflict- and disaster-affected countries show that mental health reform efforts may commence in the midst of emergency and if capitalised upon can have positive impact on the long-term development of mental health systems[6]. However, NGOs alone cannot achieve system-strengthening goals, highlighting the need for strong partnerships with government. The government, except when party to the conflict, bears primary responsibility for providing key mental health services to its population as access to health services is a basic human right. NGOs can support the government through a clearly defined public-private partnership approach demonstrated to be effective in many low- and middle-income countries. For example, over eight years in Burundi, NGO activities shifted from the delivery of services to strengthening the capacity of government staff and embedding mental health and psycho-social support within existing health services and social systems [57]. Similarly, Raja et al. (2012) argue that strategic engagement and involvement of government is critically important to influencing mental health practice and policy. Lessons learnt from Uganda also stress the

importance of coordination and joint planning between government and NGOs [56].

Third, the quality of training courses and clinical services of NGOs cannot be independently verified due to lack of accreditation for NGO training courses and a regulatory body that monitors the quality of clinical practices. This is a serious threat to quality of services and therefore the longer-term sustainability of psychosocial human resources developed by NGOs and counselling services provided by them.

In line with the humanitarian principle of ‘First Do No Harm’, NGOs should work towards development of minimum standards for training and clinical practices, with facilitation from the government in accreditation and licensing processes. Even fully trained staff require regular refresher training and on-site clinical supervision mechanisms to ensure service quality is maintained [15, 56].

Fourth, in the absence of a central coordinating body for mental health within the government, coordination and collaboration have been challenging. The competing interests of several governmental and non-governmental stakeholders appear to have given rise to confusion, tension, and frustration. The sharp division can only be minimised by a legitimate government body responsible for coordination of mental health activities. NGOs can advocate and help in establishing a coordinating body, as has been demonstrated elsewhere. In Afghanistan, for example, NGOs assisted the

government in establishing mental health department within the Ministry of Public Health, which greatly facilitated policy development and service coordination [55].

Way forward

We propose concrete roles that NGOs could potentially play in post-conflict Nepal where the impact of the conflict is still prevalent in many communities. First, NGOs could contribute to government efforts to integrate mental health in primary healthcare as suggested by WHO's mhGAP. To do this, NGOs could utilise their knowledge and skills on training, research and service delivery and support the government in developing training curriculum, treatment protocols, and supervision guidelines. This would address, to some extent, the challenges related to the availability and sustainability of primary mental health services.

Second, micro-level programmes conducted by NGOs in certain geographic areas, no matter how well and effective, have not been scaled up to a national level. Therefore, in order to address the challenges related to policy formulation and revision, NGOs should use their grassroots knowledge and experiences by linking field priorities to national policies and programmes. The government too needs to be proactive in collaborating with NGOs and the private sector [60]. This can be best done by a jointly developed public-private partnership strategy [56, 61] which acknowledges the central stewardship role of government and importance of NGOs

for assisting the government, providing critical but positive comments and advocating the importance of quality and equitable government-delivered services based on a health systems strengthening approaches[57].

Third, there is no national quality control mechanism for mental health and psycho-social support services. Therefore, the government, together with NGOs, needs to establish a mechanism like national mental health council to assess the quality of services provided. There has to be a reciprocal accountability that NGOs hold the government accountable but the government also has a role in ensuring NGOs are accountable to the populations.

Fourth, there is also an urgent need to standardise the training curriculum, manage the accreditation of training courses, and develop the licensing mechanisms for psycho-social counselors.

Conclusion

Nepali NGOs working on mental health and psycho-social support, despite facing several challenges, have contributed to the awareness, prevention, and treatment of mental health and psycho-social problems. Human workforce development, service delivery, and awareness-raising have been the core areas of focus for most NGOs, while some have also been involved in mental health research and scientific publication. As these NGOs already work on several health system building blocks, they can play an

important role in post-conflict mental health system strengthening. Although there is little doubt about the important role that NGOs can play in post-conflict Nepal, there must now be more attention to stewardship from the government to facilitate sustainability of services, acceptance by other stakeholders, and ensuring continued funding. The credibility of NGOs and their services is negatively impacted by the lack of accreditation for training courses and lack of provisions for monitoring and licensing of counselling services. It is now time for the government to take leadership and assume a central coordinating role. NGOs can complement the work of the government through a public-private partnership approach.

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CHAPTER 3

Current situations and future directions for mental health system governance in Nepal: Findings from a qualitative study

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Abstract

Background: Assessing and understanding health systems governance is crucial to ensure accountability and transparency, and to improve the performance of mental health systems. There is a lack of systematic procedures to assess governance in mental health systems at a country level. The aim of this study was to appraise mental health systems governance in Nepal, with the view to making recommendations for improvements.

Methods: In-depth individual interviews were conducted with national-level policymakers (n=17) and district-level planners (n=11). The interview checklist was developed using an existing health systems governance framework developed by Siddiqi and colleagues as a guide. Data analysis was done with NVivo 10, using the procedure of framework analysis.

Results: The mental health systems governance assessment reveals a few enabling factors and many barriers. Factors enabling good governance include availability of mental health policy, inclusion of mental health in other general health policies and plans, increasing presence of Non-Governmental Organizations (NGOs) and service user organizations in policy forums, and implementation of a few mental health projects through government-NGO collaborations. Legal and policy barriers include the failure to officially revise or fully implement the mental health policy of 1996, the existence of legislation and several laws that have discriminatory provisions for people with mental illness, and

lack of a mental health act and associated regulations to protect against this. Other barriers include lack of a mental health unit within the Ministry of Health, absence of district-level mental health planning, inadequate mental health record-keeping systems, inequitable allocation of funding for mental health, very few health workers trained in mental health, and the lack of availability of psychotropic drugs at the primary health care level.

Conclusions: In the last few years, some positive developments have emerged in terms of policy recognition for mental health, as well as the increased presence of NGOs, increased presence of service users or care givers in mental health governance, albeit restricted to only some of its domains. However, the improvements at the policy level have not been translated into implementation due to lack of strong leadership and governance mechanisms.

Key words: Governance; mental health services; mental health system; global mental health; Nepal; low- and middle-income countries.

Background

Governance is a key determinant for economic and social advancement and overall health systems development [1]. As different parts of health systems interact with each other, it is evident that assessing and understanding governance are crucial to improve the performance of health systems [2]. WHO's 2000 World Health Report describes governance as 'stewardship', which

was defined as “*setting and enforcing the rules of the game and providing strategic direction for all the different actors involved*” [3]. In 2007, ‘governance and leadership’ was included as one of six building blocks of a health system (others included the health workforce, health financing, service delivery, information management and medical products and technology), and was defined as “*ensuring strategic policy frameworks exist and are combined with effective oversight, coalition building, the provision of appropriate regulations and incentives, attention to system design and accountability*” [4].

In the last decade, health governance has received significant academic attention and has been recognized as a critical element of the health systems strengthening agenda [5]. However, globally, governance for mental health systems still remains conceptually underdeveloped despite initiatives taken to improve clinical governance of mental health through an integrated organization-wide (institutional) approach for continuous quality improvement [6]. This issue of mental health systems governance warrants further attention, given that mental health problems account for about 12% of global burden of disease [7].

The little progress that has been made in clinical governance of mental health is associated with the limited capacity to the monitoring and standardization of drug prescription practices [8], leaving out many other aspects of mental health systems

governance which play vital roles for strengthening mental health systems. Effective and efficient mental health systems governance is one of the strategies to deal with the high burden of mental illness in low- and middle-income countries. In Nepal, although there is no nationally representative data on disease burden, it can be assumed that, due to lack of resources, expertise and overall governance, both the prevalence and burden of disease for mental health is higher than the global figure. The small-scale studies available have indicated that around 20-25% of all patients visiting primary health care facilities have shown psychiatric morbidity [9], while suicide accounted for 16% of deaths among women of reproductive age [10].

It is increasingly recognized that, in order to achieve the intended results in the overall development of health systems, not only the resources but also the governance and accountability mechanisms need to be in place [11]. The roles of the Ministry of Health, service providers and service users need to be taken into account [12]; for that, governance processes and accountability mechanisms that are responsible for the overall development of the health systems need to be implemented and assessed periodically to identify and address system-level barriers. To do this, better understanding of mental health needs, service availability and utilization, governance procedures and mechanisms, and the interaction between these variables is essential. There are a few

studies in Nepal that have touched upon some themes of mental health systems such as policy and legislative frameworks [14, 15], but their focus was mainly on mental health service delivery rather than on mental health governance. Since 2013 mental health systems related studies are conducted as part of the Emerging Mental Health Systems in Low- and Middle-Income Countries (EMERALD) research program which aims to support mental health systems strengthening in six countries (Ethiopia, India, Nepal, Nigeria, South Africa and Uganda) [13].

In this paper, we used Siddiqi and colleagues' health system governance assessment framework to report on systems-level constraints and facilitating factors because it provides a set of questions that cover each governance principle at the national, policy formulation and implementation level. This framework has been previously applied in Pakistan, where there are similar health system barriers and opportunities compared to Nepal [1]. The ten governance principles of Siddiqi and colleagues' framework and the themes included in this study are presented in Table 1.

Table 1: Governance principles and associated themes adopted from Siddiqi et al., 2009

Governance Principles	Broader themes included in the study
Strategic vision	Facilitative factors and barriers to development and implementation of plans and policies
Participation and consensus orientation	Facilitative factors and barriers to coordination and consultation with service providers, service users and other sectors outside of health
Rule of law	Facilitative factors and barriers to the development and enforcement of laws, as well as synergy between laws
Transparency	Facilitating factors and barriers to ensuring transparency in resources allocation, decision making, appointment and transfer of staff
Responsiveness and integration of care	Facilitating factors and barriers to integration of mental health in the health facility as well as in the community. Burden of mental illness, priority given to mental health.
Equity and inclusiveness	Facilitating factors and barriers to mental health financing, access to services and anti-stigma programs
Effectiveness and efficiency	Facilitating factors and barriers to human resources capacity building, mental health infrastructure development and supply chain management of psychotropic drugs
Accountability	. Facilitating factors and barriers to ensuring effective enforcement of accountability measures. The role of press, elected bodies and judiciary in

	ensuring accountability.
Intelligence and information	Facilitating factors and barriers to mental health data recording, reporting, analysis and dissemination.
Ethics	Facilitating factors and barriers to service user satisfaction and quality assurance, as well as mechanisms for safeguards against unethical research.

The Nepalese health governance context

The unstable political history of Nepal (internal conflicts among the rulers, several political movements against the government and frequent changes of government during the Rana Regime, multiparty democracy, and Maoist insurgency) has resulted in overall poor governance but has particularly affected governance in the health sector. At the same time, there exist quite a few laws and policies aimed at strengthening governance in the health sector. For example, the 2006 Interim Constitution of Nepal, promotes a more decentralized system of governance and guarantees the rights to equality of all citizens regardless of their social, cultural or economic background and physical or mental health status [16]. Similarly, the Local Self-Governance Act of 1999 gives authority to the local bodies to operate and manage health institutions at local level [17]. Following this, the Ministry of Health handed over 1,433 health institutions to local health management committees,

expecting changes in terms of decision-making power structure and accountability mechanisms. However, no noticeable changes have been observed, and the health system could not ensure the needs and utilization of health services, nor could it involve local people in decisions which have an impact on the health situation of the local community [11].

Methods

Setting

This study was carried out at two sites in Nepal: 1) the Chitwan district, which included district-level health managers and planners, and 2) Kathmandu, the capital city, which included national-level policymakers and planners. Because context has an effect on governance, these sites were chosen to compare the national urban setting (Kathmandu) with a district rural setting (Chitwan). The Chitwan district has a population of almost 580,000 and is a regional center for business and medical services. Hospital-based mental health services are being provided by government as well as private hospitals based at district headquarters. Mental health services in the community were non-existent until 2011; since then, a pilot community mental health program has been implemented in the health facilities of Chitwan through government-NGO collaboration [18].

Kathmandu city was selected to include national-level policymakers and planners working in the Ministry of Health, Department of Health Services, government hospitals and departments providing mental health services. In Kathmandu valley, both medical and psychosocial support is available through government as well as private sectors. Some NGOs and private groups provide residential treatment services for people with mental illness.

Sampling

The sampling of respondents for the study was divided into two broad categories namely (a) district-level health care managers and planners, and (b) national-level policymakers. Purposive sampling was used to identify key informants based on their current role and position in mental health care policy development and management, and potential influence for future policy development. Based on the study team's knowledge, possible respondents were identified and approached. At the district level, health staff involved in mental health programs at the District Public Health Office (DPHO), district hospitals and primary health care facilities were approached for an interview. The selected district level participants (n=11) included health managers such as medical superintendents, health assistants, public health officers and public health inspectors. At the national level, the research team decided to select participants from various professional

backgrounds (clinical, human rights, law enforcement, health policy and planning, psychology and mental health research) relevant to mental health policy formulation. The selected national-level participants (n=17) included: psychiatrists, psychologists, public health officers , under-secretaries from ministries, primary health care in-charges, human rights workers, a police officer, and a research officer who were involved in mental health policy and planning. Table 2 provides the characteristics of the respondents.

Table 2: Characteristics of respondents

Characteristics	Respondent n (%)
Gender	
Male	23 (82.14)
Female	5 (17.85)
Total	28 (100)
Profession	
Psychiatrist	4 (14.28)
Human rights worker	4 (14.28)
Public Health Officer	8 (28.57)
Psychologist	2 (7.14)
Ministry representative	4 (14.28)
Primary health care in-charge	4 (14.28)
Researcher	1 (3.57)
Police officer	1 (3.57)
Total	28 (100)

Procedures

A semi-structured interview schedule was developed guided by Siddiqi and colleagues' health system governance framework [1] and adapted to the Nepalese context. For the contextualization process, first the English questionnaire was translated to Nepali by two academic researchers. Then each question of the draft translation was discussed among the research team to determine whether or not the translation captured the real meaning of the question. Once the Nepali textual translation was agreed

(consensus), an interview role-play on each question was done to explore the type of responses the question would generate. The validity of the translation was evaluated on two criteria: would the responses make sense in the study locations and were the responses valid for assessing the specific area of the governance framework. The major areas covered by the interview schedule were: (a) service planning and management for mental health care integration, (b) human resources, (c) equipment and infrastructure for mental health care integration, (d) capacity-building needs, (e) laws and regulations pertaining to mental health, (f) funding, (g) monitoring of mental health policies and services, and (h) quality assurance and ethics.

A team of six experienced researchers (university-level education and average three years of research experience) collected data between March and June, 2014. All of them had participated in the translation and validation of the interview checklist and received a one-week training on qualitative research methods, prior to data collection. In total, 28 interviews (of approximately 45 minutes to one hour long) were conducted by visiting the participants at their work places. The interviews were audio-taped, transcribed and then translated into English by bilingual translators. The researchers made check for accuracy of this translation. As many participants made reference to national policies and provisions related to governance but did not know the details of such provisions,

additional data was collected by reviewing relevant national-level policy documents. The findings of the document review were charted as per the governance principles and, where relevant, used to substantiate the arguments made by the participants.

Data analysis

Given the descriptive and exploratory nature of the study, we adopted a qualitative research methodology informed by a framework method of data management and analysis [19]. The five stages of framework analysis (familiarization, identifying a thematic framework, indexing, charting and mapping, and interpretation [20]) suited this study as the approach makes use of the priori themes identified by Siddiqi and colleagues' health governance framework.

A random selection of the transcripts were read separately by two researchers (DG and RP) who then generated broad themes and codes within the themes. To incorporate alternative viewpoints, the two sets of 'open codes' developed by the researchers were shared for 'peer-concept' validation with members of the EMERALD project who were involved in research design and data collection. Based on discussion of the preliminary framework, adaptations were made to develop a final analytical framework keeping the categories of Siddiqi and colleagues' framework as parent themes [1]. The transcripts were uploaded in qualitative data analysis

software, NVivo-10. The analytical framework was applied to all the uploaded transcripts and, during the coding process, it was further refined. Using the framework matrix option in NVivo, the data were charted and summarized. The framework matrices were exported from NVivo to an Excel Spreadsheet and cross-checked by the researchers who were involved in data collection. When inconsistencies were noted, they were verified with original transcripts.

The selection of text under each parent theme mentioned in the results section is based on the data derived from this procedure (Table3).

Table 3: Mental health systems governance matrix of Nepal

Governance Principles	Summary of challenges and enabling factors			Recommendations
	National level	Health policy formulation level	Policy implementation level	
Strategic vision	Interim constitution 2006 recognizes health as a fundamental right.	National mental health policy 1996 exists; no revisions to date.	Lack of implementation of 1996 mental health policy.	Integrate mental health policy provisions in five year health plan; establish an accountable mental health unit in MoH.
Participation and consensus orientation	Lack of participation of civil society, private sector and government departments in mental health decision making.	Increasing consultation with NGOs and other stakeholders in mental health policy formulation.	In some districts, the district public health office and NGOs are partnering to provide mental health services in primary health care centers.	Establish coordination and collaboration within and beyond health sectors; build consensus among stakeholders regarding involvement of service users in policy, planning and service delivery.

Rule of law	Consumer Protection Act 1998 bans the production and sale of goods which are harmful to consumers' health.	Fourth revisions of draft mental health act, but no official endorsement.	Mechanisms to monitor misuse of psychotropic drugs in place but rarely implemented.	Ratify mental health legislation in line with national and international human rights laws and legislation, and strictly enforce legal provisions in practice.
Transparency	Ranked 126 out of 175 by Transparency International on corruption perception index.	Processes and mechanism for ensuring transparency in mental health resource allocation and expenditure not well defined.	Performance assessment, promotion and transfer of district health manager and district health staff differ in policy and practice.	Develop mechanisms and procedures for monitoring and supervision of mental health programs to ensure transparency in health sector.
Responsiveness to patients' health needs	The government policy and programs (2014) state the provision for national insurance program.	Health Policy 2014 recognizes the need to increase state's investment to cover all health care expenses of disabled people, including psychosocial disability.	In the absence of clear policy guidelines to address responsiveness, the medical and non-medical expectations of populations not met.	Arrange motivational incentives and facilities for health worker retention in rural areas; strengthen mental health information use for the allocation of budget.

Equity and inclusiveness	Social security allowance is given to elderly, widow and disabled, including psychosocial disability.	Nepal Health Policy 2014 mentions that health services will be provided to poor, marginalized and vulnerable population on the principles of equity and social justice.	Knowledge about existence of disability allowances for people with mental illness is low, so very few people have received allowances.	Disseminate information about services available in the community for treatment of mental illness and benefits provided by the government.
Effectiveness and efficiency	Limited communication and coordination, between bureaucrats and technocrats (clinicians).	Frequent turnover of policymakers; no mental health unit under MoH for policy and planning.	Other support systems, such as supply of psychotropic drugs and regular supervision and monitoring, are lacking.	Regulate policy on staff turnover; provide training to health workers; ensure regular supply of essential psychotropic drugs and arrange separate counselling room within primary health care facilities.
Accountability	Public accounts committee of the parliament looks after accountability.	Mechanisms and processes for overseeing financial and administrative adherence in place.	No evidence on the effective enforcement of accountability measures.	Implement existing mechanisms and processes to make the health system accountable to the population in need of mental health

				services.
Intelligence and information	No national level study on mental health conducted.	The HMIS data not used in mental health policy, planning and service provision.	Mental health data collected from Out Patients Department registers maintained in district health facilities.	Build capacity of government staff for systematic record keeping, and monitoring and evaluation of mental health programs.
Ethics	Ethics of mental health research is monitored by Nepal Health Research Council.	To ensure bioethics, Nepal Health Research Council has an ethical review committee, and a monitoring and evaluation section.	Nepal Health Research Council monitoring team makes field visits to oversee the research activities of the organizations.	Sensitize researchers and health workers towards more ethical practice in the field of mental health research and service delivery.

Results

Strategic vision and rule of law

Some respondents had the opinion that existing policies and plans related to mental health were not implemented in practice due to lack of leadership and infrastructure. The example provided by some of these respondents included the mental health policy of 1996 and the Nepal Health Sector Program II (NHSP II), which recommended the integration of mental health into primary health care. However, in almost all districts of Nepal, mental health services are not available from primary health care centers; even district hospitals in large parts of Nepal do not have mental health services. A national-level policymaker said, *“If you see Nepal Health Sector Program II (NHSP II), we have kept Mental Health as an important pillar in the Non-Communicable Disease chapter thinking that it is important component.....but we have not been able to move forward in this process as we had to....”* (National Representative 02, Male).

This awareness of the non-implementation of NHSP II was particularly mentioned in relation to the failure to include mental health services within the Essential Health Care Services (EHCS) package, and piloting and scaling up of community-based mental health care. Likewise, a few respondents reported that NHSP II had the provision to appoint a focal point for mental health within the Ministry of Health (MoH), but no such focal point currently exists.

Similarly, most of the national-level respondents mentioned that the Non-Communicable Disease Multi-sectoral Action Plan (2014-2020) had the provision for the establishment of a mental health unit, but this also does not yet exist.

Some respondents mentioned that, in the absence of an official mental health act (despite the draft act being revised four times), many people with mental illness are suffering from the discriminatory provisions in other laws and legislation. A respondent from national level said:

“There still exists discriminatory provisions in existing laws such as Civil Code of Conduct, NGOs registration act. The discriminatory laws related to mental health should be removed. State should be playing the role of guardian and ensure the right of all the citizens including people living with mental illness” (National Policymaker 11, Male).

Most of the respondents found the government was not committed to mental health and, as a result, the situation has not much improved since 1996: *“No matter how much it [government] says that it isn’t [the situation of mental health services], evidence shows that in 20 years it is still similar. Another thing is, generally, mental health problems are not visible. In our Nepal, they say in the villages that ‘Ban dadheko sabaile dekcha, maan dadheko kosaile dekhdaina.’ [Everyone will find out if the forest is burning but no one will find out if a heart is burning]”* (National Policymaker13, Male).

Most respondents recognized this scenario for mental health as this has not been prioritized in Nepal. For example, respondents reported that there is no functioning unit or regulating mechanism of mental health in the MoH. Some respondents with a human rights background recommended revising the existing policy documents to include human rights perspectives and give priority to all forms of disability, including mental illness, so that mental health services are accessible to all, without discrimination. They stressed the importance of ‘equality’ in providing treatment and suggested policy provision for a human rights monitor to assess the situation of mental health services throughout Nepal. The policy provisions for psychosocial care for people with mental illness, and focus for gender issues and child mental health, were recommended by all the respondents.

Transparency and accountability

Compared to other governance principles, transparency and accountability were much less discussed by the respondents. They either did not have information on these themes or they did not want to share this. The district-level policymakers did not clearly respond to questions regarding transparency of budget and decision making, and there were mixed responses from the national-level policymakers. A few national-level policymakers thought that there is transparency of the mental health budget since budgeting is done through participatory sharing and discussions, budgets are audited

every year, and money is spent as directed by the law. However, other participants were of the view that the mental health budget was not transparent since it has not been allocated systematically and there is no public information on the budgetary decisions.

Some respondents who talked about transparency referred to it mainly in terms of budget allocation, budget expenditure and human resources management. A participant said, “*Since there is no clear budget allocation for mental health, it cannot be said that the programs and budget are transparent.*” (National Representative 05, Male). In terms of accountability, this was defined by the participants as responsiveness on the part of policymakers and health care managers to meet the mental health needs of the population.

Monitoring of mental health services and policies

According to some respondents, there was no monitoring conducted and there was a lack of clarity as to who is responsible for this function. Most national-level respondents thought that the (MoH) was the responsible body for monitoring mental health policies and services. Others thought that monitoring was the duty of the Department of Health Services (DoHS). Some respondents identified a lack of qualified human resources, clarity of roles and tools for monitoring as some of the barriers to effective monitoring: “*We haven’t been able to monitor all the organizations fully. This is one weakness. We aren’t able to go to the field and do the*

monitoring. We are working on improving this part.” (National Representative 15, Female).

Some of the respondents were of the opinion that if these monitoring and evaluation (M&E) structures could be oriented towards mental health, the monitoring of mental health services could be easily implemented on a regular basis. Respondents also identified factors that could enable monitoring of mental health services in the existing health care system. For example, “*Public Health Administration, Monitoring Evaluation Division under Ministry of Health monitors overall health system*” and ‘*Integrated Supervision Program*’ *does the overall monitoring and supervision of all health services in general.*” (National Representative 05, Male).

Responsiveness and integration of care

In some respondents’ views, both responsiveness to the mental health needs of the population and integration of mental health in primary health care were ignored by the government. There is only one mental hospital at the central level, and respondents found that this was insufficient to cater for the needs of the country. One of the facilitating factors for responsiveness was reported to be the existence of the Good Governance and Management Act 2008, which has mechanisms redressing grievances at the national, regional, zonal and district level. However, some respondents were of the opinion that such mechanisms had not been practiced in the case of mental health. One national-level policymaker said:

“During the monitoring, no such type of mechanism was seen which listened to the complaints or grievances regarding mental health...” (National Representative 11, Male). In the absence of proper monitoring mechanisms, some respondents found that the health facilities have not been accountable or responsive to the mental health needs of the population.

Participation, coordination and collaboration

Involvement in policy and planning

Respondents reported that, in recent years, the participation in mental health policy and planning of various stakeholders from NGOs, the private sector and the service user community has improved. MoH has been formulating draft policies related to mental health through consultation workshops and meetings. However, some of the respondents expressed that the participation of service users, their caregivers and district-level service providers in policy and planning remained limited.

There were diverging views and opinions about service users’ involvement in policymaking. Some respondents found service user and caregiver involvement to be essential. For example, *“without their involvement, policymaking would be incomplete.”* (District Representative 09, Male), *“Since they are the one[s] who are facing the problem, their input is a must”* (District Representative 01, Male), and *““Nothing about us, without us’. So I think participation will come as a first condition.”* (National

Representative 11, Male). Among those who stressed the need for service user involvement, some said that there should be criteria for selecting service users such that only those individuals who can contribute in policy and planning should be consulted.

There were also views that policymaking was not an ideal platform for service user or caregiver involvement. Some respondents thought that mental health policy development is the domain of mental health experts where service users have no role. A respondent mentioned, “*If we plan to involve them at the initial phase of policy making, then it would sound like, ‘Tauko le Puchar hallaune ki puchar le tauko hallaune’* [Whether head shakes the tail or tail shakes the head - it is always the head that shakes the tail, so that involvement of service users in policy and planning seem irrelevant]” (National Representative 09, Male).

Involvement in service delivery

Some district-level respondents found that involvement of other government institutions and NGOs in service delivery has improved, especially in programs run by NGOs in collaboration with government agencies: “*Service is delivered in consultation with sectors like VDC [village development committee], police or teacher.*” (District Representative 09, Male). However, coordination and collaboration with stakeholders in service delivery and service integration was thought to be insufficient by some of the district-level respondents. They suggested greater

coordination and collaboration among schools, VDCs, NGOs and health facilities for integration of mental health services into primary health care.

Effectiveness and efficiency

Human resources capacity

Some respondents identified limited training of health workers in mental health and frequent transfers of health staff trained in mental health as two major problems in human resources for mental health. According to the respondents, the changes in the national government have brought about high staff turnover at district level, even before completing the mandatory two years of service in a place.

Lack of awareness and knowledge about mental health issues among health workers was seen by the respondents as another barrier. The respondents acknowledged that most health workers lacked this knowledge because their pre-service training did not cover mental health and even if it did, due to lack of practice, the health workers had mostly forgotten what had they learnt. One strategy suggested by several of the respondents to overcome this problem was task-sharing by mobilizing village-level health workers known as Female Community Health Volunteers (FCHVs). A district-level respondent said: “*Clients do openly share their problem [with FCHVs]... Since they work at community*

level, they are more aware of peoples who show abnormal activity.” (District Representative 03, Male).

Budget allocation and utilization

Most of the national-level respondents said that the proportion of the health budget allocated to mental health has not been publicly stated. In addition, they said that a budget for mental health is allocated only for the mental hospital in Kathmandu and does not go to other hospitals or mental health programs. However, other national-level respondents mentioned that, as part of integrated health care programs, a budget for mental health is allocated to cover the cost of psychiatric wards in regional hospitals. Similarly, a few respondents mentioned that other ministries such as the Ministry of Peace and Reconstruction and the Ministry of Women, Children and Social Welfare are running psychosocial and mental health programs, and said that budgets allocated to these programs have not been accounted for in the total budget allocated to mental health. Still, respondents reported that, even including the budget spent by district and regional health programs and other ministries, the total budget allocated to mental health does not amount to more than 2% of the total health budget. This they found inequitable compared to the disease burden of mental illness in Nepal.

Supply of psychotropic drugs

Some respondents agreed that there was an insufficient and irregular supply of psychotropic drugs at the district level, which was attributed to insufficient budget and lack of prioritization for mental health. Some district-level respondents believed that other health needs, such as maternal and child health, take precedence over mental health and therefore, the purchase of psychotropic drugs are insufficiently prioritized. A district health worker explained: *“There is no provision of supplying additional drugs... It is even difficult to supply adequate amount of [general] medicine within our budget; in this case, if mental health drug is added, then the situation turns worse.”* (District Representative 01, Male).

Few psychotropic drugs were included in the free drug list, and only two to four drugs were available at the district level. Some district-level respondents criticized that the drugs allocation, coordinated centrally, did not meet the demand. For the effective management of drug supply, respondents recommended that there should be flexible and open policies that allow the districts to purchase the drugs that are needed, even if they are not included in the free drug list.

Equity and inclusiveness

Access to services

Some respondents felt that mental health services were not accessible to all. According to the respondents, services were

mostly centered in Kathmandu and some urban areas. In addition, only limited services were available through the government health facilities. Some respondents mentioned that, along with geography and cultural factors, poverty and stigma associated with mental illness are major barriers for access to mental health services. According to these respondents, those who can afford it use modern treatment by traveling far distances, while those who cannot afford to travel ‘outside of the community’ visit traditional healers in their own community. A participant reported, “*Sakne Raja ko ma janu nasakne deutako ma janu*’ [those who can, they go to the King and those who can’t go to God’]. *While doing the treatment, it is similar thing. Those who can afford, go to medical doctor and those who can’t, go to traditional healer.*” (National Representative 13, Male). In order to increase access to mental health services in the community, some respondents suggested that the health workers should be provided with training and supervision in mental health and that anti-stigma programs should be implemented in the community. A district-level policymaker said, “*To reduce stigma and discrimination, community-level health workers can be involved because they are directly in touch with the community ... They can play a vital role in the rehabilitation process.*” (District Representative 06, Male).

Some respondents thought that involvement of service users was essential to reduce stigma. According to a district-level

polycymaker, people, who had mental health problems in the past, but are no longer suffering from mental illness, need to be provided with training on mental health and mobilized as trainers: “*With the known trainer, they develop trust about what s/he just mentioned because they knew s/he had been a sufferer in the past.*” (District Representative 02, Male).

Ethics

Respondents were asked whether ethics were applied during mental health research and service delivery. Some of them said that there were no mental-health-specific ethical guidelines; however, general health ethics were applied for both mental health research and treatment provisions. For example, for mental health research, ethical approval must be obtained from the Nepal Health Research Council (NHRC) where proposals are evaluated against general health research ethics. Likewise, the MoH, while regulating health service delivery, also monitors whether or not mental health services are provided in an ethical manner. A few respondents said that if complaints of human rights violation of patients arise, then the MoH addresses such issues. A participant mentioned, “*If any cases regarding violation of rights of the patient comes, then ministry forms a committee to address the issue and based on the report of the committee it takes necessary actions.*” (National Representative 05, Male).

Mental health information system

The lack of data on the prevalence of mental illness was identified by some respondents as a barrier to prioritizing mental health and allocating necessary resources. A national level representative said: *“As no research [at national level] has been conducted, we do not have background information. So we are not aware of our priority. Government can develop priority area with the help of research of community status.”* (National Representative 08, Male).

Many respondents lacked knowledge about the types of mental health information available from the Health Management Information Systems (HMIS). Those who were aware raised questions about the quality of record and use of the data gathered. A respondent said, *“I don't think we have good monitoring system ... it is haphazard.”* (National Representative 01, Female). Another participant said, *“Case incidences and prevalence are never discussed nor are meetings conducted for discussion.”* (District Representative 03, Male).

Strategies to improve record keeping were suggested by a few of the respondents. They recommended: the development of new mental health indicators similar to the Integrated Management of Childhood Illness (IMCI) indicators and clarity on roles and responsibilities related to record keeping, data analysis and utilization. Another suggestion was to strengthen existing HMIS sections to better manage mental health-related information.

Discussion

The findings revealed a few enabling factors and many challenges in mental health systems governance in Nepal, as reported by health care policy makers and managers. The enabling policy factors included constitutional provision for health as a human right, inclusion of mental health in the government's five-year health plan, provisions for mental health care in the recent National Health Policy, and inclusion of mental health care in the Non-Communicable Disease Multi-sectoral Action Plan. Other facilitating factors came from increasing participation of NGOs and service user organizations in policy forums, and implementation of mental health care projects in Primary Health Care Centers through government-NGO collaboration.

Policy challenges included non-implementation of mental health policy of 1996, lack of a mental health act despite a fourth revision of the draft, and lack of district-level consultation and participation for mental health policy formulation and planning. Other limiting factors included the inadequate mental health care human resources, inequitable allocation of budget to mental health care, lack of mental health services at the district and primary health care level, inadequate supply of psychotropic drugs, poor mental health care recording systems and insufficient infrastructure for delivery of mental health and psychosocial services. The application of Siddiqi and colleagues' health systems governance framework has

identified the need for: (1) proper implementation of existing policy provisions by assigning dedicated leadership and ensuring governance procedures and mechanisms at the ministry level; (2) greater coordination and collaboration within and outside the health sector through a systems thinking approach; (3) the restructuring of the current health system to better integrate mental health into primary health care; and (4) development and implementation of accountability and transparency measures both at national and district levels. These four domains of needs will be further explained below.

Implementation of existing mental health policy provisions

Having policies on paper is insufficient; the proper implementation of such policy provisions is needed to ensure access and utilization of mental health services and to reduce the treatment gap. Proper implementation is only possible when governance structures and mechanisms are in place, and there are dedicated people to implement these governance structures. Therefore, good governance is necessary for ensuring effective health care delivery [21] and policy implementation [22].

Good governance is feasible when there is a strong leadership. The absence of such leadership (e.g. through a mental health unit) and lack of clear mental health governance structures in the MoH has prevented the implementation of available provisions in national mental health policy. Greater clarity on mental health governance

structures would not only help improve intra-and inter-ministerial coordination but also provide platforms for debate and improvement in mental health provisioning. To achieve this, NGOs and the private sector could play important catalyst and advocacy roles for establishing a central coordination unit for mental health [23]. Many countries affected by conflict and disasters have seized opportunities (during and after the emergency) to make systemic changes in their national mental health systems [24]. The example of Afghanistan shows that NGOs and external development partners played a crucial role in the development of a mental health department there [25].

Coordination and collaboration

The findings of this study suggest that government institutions work in isolation with regard to mental health care, and coordination with other relevant stakeholders within and outside of MoH is very limited. As there are no or few staff assigned to mental health within the MoH, no one appears to assume responsibility or accountability with regard to mental health care.

The study participants identified that, due to the lack of proper policy direction and guidance from policymakers, there are delays in budget release, which affects the timely training of health workers and the distribution of psychotropic medicines to rural areas. Consequently, patients do not receive medicines on time. Impoverished patients then relapse, and while those who can afford

to pay (or borrow) for private practices increase their financial burden. Due to these and many other governance-related factors, the patients and their family members lose confidence in the public health system. To change this situation and regain the trust of patients and their family, there is a greater need for intra-and inter-ministerial coordination and collaboration. As mental health care issues are cross-cutting, we argue for a ‘systematic’ approach for coordination, not only among and across health system building blocks [26] but also beyond the health sector [27], in identifying and addressing barriers to health systems performance in order to improve governance and overall mental health care in Nepal.

Restructuring the current health system to better integrate mental health

Although the mental health policy and Nepal Health Sector Plan-II promote integration of mental health into primary health care [11], policy provisions have not been applied in practice due to the lack of mental health governance mechanisms at the national as well as the district level. Development of district-level mental health governance is needed to bridge policy and practice. For example, one public health officer from the District Public Health Office could be assigned as a mental health focal person to plan and coordinate all district-level mental health activities. Also, a greater emphasis on community mental health programs can help to deinstitutionalize mental health care [28] and increase awareness

among community members, thereby helping to reduce stigma related to mental illness.

As there are relatively few psychiatrists in Nepal, it would not be realistic to deploy them in all 75 districts of Nepal. Therefore, while restructuring the current health systems, Nepal needs to adopt a task-sharing approach [29, 30]. This would mean that prescriptions and medications can be managed by primary health care workers, as suggested by the Mental Health Gap Action Program [31], while identification and referral of people with mental illness can be done by Female Community Health Volunteers (FCHVs) [15].

Despite the challenges related to the overburdening of health volunteers and primary health care workers [32], we argue that integration of mental health into primary health care centers is now feasible, because of the enabling factors that are in place. For instance, existing policies promote integration of mental health into primary health care [11], the government has recently included six psychotropic drugs under the free essential drug list, efforts are under way to develop standardized mental health training manuals, and currently the Health Management Information System (HMIS) has procedures to collect mental health data. The additional cost needed for integration is low and may require only a few weeks of mental health training and quarterly supervisions by psychiatrists.

Accountability and transparency for better health system performance

The lack of accountability and transparency measures in place, limited access to health services by poor and marginalized groups, and limited engagement and participation of citizens in health affairs are pertinent health governance issues that contribute to low levels of systems effectiveness [11]. Therefore, improved accountability is an important prerequisite for improved health systems performance [33]. However, study findings suggest that concepts such as transparency, accountability and responsiveness are less developed in the field of mental health in Nepal, and there is lack of clarity as to who is responsible for monitoring mental health services and systems. Hence, there is a need for a structure at each health care level that clarifies roles and responsibilities and to ensure transparency and accountability [12]. Likewise, in order to ensure transparency in budget allocation and decision making, we argue that a system of mental health budget planning needs to be instituted and the capacity of existing HMIS needs to be strengthened. Similarly, grievance redressing mechanisms of the Good Governance and Management Act need to be strictly implemented so that the system becomes accountable and responsive toward the needs of the population.

Strengths and limitations

The results from this study are not easily generalizable to all areas of Nepal; this is because of the presence of a mental health program in the district where interviews were conducted, which is different to many other districts where no mental health services are available. However, the results are indicative of future challenges and solutions that other districts might encounter if mental health programs develop without strengthened governance. Also, in the absence of a mental health policy body at the MoH, and lack of clarity on who are the policymakers for mental health in Nepal, the selection of respondents might have introduced bias. To minimize selection bias, we took a systematic sampling approach in order to represent different stakeholders and institutions potentially involved in mental health policy. Since policymaking is led by government staff, we only included government policymakers currently serving in office. Thus, the results do not capture the views of retired government staff or people from NGOs and the private sector who might have had a significant role in mental health policy making, and we suggest that future studies could assess mental health governance from the perspectives of other stakeholders. One of the limitations of the study is that the inter-rater reliability was not explicitly considered as all the researchers worked on the development, translation, and contextualization and pre-testing of the interview checklist. Another limitation of the study is that, due to the small numbers of

respondents for the national and district levels, it was not possible to discuss the findings per sub group. As power and prestige play an important role in Nepalese government systems, the power hierarchy between the policy makers and researchers might also have influenced the kind of data being collected and reported.

Conclusions

The findings of this study suggest that, despite having some facilitating factors, there is a lack of legal provisions for mental health as well as non-implementation of existing policies, due to the absence of leadership at the Ministry of Health and lack of governance mechanisms for mental health. Hence, mental health systems governance in Nepal faces many challenges and needs greater resource inputs and leadership to overcome these challenges. Some positive developments are seen in terms of policy recognition for mental health, as well as participation of NGOs, and some service user groups, in mental health policy and planning. However, many governance principles related to transparency, accountability, ethics, responsiveness and equity are still underdeveloped and need greater attention. Likewise, the lack of trained human resources, frequent relocation of trained health workers, inadequate budget allocation, insufficient infrastructure, poor record keeping, and stigma related to mental health are some of the barriers which need to be addressed through proper governance mechanisms at the national and district level.

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CHAPTER 4

Information systems for mental health in six low and middle income countries: cross country situation analysis

*This chapter is based on: **Upadhaya, N., Jordans, M. J., Abdulmalik, J., Ahuja, S., Alem, A., Hanlon, C., Kigozi, F., Kizza, D., Lund, C., Semrau, M., Shidhaye, R., Thornicroft, G., Komproe, I., Gureje, O. (2016). Information systems for mental health in six low and middle income countries: cross country situation analysis. International journal of mental health systems, 10(1), 60.***

Abstract

Background: Research on information systems for mental health in low and middle income countries (LMICs) is scarce. As a result, there is a lack of reliable information on mental health service needs, treatment coverage and the quality of services provided.

Methods: With the aim of informing the development and implementation of a mental health information sub-system that includes reliable and measurable indicators on mental health within the Health Management Information Systems (HMIS), a cross-country situation analysis of HMIS was conducted in six LMICs (Ethiopia, India, Nepal, Nigeria, South Africa and Uganda), participating in the 'Emerging mental health systems in low and middle income countries' (Emerald) research programme. A situation analysis tool was developed to obtain and chart information from documents in the public domain. In circumstances when information was inadequate, key government officials were contacted to verify the data collected. In this paper we compare the baseline policy context, human resources situation as well as the processes and mechanisms of collecting, verifying, reporting and disseminating mental health related HMIS data.

Results: The findings suggest that countries face substantial policy, human resource and health governance challenges for mental health HMIS, many of which are common across sites. In particular, the specific policies and plans for the governance and implementation of mental health data collection, reporting and dissemination are absent. Across sites there is inadequate

infrastructure, few HMIS experts, and inadequate technical support and supervision to junior staff, particularly in the area of mental health. Nonetheless there are also strengths in existing HMIS where a few mental health morbidity, mortality, and system level indicators are collected and reported.

Conclusions: Our study indicates the need for greater technical and resources input to strengthen routine HMIS and develop standardized HMIS indicators for mental health, focusing in particular on indicators of coverage and quality to facilitate the implementation of the WHO mental health action plan 2013-2020.

Key words: mental health, information systems, low and middle income countries

Background

The health management information system (HMIS) is an integral part of all health systems because it aims to provide reliable and timely information on treatment needs and resource demands on the health system [1]. Sauerborn and Lippeveld [2] defined such a system as “a set of components and procedures, organized with the objectives of generating information, which will improve health care management decisions at all levels of the health system”. The HMIS is a component or sub-system of the Health Information System (HIS) that refers to the health services data collected at a facility level [3]. Within the broader six components of HIS; resources, indicators, data sources, data management, information

products and dissemination and use [4], the HMIS specifically looks at medical records of hospitals or health care organizations and deals largely with the accumulation, storage and accuracy of patient or individual related data. In the long term, HMIS has the potential to improve governance, transparency, accountability, evidence-based decision making, quality of services and performance-based financing strategies that are geared towards meeting the needs of the population [5]. In the short term, HMIS is an important tool for the planning and management of health services [6], as well as resource prioritisation.

HMIS is of universal importance, particularly in low and middle-income countries (LMICs) that are characterized by poor health outcomes, human resource shortages and limited financial resources. The reality is that the health systems, including the health information systems, of LMICs are often quite weak and fragmented, such that they fail to meet the needs of service providers and policy makers [7]. In several countries, for example, a large volume of routinely collected HMIS data eventually reaches the national level without being cross-checked, analyzed or utilized [2].

Despite increasing attention and investment in recent years, HMIS in LMICs face challenges of poor data quality, lack of qualified human resources, low management capacity, inadequate infrastructure, insufficient space for HMIS and technological difficulties such as software malfunctioning, data loss due to computer viruses or irregular electricity power supply [8].

Therefore, despite its potential to be a strong health system strengthening tool, the benefits of HMIS remain largely unrealized [9].

To make the best use of HMIS for mental health system strengthening, it is important to review the existing state of affairs of mental health within HMIS. Firstly, because there is an urgent need to develop mental health services in LMICs based on the high global burden of disease attributed to mental, neurological, substance abuse (MNS) disorders and self-harm (12%) [10]; and implement the WHO mental health action plan [11] and mental health Gap Action Program (mhGAP) guidelines for the integration of mental health into primary health care [12]. Secondly, the restructuring of existing HMIS has become a necessity, in a situation where primary health care has become a global priority [13] and funding for health is accompanied by greater demand for reliable statistics to track progress [14]. Thirdly, the absence of reliable data collection to accurately capture the mental health situation within the HMIS limits the capacity of mental health professionals and advocates to lobby for more investments to address the huge burden of mental disorders. It also hinders evidence-based improvements in the organization and provision of mental health care services to address specific areas of priority needs. This is because meaningful planning and projections cannot be carried out without reliable data.

The literature regarding the development of HMIS is scarce [2] and even more so for "mental health component within HMIS", as there is a lack of health care system focus on mental health.

The 'Emerging mental health systems in low and middle income countries' (Emerald) research programme aims to support mental health systems strengthening in the six countries of Ethiopia, India, Nepal, Nigeria, South Africa and Uganda [15] A key area of focus of the Emerald program is to strengthen the mental health component of the HMIS in the participating countries, through development and field testing of suitable mental health indicators to monitor the performance of the mental health system. A necessary preliminary step is to perform a situation analysis of the current state of HMIS, and the mental health components within HMIS, in all the participating countries to map the current situation and identify the gaps. This paper presents a situation analysis to highlight the strengths, challenges and opportunities for developing and strengthening "mental health components" within routine government HMIS across the participating countries.

Methods

Setting

See Table 1 for details of the Emerald country sites. The Emerald countries represent two continents (Africa and Asia) and have three income levels (upper middle-income: South Africa; lower middle-income: India and Nigeria; and low-income, Ethiopia, Uganda and Nepal) and include a fragile state (Nepal).

Table 1: Socio-demographic characteristics of Emerald countries

	Ethiopia	India	Nepal	Nigeria	South Africa	Uganda
Population (in millions)*	95.9	1296 .2	27.1	177.5	53.7	38.8
Proportion of population living on <\$1.25 per day**	30.65	32.6 8	24.82	67.98	13.77	38.01
Human Development Index rank**	173	135	145	152	118	164
Population Growth Rate*	2.1	1.5	1.5	2.5	1.0	3.4
Maternal Mortality Rate**	350	200	170	630	300	310
Infant Mortality Rate*	50	44	46	69	42	57
Gross Domestic Product per capita (USD)**	1218	5050	2131	5440	11989	1334
% Gross Domestic Product spent on health**	4.7	3.9	5.4	5.3	8.5	9.5
% health budget spent on mental health***	0.07	2.05	0.08	0.40	4.50	0.44

Sources: (Population Reference Bureau, 2014)*[28], (UNDP, 2014)**[29], (WHO, 2011)***[30].

Broader country contexts for health information management

The HMIS, which aims to assist in the management and planning of health programmes, has diverse history in Emerald countries. For example, in Uganda the HMIS was introduced in 1997, to improve the pre-existing health information system introduced in 1985 [16]. In South Africa HMIS was established after 1994, as

during the apartheid system, health services were extremely fragmented, and there were inequitable health data standards. In 2001, South Africa was able to establish national standards, with essential data and indicator sets, which all provinces are required to report [17]. In India, as part of the National Health Rural Mission that began in 2005, the HMIS received greater emphasis and was expected to improve governance as well as the monitoring of the health system [18]. In 1991 the national health policy in Nepal recognized the need for health sector information and since then, there have been several initiatives, the latest being the revision of existing HMIS indicators to meet current needs [19]. In Ethiopia, the reformed HMIS was pilot tested in 2006/07 and since September 2009, the HMIS scale-up project has provided training to health workers of the Southern Nations and Nationalities People's Region [20]. Nigeria had a weak health system when it became independent in 1960. It began health reforms after the Alma Ata conference of 1978, but required 10 years to establish the national health policy in 1988 which contained provisions for a robust country HMIS [21].

Study design

We conducted a cross-country situation analysis to obtain information from key documents in the public domain, and supplemented this by contact with key officials in government services where necessary.

Instrument

The instrument was developed by three of the authors (NU, MJ, and OG) and was revised after inputs from consortium partners. The situation analysis tool (<http://www.emerald-project.eu/tools-instruments/>) had nine sections which covered background of the HMIS, plans and policies related to HMIS, the process of recording and collating data, monitoring, evaluation and feedback procedures, dissemination and utilisation of data, human resources, availability of mental health indicators, coordination and linkages, and an open section for any other relevant issues not covered in the previous sections.

Data collection

The coordinators and research staff in each of the study sites completed the situation analysis by reviewing secondary documents and engaging in informal interviews with government HMIS staff between March and May 2013. All the sources utilised to answer the situation analysis tool were documented and were updated as and when new information was available. The country teams reviewed the completed in-country data for comprehensiveness and comprehensibility. In cases where inconsistencies were noted, further cross-checking of the collected information was performed.

Data analysis

The data from all six countries were collated and tabulated in an Excel spreadsheet, based on the nine sections outlined above. The

responses for each question were coded and summarized. During this process two researchers checked if all the questions were answered properly and if responses were understandable. The aspects that required further clarifications were noted. The coding and summarization process meant that similar information was grouped into one category or theme, and for each theme a summary table was developed. Preliminary results were sent to all country partners with requests for additional information, clarifications and for a validation check of the findings. Further feedback and information was incorporated to derive the final results.

Results

Policy context for mental health and HMIS

All six countries have an operational HMIS that is overseen by the respective departments or directorates under the Ministry of Health. None of the countries possess a separate policy for mental health information management, but the mental health policies in some countries (Nepal, South Africa and Uganda) and the mental health strategy in Ethiopia have sections on mental health data collection and management (See Table 2).

Table 2: Policies and plans related to mental health and HMIS

Themes	Ethiopia	India	Nepal	Nigeria	South Africa	Uganda
Mental health policy or plan	Yes ¹	Yes ²	Yes	Yes	Policy drafted	Yes
Provisions for MHIS ³ in mental health policy	Yes, but not implemented	Yes	Yes. Plan to maintain record systems	No	Yes. A section on MHIS	Yes
Provisions in mental health policy for social welfare benefits	No	Yes, talks about monetary and tax benefits	No	No	Covered in other health policies	No
General health policies that govern HMIS	5-yearly health plan	National Health Policy 2002 and Draft National	National Health Policy and Nepal Health Sector Programme -2	Revised Policy Programme and Strategic Plan	White Paper for the Health System District HMIS policy	Health Policy

¹ Ethiopia has a National Mental Health Strategy which is the equivalent of a policy/plan

² When the data for this study was collected between March-May, 2013, there was no mental health policy in India. It was only in October 2014, India released its first mental health policy in which monitoring and evaluation of national mental health programme has been emphasised.

³ Mental Health Information System

General health plans that govern HMIS	Health Sector Development Plan IV (2010/11 - 2014/2015)	The National Rural Health Mission(2005-2012)	Second Term Health Plan1997 - 2017	Long Health Plan	National 5-year Health Plan	3- 5-year health plan	Health Sector Strategic Plan2010/11-2014/15
Standard operating procedures for mental health	No	No	No		No	Yes	No
Initiatives to develop MHIS	Yes	No	No		No	Yes	No

Ethiopia and South Africa, realizing the need for quality data on mental health, have taken policy level advocacy initiatives to integrate mental health indicators within routine HMIS, rather than having a parallel system for mental health information management. As a result, the South African Standard Operating Procedures (SOPs) include processes on how to collect, record and report mental health data in HMIS.

Apart from South Africa, none of the countries have specific HMIS policies for general health conditions, although health policies and plans of those countries mention HMIS guidelines and standard operating procedures (SOPs) which could be helpful in the development of mental health components within HMIS. For example, the three to five year health plans in Uganda, South Africa, Ethiopia and Nigeria have laid out plans to implement HMIS. In Nepal, the second long term health plan (1997-2017) and health sector strategy (2002) have emphasized the need for the establishment of a health sector information system (HSIS). In Ethiopia, high-level goals for strengthening HMIS are specified in the ‘National Health Policy of the Transitional Government of Ethiopia, 1993’. The Health sector development plan IV, 2010/2011-2014/2015, includes a commitment to electronic HMIS and specifies the indicators to be measured routinely. In Nigeria, each state Ministry of Health implements the national HMIS plan.

Situation of HMIS human resources

Limited human resources are involved in HMIS and staff are mostly junior data entry clerks. In all six countries, there is a small pool of HMIS experts. The pre-service training of HMIS human resources is limited to a few lectures within post-graduate courses of medicine and public health, except in Uganda and Ethiopia which have specialized university courses.

In Uganda course in Public Health Informatics is being delivered through the School of Public Health at Makerere University; a diploma course in medical records and HMIS is also offered by the Uganda Institute of Allied Health and Management Sciences

Table 3: Human resources for HMIS in the six Emerald countries.

Themes	Ethiopia	India	Nepal	Nigeria	South Africa	Uganda
Minimum qualification needed to start career in HMIS.	Level IV diploma	Graduate in any discipline	Diploma in statistics	Bachelor	This varies widely	Certificate in HMIS
Qualification for HMIS expert	Information not available	BSc and MSc in statistics	MA in Statistics and work experiences	BSc in Health information and work experience	None as the expertise is interdisciplinary	Master degree in biostatistics
Number of HMIS specialists	Number not available	20	5	Number not available	Number not available	3
Number of HMIS trainers	Number not available	Number not available	About 200	About 200	Number not available	About 10
Standard HMIS training manuals	Yes	Yes	Yes	Yes	Yes	Yes
Specialized courses in HMIS	Yes	No	No	Yes, but very few	No	Yes

In Ethiopia, there are three universities that offer bachelors (Gondar University) and masters (Addis Ababa, Gondar and Mekelle University) degree courses in health informatics. Apart from these universities there are over seven health information technician (HIT) training regional colleges which have so far trained 2488 people on health informatics. The qualification required to become an HMIS specialist varies across countries, but in all countries previous work experience in HMIS field is required. Nigeria requires a minimum qualification of a Bachelor's degree in Statistics or Health Management while Nepal and India require a Master's degree in Statistics or Information Technology. In South Africa, there are no HMIS specialists, because health information management is considered interdisciplinary, so staff from the respective departments manage the health information. India, Nepal and Uganda have twenty, five and three specialists respectively; the remaining countries have no information on the number of specialist staff. Nepal and Nigeria have 200 HMIS trainers each while Uganda has a pool of 10 national trainers. There is no information available for the number of HMIS trainers in Ethiopia and India.

Across sites, in-service training was given by the HMIS department, though on an ad-hoc basis. All countries had HMIS training manuals, which were widely used in India, Nepal and Uganda. Most of the countries had dedicated HMIS staff at a central and regional level. None of the countries had such staff at the primary health care level but rather utilized other cadres of

health care staff such as nurses, auxiliary health workers, community health workers and health assistants to collect and manage the data.

Mental health indicators collected from routine HMIS

Despite the existence of mental health services, a very limited range of mental health indicators are collected as part of routine HMIS in Ethiopia, Nepal, South Africa and Uganda. In general, the countries tended to collect routine data on health service contacts of people with mental health problems (disease categories) rather than mental health system information such as number of health workers trained in mental health, number of beds available for mental health, the admission rate and number of people being supported from social security funds, as summarised in Table 4. The indicators presented in Table 4 are those reported in HMIS related documents of the six countries.

Table 4: Mental health indicators in HMIS

Themes	Ethiopia	India	Nepal	Nigeria	South Africa	Uganda
Mental health indicators in national HMIS	Yes	No ⁴	Yes	No ⁵	Yes	Yes
Mental health out-patient department (OPD) attendances included	Yes	No	Yes	No	No	Yes
Mental health referrals recorded	No	No	No	No	No	Yes
Psychiatric in-patient bed occupancy rate	No	No	Yes	No	Yes	Yes
Mental health training data reflected	No	No	Yes	No	No	No
Average length of stay at the hospital	No	No	No	No	Yes	Yes

⁴ However, State level mental health programme have guidelines for reporting data on MH in states like Madhya Pradesh. Data on admission in tertiary level mental hospital and days spent in mental hospital are recorded

⁵ However, data on mental health outpatient visit, patients treated at day care facilities, psychiatric bed of general hospitals and mental hospital are collected.

We found that all countries record some mental health indicators, but that these countries vary in their categorization of mental health problems. In Ethiopia, data on five disease categories (mental and behavioural disorder, epilepsy, dementia, depression and schizophrenia) are collected at secondary level of care; while only two conditions (behavioural disorders” and “epilepsy”) are collected at the primary care level. In Nepal, mainly the morbidity and mortality data on a total of 67 disease categories (including depression, psychosis, anxiety, mental retardation, conversion disorder, alcoholism and self-harm/suicide) relating to mental health, based on ICD 10 categorization, are collected at the regional and national hospital level, while at the district and PHC level data on seven disease categories are collected. In Uganda, data on eight disease categories (anxiety disorder, mania, depression, schizophrenia, alcohol and drug use, epilepsy, childhood mental disorders and other forms of mental illness) are recorded.

In South Africa, mental health indicators relating to mental health case load, mental health visits and voluntary and involuntary admission rates of people below 18 years and older are recorded. South Africa and Uganda are the Emerald countries which have Child and Adolescent Mental Health Indicators in their current HMIS. In Ethiopia, the data are disaggregated into child/adult so information on child mental health is available.

The insufficiency of mental health indicators in existing HMIS in Ethiopia and South Africa has been recognized and efforts to

include additional indicators are being made. As a result, the Ethiopian national mental health strategy has specified various mental health indicators to be included in HMIS. In South Africa a proposal to expand the list of available indicators is suggested in the National Mental Health Policy Framework and Strategic Plan 2013.

In the remaining countries no such initiatives have been taken yet. However, all countries are in the process of considering possible amendments of existing HMIS to include additional mental health indicators. The envisaged strategies and processes required to amend HMIS in the respective countries include: advocating for change with the planning and policy directorate (Ethiopia), conduct focus group discussions with stakeholders, make a list of prioritized indicators and submit them to the government (India), consult stakeholders and advocate for a new policy (Nepal), amend the mental health policy by legislation and engage with the Directors of Planning, Research and Statistics at the Federal and State Ministries of Health (Nigeria), engage national and provincial managers in initial adaptation of the mental health action plan and its endorsement by the Department of Health (South Africa), and hold regular review meetings and submit a request for amendments (Uganda).

The Emerald countries also face several challenges with regards to including additional mental health indicators in the HMIS, which include: concern from policy makers about indicator overload and

competing priorities (Ethiopia), low priority of mental health and consequently a low availability of resources and skilled human resources (India and Nepal), the lack of political will for mental health reform and slow process of effecting changes (Nigeria), growing competition among several programs to incorporate additional indicators in HMIS (South Africa) and the length of the existing HMIS tool and lack of qualified staff at the health facility level (Uganda).

Processes and mechanisms for data collection and management

While for other general health conditions the lowest level of HMIS data collection is the community, the primary health care centre and district level are the lowest level for mental health data. All six countries have standard HMIS formats for data collection.

Though electronic HMIS are being piloted in certain health facilities, Ethiopia largely uses paper forms, whereas the other five countries use both paper and electronic formats for data collection. In Nepal, India and South Africa, data from the district level upwards is compiled electronically, either through an online system or web portal.

The HMIS in all six countries are subject to systematic monitoring and evaluation, and data control mechanisms. All countries make checks for completeness, timeliness and validity of data. Different countries utilise different processes; Lot Quality Assurance Sampling (Ethiopia), systematic monitoring and evaluation (M&E) and 52 validation questions (India), review meetings, data

verification meetings and field visits (Nepal), data review and verification meetings (Nigeria) and Standard Operation Procedures (South Africa) are used.

Data verification meetings are the most commonly used method for data quality control but the frequency of the meetings varies across countries. Nepal has half yearly verification meetings while South Africa conducts data clean-up workshops monthly (at the health facility level) and quarterly (at the provincial and national level).

Table 5: Data collection, compilation, reporting and dissemination

Themes	Ethiopia	India	Nepal	Nigeria	South Africa	Uganda
Data collection	Only Paper and pencil	Paper pencil and electronic	Paper pencil and electronic	Paper pencil and electronic	Paper pencil and electronic	Paper pencil and electronic
Data compilation	Manually	HMIS web portal	HMIS online data entry system	Manually and electronically	Manually and electronically	Manually and electronically
Data analysis	Annually	Monthly	Quarterly and annually	Quarterly and annually	Quarterly	Quarterly
Frequency of data reporting to MoH	Quarterly	Monthly, quarterly and annually	Monthly	Monthly	Quarterly	Monthly, quarterly and annually
Data quality control mechanisms	Yes	Yes	Yes	Yes	Yes	Yes
Feedback mechanisms to the lowest level	Not clear	Yes	Yes	Not specified	Yes	Yes

Dissemination of HMIS data	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Public access of HMIS report	Yes	Yes	Yes	Yes	No	Yes	Yes

In Nigeria, monthly data collation occurs at the district level while the verification exercises takes place (monthly) at the state level. The processes of data cross-checking also vary. India compares different indicators and analyses several interviews to cross-check the data, whereas in Uganda feedback is also given through “Barazas” (consumer and stakeholders group) meetings.

The countries also vary in their dissemination plans. India has a national dissemination plan and HMIS data are disseminated through periodic workshops conducted at different levels. In Ethiopia, Nepal and Nigeria data are disseminated annually in the form of public reports. In the case of Uganda, dissemination is done through quarterly review meetings at the ministry, district and lower health facility level. All countries have public access to government data. However, in Nepal, Nigeria and South Africa, this can be fully accessed following approval of a formal request.

Discussion

The six Emerald countries face substantial contextual and health governance challenges in developing and implementing information systems that are able to adequately record, report, analyse and disseminate mental health information. Irrespective of income level (based on countries' gross national income), similar challenges and opportunities are seen in developing and implementing HMIS. The Ugandan and South African mental health policies specifically mention HMIS. The Ethiopian mental

health strategy also has provisions for mental health information collection and management, but it is not yet implemented. In other countries there is no specific explanation on how and from where mental health information should be collected. This cross-sectional situation analysis shows that there are no separate mental health information systems, but that some mental health indicators are collected through routine HMIS. In general, the countries tended to report the status of mental health (morbidity and mortality indicators per disease category) rather than system level indicators such as quality and utilization of services, average length of stay, bed occupancy rate, rates of admissions and social welfare benefits given to people living with mental health problems to cover treatment expenses. Notably, mental health referrals and mental health training data are scarcely collected.

Due to funding and government priorities, the HMIS in Emerald countries appear to be more geared to communicable diseases, overlooking the information management systems need for non-communicable diseases like mental health. With the epidemiological transition from communicable to non-communicable diseases (NCDs) the kind of indicators needed for mental health are also relevant for other NCDs so the political emphasis on NCDs may support the changes in mental health. The capacity to track changes in treatment coverage and quality of care is essential for monitoring the impact of mental health programs [22]. It is therefore important to install or strengthen the existing

information systems that can appropriately inform the planning and implementation of mental health care. The inclusion of new indicators within the HMIS is not an easy task; several challenges need to be overcome. In order to develop functional mental health information sub-systems within HMIS, there is a strong need for lobbying and advocacy with stakeholders at the district, regional and ministry level, in order to convince policy makers to develop political will for mental health reform and to break the cycle of slow progress in effecting changes.

The findings indicate that there are procedures and mechanisms in place for data collection, compilation, reporting, analysis, feedback and dissemination, but due to low number of HMIS experts and HMIS staff trained on mental health, it is difficult to fully implement the procedures and mechanisms. The low number of HMIS experts in study countries (twenty in India, five in Nepal, three in Uganda and none in remaining countries) shows that countries depend upon junior level and in general non-qualified staff for the majority of health information management. This raises questions about timely supervision of junior staff and the quality of data generated by staff without much technical guidance. The lack of specialist HMIS-related courses in academic institutions and lack of political will of policy makers and planners within ministries of health might be some of the causes for the low number of HIMS experts in these countries.

There have been some positive developments in Ethiopia, and Uganda, however, where institutions have started providing specialized courses on HMIS. The lessons gleaned from these countries could be useful in advocating for specialized HMIS courses in other Emerald countries. Agreeing with P Littlejohns, JC Wyatt and L Garvican [23], who argued that educational efforts of HMIS staff often concentrate on how to use the system rather than why it should be used, we stress the important role of academic institutions in providing specialized courses on health informatics and thereby contributing to HMIS strengthening.

The findings of the study suggest that mental health data collected through routine HMIS in study countries is inadequate and does not reach policy makers on time to influence policies. This may be due to a lack of consensus about the information needed, between data producers and data users at each level of the health system [2]. This could be further linked with a lack of clear policy guidelines on mental health data collection and management. Secondly, due to the lengthy process of data collection, recording, reporting and analyzing, the findings do not reach decision makers in a timely way; hence decisions are often made without any information input [2].

In order for health information to influence policy making decisions, the data have to be of high quality and relevant for decision makers at each management level [2]. The decision makers, such as policy makers, planners and health service

managers, at the district and national level require evidence based information to formulate policy and planning. It is debatable as to which data sources are preferable for developing and tracking health system targets. It has been argued that household and facility surveys yield better quality information than routine HMIS [5] because they are less biased and conducted by a dedicated team of more skilled researchers. Others perceive HMIS to be costly, producing low quality and irrelevant information [24], thereby contributing less to the decision-making process. We argue that, despite many challenges such as poor design and low capacity of health workers to manage information, HMIS do allow for routine tracking of progress towards organizational objectives and improving health system performance. We are of the view that the HMIS data are more timely and relevant to inform decision-making by managers of health services compared to population surveys that do little to inform the day- to- day management of health services. However, we acknowledge that HMIS is not the only data source relevant for decision makers. There are various other data sources, for example, causes of death obtained from civil registration which can provide suicide rates; while population surveys which can provide prevalence estimates for mental health problems. The study findings also suggest that countries do not see the alternative of HMIS rather they are in the process of developing mental health indicators within HMIS. We also believe that the current HMIS, if re-structured properly with adequate human

resources, can yield reliable mental health information that is useful for improving service provision and policy making.

Introducing a separate mental health information system (MHIS) is unrealistic and undesirable in LMICs where mental health is still largely neglected and public sector mental health human resources are in short supply, even more so for HMIS staff trained in mental health. Also, due to inadequate government attention to mental health, a very limited budget is allocated which would be unlikely to sustain a separate/independent mental health information system. Secondly, a separate MHIS would be against the principle of integration of mental health into general health care. We argue therefore against a parallel MHIS and stress the importance of re-structuring of the current HMIS to include sufficient mental health indicators. The re-structuring should also include provision of infrastructure and software support and training of HMIS staff regarding mental health in general and mental health information management in particular.

The HMIS of six countries under study already collect mental health information, so we see that there is an opportunity to strengthen existing HMIS to obtain better quality mental health data. HMIS is not just introducing statistical techniques, it is "introducing a new management approach with wider organizational consequences"[25]. Therefore, it is important to re-structure not only the HMIS but also the health governance

mechanisms and organizational management culture to get better mental health information that will be useful for service provision and policy making. In theory, many approaches to HMIS such as managerial, infrastructural and organizational exist in the literature [9], but in practice greater emphasis is placed on technical approaches of systematic data collection, ignoring the reality that HMIS goes beyond technical aspects and incorporates complex social, institutional and cognitive realities [9, 26].

Limitations of the study

One of the limitations of the study is that it largely relied on secondary information available in the public domain. The study therefore might not have given a complete picture of all the available information. Efforts were made to validate the information by informally interviewing the responsible government officials. Secondly, the study gives the overall context of the HMIS and the mental health indicators within it but it does not assess the performance of HMIS. An assessment using an established assessment framework such as the Performance of Routine Information System Management (PRISM) as suggested by A Aqil, T Lippeveld and D Hozumi [5] and the Health Matrix Network's assessment tool might have been ideal. But, in the context of limited time and resources, this was not possible. Thirdly, in the absence of previously published reports, this cross-country situation analysis was unable to investigate the attitudinal aspects of policy makers, planners and health workers' willingness

to develop and implement mental health information sub-systems within HMIS. This will be addressed in another study, planned to evaluate the effectiveness of additional mental health indicators, integrated into the routine health management information system. Another limitation is that we have only considered HMIS for government health services. Thus, it does not provide information about the private sector which provides a significant proportion of health services in many LMICs. Nonetheless, this situation analysis provides data and contextual factors that have value for the development, implementation and evaluation of mental health information sub-system within routine HMIS.

The future of mental health information systems in low and middle income countries

We propose the following five steps for developing and managing mental health information sub-systems that are integrated into routine HMIS. Firstly, there needs to be policy and management level clarity on organisational and system level changes that are required for the integration of mental health components into routine HMIS. We believe that the organizational change should be as part of the system development process, not merely as a technical innovation. Secondly, there is a need to examine information systems through information audits to identify factors that would facilitate or inhibit adoption of mental health information sub-systems within routine HMIS. The evaluation of HMIS should be multi-dimensional, covering many aspects beyond

technical functionalities [23]. Thirdly, capacity building in HMIS human resources needs to be strengthened [25] and staff should be trained in mental health, to collect and report data correctly. Given the lack of HMIS specialists and trainers available in-country across the sites, the regular onsite supervision of junior staff is not realistic. An alternative could be the implementation of a training of trainers (ToT) program in mental health information sub-systems within HMIS. Support to the newly-trained trainers through distance supervision, using modern telecommunication needs to be considered. Fourthly, a data handling mechanism should be developed or strengthened at all levels of the health care system. Finally, a culture of information use at each level of health facilities needs to be encouraged and in that capacity senior level health managers and decision makers could play an exemplary role by using and encouraging the use of health information [27].

Conclusions

The six countries are at different stages in the development of HMIS as well as in the collection and reporting of mental health indicators, but the challenges and opportunities are similar across countries. The workforce, infrastructure, and software-related challenges are common. Strong policy and strategic vision for mental health aspects of HMIS is lacking in all the countries. The current HMIS in some of the countries collects few mental health data and there is a need to add indicators related to service need, coverage and utilization. There are very limited HMIS experts

available and therefore the bulk of the work is done by junior staff without expertise and experience.

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CHAPTER 5

Psychotropic drugs in Nepal: perceptions on use and supply chain management

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Abstract

Background: Psychotropic drugs play an important role in the treatment of mental, neurological and substance use disorders. Despite the advancement of the use of psycho-pharmaceuticals in the developed countries, the psychotropic drug production and supply chain management in low- and middle- income countries are still poorly developed. This study aims to explore the perceptions of stakeholders involved in all stages of the psychotropic drug supply chain about the need, quality, availability and effectiveness of psychotropic drugs, as well as barriers to their supply chain management.

Methods: The study was conducted among 65 respondents from the Kathmandu, Chitwan and Pyuthan districts, grouped into four categories: producers, promoters and distributors ($N=22$), policy makers and government actors ($N=8$), service providers ($N=21$) and service users/family members ($N=14$).

Results: The respondents reported that psychotropic drugs, despite having side effects, are 1) needed, 2) available in major regional centers and 3) are effective for treating mental health problems. The stigma associated with mental illness, however, forces patients and family members to hide their use of psychotropic drugs. The study found that the process of psychotropic drug supply chain management is similar to other general drugs, with the exceptions of strict pre-approval process, quantity restriction (for production

and import), and mandatory record keeping. Despite these regulatory provisions, respondents believed that the misuse of psychotropic drugs is widespread and companies are providing incentives to prescribers and retailers to retain their brand in the market.

Conclusions: The production and supply chain management of psychotropic drugs is influenced by the vested interests of pharmaceutical companies, prescribers and pharmacists. In the context of the government of Nepal's policy of integrating mental health into primary health care and increased consumption of psychotropic drugs in Nepal, there is a need for massive education and awareness as well as strict monitoring and supervision to avoid the misuse of psychotropic drugs.

Key words: psychotropic drugs, Nepal, supply chain management, mental health

Background

Psychotropic drugs play an important role in the treatment of mental, neurological and substance use (MNS) disorders [1] and therefore availability of, and access to, these drugs have been considered vital in mental health care [2]. Psycho-pharmaceutical advancements could increase the effectiveness and efficiency of mental health treatments, but this potential has not been realized in low and middle income countries where treatment for MNS

disorders is inadequate [3]. Many people with MNS disorders in low and middle income countries remain untreated because of inadequate access to psychotropic medicines [4], especially for those disorders such as psychosis and bipolar disorder for which psychotropic drugs are the first line of the treatment. To reduce this treatment gap, the World Health Organization (WHO) has recommended the implementation of the Mental Health Gap Action Program (mhGAP) in primary health care settings [5]. However, interventions with psychotropic drugs are different from psychotherapy or case management, and involve greater risks of inappropriate use and unintended consequences (side effects and further complications). Therefore, in the context of psychotropic drugs being included in the mhGAP intervention in primary care settings, it is important to assess the entire psychotropic drug cycle from production to consumption. This is because the access, utilization and efficacy of psychotropic drugs are affected by both the perception of the people using the drug as well as the organizations and actors involved in drug production and supply chain management. Although drug efficacy is evaluated by pharmacological action, studies have shown that this one-dimensional perspective is insufficient; the ‘real impact of the medicines’ is connected to several interwoven dimensions of individual biology and socio-cultural dynamics [6]. Therefore, psychotropic drugs can have several meanings for people who use them [7], and can have different effects (contrary to the biomedical

principle that psychotropic drugs prescribed in certain doses have identical effects in all patients) depending on the illness experiences of individuals and how they interpret the effectiveness of psychotropic drugs in the context of their lives [6]. In high income countries, adequate access to psychotropic drugs is achieved by sustainable financing and reliable supply systems [4], whereas low- and middle- income countries (LMICs) have inadequate finance and supply systems thus limiting the access to psychotropic drugs. Additionally, in low- income countries little awareness of mental health problems and socio-culturally constructed explanatory models of illness and treatment pathways determine which service to access. Similarly, the prescribing behaviour and consumption of drugs as per the prescription are affected by the socio-cultural context and belief systems of stakeholders. As a consequence, the attitude of the society towards mental illness influences the help-seeking behavior. In Nepal, due to stigma associated with mental illness, many people hesitate to seek services and do not arrive to health facilities for the treatment of their mental health problems. This affects the demand and supply of psychotropic drugs. The production of drugs follow protocols that primarily focus on cost effectiveness and drug efficacy, whereas drug distribution, prescription and use is less structured and more influenced by the perspectives of people involved [8]. This is important to consider because the meaning

and expectation the client associates with the use of psychotropic drugs has a significant impact on the effectiveness of the drug.

In Nepal, psychotropic drugs are available from Nepalese and Indian pharmaceutical companies and are regulated under the Narcotic Drugs (Control) Act 1976. Within the Ministry of Health (MoH), the Department of Drug Administration (DDA) established in 1979 is responsible for regulating import and production, as well as monitoring, distribution, prescription and record keeping of psychotropic drugs in Nepal. Guided by the drug policy of 1995, the national list of essential medicines, Nepal (2011) includes 15 psychotropic drugs and the free drug list approved by MoH in 2014 includes five psychotropic drugs (as given in supplementary table). Despite these policy commitments to make psychotropic drugs available in Nepal, access to psychotropic medicines in much of the country is still limited. This problem is compounded by a dearth of literature on supply chain management of psychotropic drugs, therefore the barriers to improving mental health care access are not well understood. To improve psychotropic supply chains, the barriers and the enablers in current supply chains need to be identified and properly addressed. One study on pharmaceuticals in South Asia included an anti-depressant drug, fluoxetine [9] used in Nepal. However, this research did not include any other psychotropic drugs. Furthermore, no studies from Nepal have described the perceptions of people involved in the entire psychotropic drug supply chain.

To address this knowledge gap and provide input for the adequate roll out of the mhGAP intervention in Nepal's primary health care, our study aimed to explore the perceptions of stakeholders (involved in all stages of the psychotropic drug supply chain from production to consumption) about the need, quality, availability and effectiveness of psychotropic drugs in Nepal as well as the barriers to effective psychotropic drug supply chain management.

Methods

Setting

This study was conducted in the Kathmandu, Chitwan, and Pyuthan districts of Nepal. Kathmandu, the capital city, was selected specifically in order to include policy makers and government agencies involved in the supply chain management of drugs. Chitwan and Pyuthan both were purposively selected because a government-Non Governmental Organization (NGO) model mental health program was being implemented in these districts. The program for improving mental health care (PRIME) in Chitwan and the mental health beyond facilities (MHBF) project in Pyuthan involved training primary health care staff on management of psychotropic drugs and basic counseling as part of a comprehensive District Mental Health Care Plan, based on WHO's mhGAP[10]. The services ranged from community mobilization, family support, psychosocial counseling and psychotropic medication. Chitwan represented a district with more

advanced medical facilities, having a psychiatric ward in the government regional hospital and private medical colleges, whereas Pyuthan represented a hilly rural area with limited health facilities.

Sampling

For the study, the sample (N=65) was conveniently selected through a process of purposive and snowball sampling, identifying people involved at any stage of the psychotropic drug supply chain in Nepal. The sample was divided into four major categories, (a) producers, promoters and distributors; (b) policy makers and government actors; (c) service providers; and (d) service users and family members. The respondents for category "a" (N=22; 9 from Kathmandu, 9 from Chitwan and 4 from Pyuthan) included people involved in the production, import, dispensing, and promotion of psychotropic drugs. For category "b" the respondents (N=8; 6 from Kathmandu and 2 from Chitwan) were government planners and policy makers working in ministry of health, its departments in Kathmandu, and district public health office, Chitwan. The respondents for category "c" (N=21; 3 from Kathmandu, 9 from Chitwan and 9 from Pyuthan) included health workers (both specialists such as psychiatrists, psychiatric nurses and generalists such as medical officers and primary health care workers) providing mental health services in the study locations. The category "d" respondents (N=14; 8 from

Kathmandu, 5 from Chitwan and 1 from Pyuthan) included people who had used psychotropic drugs for the past six months and their family members.

Data collection instruments and process

The template for semi-structured interview “topic guides” was constructed for the above-mentioned categories of respondents. The major areas of focus for the questions were: processes involved in supply chain management, perceptions of need and use of psychotropic drugs, challenges in supply chain management, relationships with other stakeholders in the supply chain management, and recommendations for effective management of psychotropic drugs. The “topic guides” were pilot tested through interviews with a member from each category in a non-study district in Nepal. Based on the results of the pilot interviews, the questions were simplified, their sequence were re-ordered and some probing questions were added.

The data collection took place between September 2013 and March 2014. Data collection for service users was conducted during home visits and health center visits, while interviews with respondents from other categories were conducted through work place visits. The respondents were asked to choose the place for the interview to ensure privacy and confidentiality, as well as to make sure that they would be at ease and could respond freely, comfortably and honestly. Where possible, the researchers also

observed the interaction between patients and retailers, patients and prescribers, marketing representatives and retailers. These observations were noted and written-up as field notes on the same day. All interviews were conducted in the Nepali language by a team of six experienced Nepalese researchers. The researchers had participated in a one-week workshop which helped them to familiarize themselves with the research design and methods, and to update their understanding on qualitative data collection processes. During the workshop, mock interviews and role plays were conducted for researchers to assess their comprehension of the topic guides. Data was collected through digital audio recordings, note taking, and field observations. The respondents were informed about the nature, objectives, and use of the study, and verbal consent was obtained from each respondent after the assurance of confidentiality.

Data Analysis

Thematic analysis was used in the data analysis process. Researchers transcribed the interviews immediately after meeting the respondents. The transcripts were translated into English by professional translators and checked by the research supervisor. The translation was necessary as the data needed to be shared with the research team members of an international consortium project called Emerging Mental Health Systems in Low- and Middle-Income Countries (Emerald), of which this study was a part. The

Emerald project aims to strengthen the systems and processes that are necessary for effective mental health service delivery [11]. Ten percent of the interviews, along with field notes and observations, were randomly selected and read separately by four researchers, who identified, compared, and discussed broad themes from the data. On the basis of previously discussed themes, two researchers (DG and RP) separately coded 35% of the data manually, and the new themes that emerged during the coding process were added. The codes were discussed with research team members to evaluate comparability and reliability between researcher identified themes, and a coding framework with themes and sub-themes was developed. The finalized coding framework was subsequently applied to the entire dataset using the qualitative data analysis software, NVivo 10.

Results

The findings are grouped under the broader themes ‘processes’, ‘perceptions’ and ‘barriers/issues’. In this study, respondents’ comments referred to all mental disorders and psychotropic drugs available and used in Nepal.

Psychotropic drug supply chain in Nepal

As depicted in figure 1, according to the respondents, the process of psychotropic drug production starts with the import of raw materials; this is because these materials are not available in Nepal.

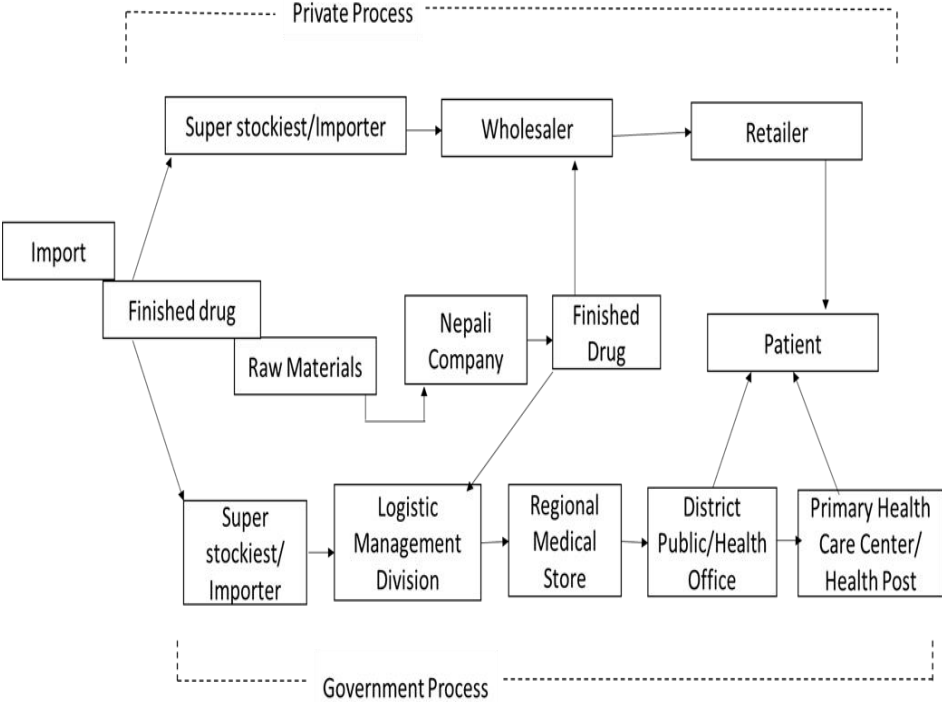


Figure 1: Process of psychotropic drug supply chain management in Nepal

With prior approval from the Department of Drug Administration of the Ministry of Health and Counter Narcotic division in the Ministry of Home Affairs, Nepalese pharmaceutical companies

import raw materials mainly from India. As per the specimen approved by the DDA, Nepalese companies produce psychotropic drugs and send to the wholesalers (also known as stockiest or distributors). For drugs produced outside of Nepal, the company's agent in Nepal (also called a 'super-stockiest') needs to register the imported drugs with the DDA and obtain the approval for the quantity of drugs to be imported each time. All pre-approval documents from the DDA should be submitted to the Ministry of Home Affairs for final approval. In the private sector, retailers place an order with the wholesalers and the wholesalers dispatch the medicine to retailers via transport companies. In the government sector, companies (or their agents, in the case of foreign companies) are selected to provide medicines through a tendering process. The medicines are procured either centrally or at the district level. The district level procurement is small in quantity and is meant to meet the demand of drugs in accordance with patient flow. For the central level procurement, the Primary Health Care Revitalization Department (PHCRD) is responsible for the planning and budgeting of drugs under the free drug list. Some psychotropic drugs are included in the free drug list so PHCRD provides the list of drugs to be procured to Logistics Management Division (LMD), which then procures and distributes through five Regional Medical Stores (RMSs). The RMSs supply the medicines to District Hospitals and the District Public Health Office based on demand. When the medicines are procured centrally and distributed

through RMSs, it is called the "push" system and when the medicines are procured at the district level to meet the increased demand, it is called "pull" system. According to the respondents, the supply chain management process of psychotropic drugs is similar to all other general (non-mental health) drugs, but extra precautions and restrictions are imposed because of the chances of being misused, during import, production, transport, storage and distribution. For example, to limit the chances of misuse, all psychotropic drugs are separated from other general drugs and stored in a locked cupboard to which only authorized persons have access. According to the rules set by the DDA, the psychotropic drugs cannot be sold or bought without prescription. The expired drugs are returned to the company through wholesalers, or disposed of by burning and burying the medicines.

Perceptions on need, quality, availability and use of psychotropic drugs

Table 1 provides a summary of respondents' perceptions per category, while the narrative that follows focuses on overarching perceptions held amongst all respondent categories.

Table 1: Perceptions on need, quality, availability and use of psychotropic drugs

Stakeholders	Need	Quality/ Effectiveness	Availability	Use/stigma
Producers, promoters and distributors	Medicine along with other alternative healing.	Both drugs produced in Nepal and imported from outside are of good quality and are effective.	Available where mental health services are being provided.	There is negative societal attitude towards people who use psychotropic drugs.
Policy makers and government actors	Yes for severe cases only, for other cases as a last resort.	Drugs are of good quality, although people believe that foreign drugs are	Available at the district level where mental health services	There is stigma for people with mental illness which affects the access and use of psychotropic drugs.

		more effective.	are available.	
Service providers	Medicine for severe cases, counseling and other therapy for minor cases.	Some medicines produced in Nepal are of low quality and less effective.	The availability of drugs have increased drastically, but not to all areas of Nepal.	There is not only stigma for those who use psychotropic drugs but also to those who provide mental health services.
Service users and family members	For severe cases only Medicines with other therapies are needed.	Medicines are of good quality and are effective.	Drugs are available at the district or at regional centers only.	There is huge stigma for those who use psychotropic drugs. Consequently, patients and family members try to hide as much as possible.

Need of psychotropic medicines for the treatment of mental health problems

Most of the respondents were of the opinion that psychotropic drugs are needed to treat people with mental illness but that drugs alone were not the preferred treatment. Most respondents emphasized the importance of counseling, a supportive family environment, and other behavioral and psychotherapies along with the medications. A medical doctor from Chitwan said, *"Both counseling and medicine usage are equally important for patients with mental health problems. Patients need counseling about the medicines too"*. A service user from Kathmandu agreed with the notion of an integrated approach by saying: *"other secondary treatment methods like cognitive behaviour therapy and other behaviour therapies should be done. Only taking medicines is not good"*.

The psychiatric nurses were of the opinion that drugs were necessary only for individuals with severe mental health problems. A nurse from Chitwan elaborated this by saying, *"if the problem is psychosomatic then drugs are not required. Counseling and an understanding family are better. But in chronic cases, drugs are necessary. For instance, [cases of] Schizophrenia, MDP (Manic Depressive Psychosis), Severe Depression need medication"*.

Some respondents said that drugs should be used as a last resort when other methods have not worked. This is evident by the following excerpt from a government officer:

"If there is no such environment, or if there is no family or social support, or if the social or family support doesn't help the problem, then as a last resort there is always medication".

The medical representative and psychiatrist from Kathmandu, however, placed emphasis on medication as the primary focus, supplemented by other interventions, such as family support: *"medicine is the most important, followed by family support and understanding"*.

The service users also agreed on the need for drugs but said that doctors prescribe drugs even when there is no need. A service user from Kathmandu said, *"We should definitely give medicines to severe psychotic patients. They [doctors] prescribe medicines for such mild depression also, so that the patients get lifelong dependency [on drugs]. Due to this, the company also has lifelong business and doctors also get more money, this is the situation here"*.

Quality and effectiveness of psychotropic drugs

Nepalese producers reported that their product was of good quality as they are following the WHO good manufacturing practices guidelines and quality checks of raw materials and the finished

product are regularly done. A producer from Chitwan said, "*We have a quality control laboratory too. This lab tests the quality of the raw materials which have been imported or bought.....when the right quantity comes, we check for the right quality as per specification*". Despite this, the prescribers and the general public thought that the foreign drugs are better quality and more effective than those produced in Nepal. A Kathmandu-based psychiatrist expressed a similar sentiment, he said, "*most of the drugs from Nepali companies don't work, but the same drug from an Indian company with the same dose, does work*".

A producer from Kathmandu said that the drugs produced in Nepal are of a high quality and can compete with the drugs imported from outside of the country. He said, "*There is not such difference between the drugs produced here and those imported from abroad, they are similar. We are also able to give better quality*". A Kathmandu-based medical representative also said "*initially medicines from Indian companies were widely used, but these days prescription of Nepalese drugs has increased*".

The service users and caregivers felt that the psychotropic drugs were effective. A service user from Chitwan said, "*I have a positive view regarding it [drug]. The medicine is doing me good*". A similar perception was held by another service user who said, "*my view about the medicine, [is that] it is good. It has cured me. What*

this medicine is doing to others is a different matter. I say that this is doing me good".

A caregiver from Kathmandu had positive remarks on the effectiveness of psychotropic drugs and said, *"The medicine is really effective. If there hadn't been any doctors or medicines...then I would have faced a lot of challenges. I strongly believe that the medicine works and that it should work for everyone"*.

A psychiatric nurse from Chitwan was of the opinion that drugs were effective when taken properly and when other supportive aspects were in place. She said, *"psychotropic drugs work well for patients if they take them regularly... If we can combine diet, counseling and drugs then it helps. There is no benefit if we take psychotropic drugs as a typhoid drug"*.

Though most of the respondents said that psychotropic drugs were effective, the side effects of the drugs were mentioned mainly by service users, care givers, doctors and nurses. According to a Chitwan-based psychiatrist, *"any [psychotropic] medicine might cause a hypersensitivity reaction...for example rashes, flushing, sweating, increased rate of palpitations etc."* Weight gain was another common side effect of psychotropic drugs, as explained by a service user from Kathmandu: *"this medicine has increased my weight, actually I was not this fat. The medicine is making me dull. This is hindering my creativity, and harming my personality"*.

Some prescribers mentioned that the government's free drugs list contains old psychotropic drugs that have more side effects than the new ones available on the market. The side effects of psychotropic drugs were cited by some respondents as one of the reasons for mental health patients discontinuing the medication, and accounts for a higher rate of relapses.

Availability of psychotropic drugs

Most of the respondents were of the opinion that, compared to the past decade, the availability of psychotropic drugs had drastically increased. A psychiatrist from Chitwan said, "*ten years back when I came to Chitwan there were no drugs and it was very difficult....we used to call the company and ask them to bring the drugs....before there was no availability of drugs but slowly now all the medicines are available*". Although psychotropic drugs are not available in large parts of Nepal, the supplementary table shows that there are quite a number of psychotropic drugs available in the Nepalese market, mainly in the capital and regional centers.

Use of psychotropic drugs

The use of psychotropic drugs, especially in rural parts of Nepal, is affected by multiple factors. Some of these factors include low help seeking behavior due to lack of awareness about treatment facilities for mental health, the lack of health workers trained and authorized to prescribe psychotropic drugs, lack of mental health services,

unavailability of psychotropic drugs and stigma associated with mental illness. Mental health problems and the use of psychotropic medications are both highly stigmatized in Nepalese society. Patients often hide and do not disclose that they are taking psychotropic medication. A psychiatrist from Kathmandu shared his experiences, "*patients who have anxiety or depression ... they want to discontinue the medicine as soon as possible. It is because they don't want others to know about their problems and that they are taking psychotropic medicine*". Family prestige and cultural problems in getting children married were some of the reasons for not disclosing mental health problems. "*He [father] then said that if anyone in the village had come to know that she was taking medicines for such an illness, none of the men would have agreed to marry her*".

According to a service user from Chitwan, people in the community dominate and behave badly towards those taking psychotropic medicines, "*their view is, like I can't earn my living. They say that I can't work and earn, I should beg with a bowl. Some of them also say that I am a burden to this earth*".

Due to this high level of stigma, socialization for people taking psychotropic medication is a challenge, as expressed by a service user from Kathmandu, "*right now, I feel good being here [treatment center]. I don't think I will be fully able to socialize outside though. However, I am trying to socialize*". Sometimes,

even when community members are supportive, patients using psychotropic drugs and their family members feel inferior and experience perceived stigma. A caregiver explained: "*I don't have any difficulties but I feel in my heart. Others have not said anything but it breaks my heart that my son has got this problem...*"

Perceptions on barriers to the effective psychotropic drugs supply chain

Table 2 provides the perception of stakeholders on major issues and barriers to effective psychotropic drug supply management in Nepal which is substantiated in the following sub-themes and narratives

Table 2: Perceptions on barriers to effective supply chain management of psychotropic drugs

Stakeholders	Barriers to effective supply chain management of psychotropic drugs
Producers, promoters and distributors	<ul style="list-style-type: none"> • There is market competition. Need to spend money for bonuses and incentives. There is not much profit in psychotropic drugs but there are more hassles in its production, import and record keeping. • The drugs imported by one agent cannot be imported by another despite high market demand for that drug. • There is substitution of drugs by retailers due to higher bonuses and incentives by other companies. • Nepal is dependent on India for raw materials which is a challenge for independent manufacturing of psychotropic drugs in Nepal.
policy makers and government actors	<ul style="list-style-type: none"> • The drugs are prescribed in brand names with the hidden motives for incentives. • The storekeepers at district level have limited knowledge on drugs as

	<p>they do not have medical background.</p> <ul style="list-style-type: none"> • The inappropriate use or misuse of psychotropic drugs could increase if prescription authority is provided to primary health care workers without proper training and supervision. • The supervision and monitoring of psychotropic drugs at the district level is minimal so there are chances of misuse.
<p>Service providers</p>	<ul style="list-style-type: none"> • Old generation psychotropic drugs listed in government's free drug list have lots of side effects compared to the new generation drugs available on the market. • Some patients overdose on the drugs while others refuse to take psychotropic drugs due to side effects. • There are limited health workers in the district who can effectively diagnose and prescribe psychotropic drugs. Many medical officers do not feel confident in prescribing psychotropic drugs. • Patients are sometimes used by drug addicts to get the psychotropic

<p>Service users and family members</p>	<p>drugs.</p> <ul style="list-style-type: none"> • Psychotropic drugs are effective but they have lots of side effects. • Due to stigma it is difficult for patients and family member to share that they are using psychotropic drugs. • Psychotropic drugs are not available at the community level, therefore, patients have to travel far distances to buy the drugs. • Doctors focus more on medication even for cases that could be managed by counselling and other social support interventions.
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Prescribing authority

Among the respondents there were divergent views regarding whether the authority to prescribe psychotropic medication should be given to primary health care workers such as Health Assistants (HAs). Those who spoke in favour of it said that, in many remote areas, there are no doctors and that it is the HAs who provide health services, therefore it would be better to give the prescribing authority to HAs. A district level policy maker from Chitwan said, "*psychiatrists and MBBS doctors are not available in all areas hence up to PHC [Primary Health Care] and Health Post Level, if the HA is provided with the rights [to prescribe] then it would be better*". Those who were in favour for HAs to have the responsibility of prescribing psychotropic medicines stressed the importance of proper training and supervision to avoid misuse and mismanagement.

However, respondents who opposed HAs having these responsibilities thought that if paramedics who have not studied pathology in detail were given prescribing authorities there would be more chance of misuse or inappropriate use. A MBBS doctor said, "*... the ones who study HA they have not studied pathology. On that basis, they should not be allowed [to prescribe]*". A senior psychiatrist was of the opinion that even the MBBS doctors should not be allowed to prescribe, "*I think only psychiatrists should prescribe...even medical officers should not be allowed...people*

buy it as a general medicine...that is not good...we have to consider a lot before prescribing...". On the contrary, a psychiatric nurse said "even a HA can do it if he is given special training and if he is made understood all the things [related to psychotropic drugs]..." Some thought that HAs should not have direct prescribing authority but could be given authority to provide repeat prescriptions. A policy maker from Kathmandu said, "If the drugs have been prescribed by the specialists, then the HAs can follow-up on those cases and dispense the drugs based on those prescriptions".

This shows that the prescribing authority is also a supply chain issue because when primary health care workers are authorized to prescribe psychotropic drugs there will be more demand for such drugs. More drug demand means more stakeholders will be involved in drug production and supply chain. Secondly, besides the service availability and demand for drugs, the prescription authority to primary health care workers will also bring the issue of brand named drug prescription and incentives/bonuses provided by the companies to the prescribers affecting the supply chain cycle for psychotropic drugs.

Practice of bonuses and commissions for psychotropic drugs

The respondents accepted that there is a widespread bonus practice in Nepalese pharmaceutical setting. The doctors are especially lured by companies to prescribe drugs from certain brand names.

According to the respondents, the companies mobilize the Medical Representatives (MRs) to promote the product and to lure doctors and retailers. A psychiatric nurse said, "*we don't have meetings with them [MRs], they meet only the doctors, they give gifts to them and ask them to prescribe the medicine*". A senior psychiatrist admitted that MRs try to influence doctors to prescribe certain drugs: "*before they [MRs] used to influence....but I don't think they have influenced me..... they give us pens, they give pamphlets, they bring calendars....what will they do [give] to us?....therefore I just see the effect of the drug*". One of the producers of psychotropic drugs also admitted to providing bonuses, but said that it is difficult to compete in the market because of high bonuses provided by the multinational companies. He said, "*The biggest challenge for now is 'bonus war'. We are not able to compete in bonus. There are high bonuses from Indian companies*". The companies not only lure the prescribing doctors but also the retailers. In the words of a MR from Chitwan, "*instead of following the doctor's prescription, the companies go to the pharmacy and say, 'we will give one box free [when you buy] 10 boxes', or 'two boxes free [when you buy] 10 boxes' and attract them and lure them*".

The practice of providing bonuses and offering commission is a barrier to the availability of effective drugs as the prescribers and retailers choose only those drugs that provide the most incentives, rather than the drugs that are higher in quality and effectiveness. Some producers reported that if they did not have to invest in

chemists and doctors in the name of incentives and bonuses they would have made a lot of profit. According to them, currently the profit is not enjoyed by the production company but by middlemen (i.e. doctors and chemists/retailers).

Misuse of psychotropic drugs

Misuse of psychotropic drugs was acknowledged by most respondents. However, there were quite different views about who misuses these drugs and where misuse takes place. Some said that the misuse is by the paramedics and general practitioners because they prescribe medicines without having much knowledge about the drugs. A MR from Chitwan said, "*Since the patient gets instant relief, the general practitioners are misusing these drugs [by overprescribing psychotropic drugs]*". In addition, drug addicts approach retailers ask for psychotropic drugs and misuse them. A pharmacist from Chitwan explained the behaviour of drug addicts when they come to the pharmacy, "*if they [drug addicts] come in a black jacket the first time then again after 2 hours they will come in a red jacket, the same guys*". Some retailers provided drugs to addicts out of fear or to make money. A MR explained this by saying, "*some friends are even providing such drugs under the table. As they get certain benefits from the sale of such medicines*". This argument was supported by a Kathmandu level policy maker who said, "*During inspections we found out that those drugs [psychotropic] were misused by some medical shops [pharmacies]*".

However, paracetamol is also misused by some people. So, it is not just the psychotropic drugs. In private pharmacies, if the drug users go to pharmacies and give them extra money, then they will get the drugs without prescriptions. It needs to be monitored more carefully".

Most of the respondents thought that patients also misused the drugs by taking larger dosages than prescribed by the doctor. A psychiatric nurse said, "*.... they take an overdose of the same medicine and die...they think that it is better to die rather than take medicine daily*". According to the pharmacist from Kathmandu, the most commonly misused psychotropic drugs were Nitrazepam, Diazepam and Clonazepam.

Record keeping of psychotropic drugs

Most of the respondents from producer, promoter, wholesalers, retailer and prescriber categories said that they are aware about the record keeping provision for psychotropic drugs in a format prescribed by DDA. The format includes the name of the customer, the name of the prescribing doctor, the dose of medicine, the name of medicine, the date, and the quantity of medicine. There is also a provision that the customer should sign in on the register after they buy the medicines. A pharmacist from Kathmandu said, "*If we sell psychiatric and narcotic drugs, we get a prescription. We have to keep a record by writing the name of the patient and the name of the doctor who has prescribed the drugs*". However, most of the

respondents (wholesalers and retailers' category) admitted that record keeping was not being done properly. The retailers found it difficult to maintain the record keeping for psychotropic drugs; for them it took too much of their time in busy hours. Consequently some of the retailers stopped selling psychotropic drugs. A pharmacist from Chitwan said, "*as much as possible we try to follow that [DDA] format. But if there is a crowd you can see the problem [there is no time for record keeping], we try our best in those situations*". The monitoring mission of the DDA also found that only 50-60% of the pharmacies have completed the records.

Discussion

The majority of the respondents thought that there was a need for psychotropic drugs especially for the treatment of severe mental health problems. However, many respondents also stressed that psychosocial counseling and other social support were equally important for the treatment of MNS disorders. Most of the respondents were of the opinion that the psychotropic drugs available in the Nepalese market are of good quality and effective for the treatment of MNS disorders. The service providers and service users agreed with this argument but also pointed out the many side effects that psychotropic drugs have, especially those enlisted on the government's free drug list. Respondents who spoke about stigma said that there was a negative societal attitude towards

people who use psychotropic drugs and therefore patients and family members try to hide from others that they are using drugs for their mental health problems.

There were diverse (contradicting) views about who misuses psychotropic drugs and where misuse takes place. Some respondents said that paramedics and medical officers with less knowledge of psychiatry misuse drugs by over-prescription. Some respondents were of the opinion that patients misuse by taking over-doses; while other respondents said that misuse happens mostly from the retailer's side as they sell drugs unethically to earn a higher profit. The bonuses and commissions provided by the drug companies to prescribers and retailers were also thought to be responsible for the misuse of psychotropic drugs. In light of these findings, we later discuss issues related to the strict policy provisions but weak implementation, misuse of psychotropic drugs, bonus war, and provide some recommendations to address issues affecting the psychotropic drug supply chain management.

Highly controlled on paper but freely available in practice

Many of the psychotropic drugs are subject to greater control/restrictions due to their potential for abuse [1]. Misuse can cause damage to physical as well as mental health, while inappropriate use can reduce the efficacy of the drugs resulting from non-compliance. In Nepal, compared to general drugs, psychotropic drugs have been highly controlled by law. For

example, article 33 of drug act, 1978 has a mandatory provision of prescription and record keeping for psychotropic drugs[12]. Secondly, not only the Ministry of Health but also the Ministry of Home Affairs is involved in issues related to the psychotropic drugs. Despite these controls, psychotropic drugs continue to be misused [13]. The respondent from the DDA admitted that only about 50-60% of pharmacies have kept some form of record-keeping while, the rest have not done so at all. However, those who do keep records, many are not up to date. The lack of human resources at the DDA and the large number of medical stores to be inspected means that proper inspections are not possible so unethical practices and misuse are on the increase. Other possible reasons for misuse are the lack of implementation of existing regulations, poor quality assurance mechanisms and conflicts of interest between functions of the regulatory body which affect the availability of quality drugs [14]. Our study findings suggest an issue of trust among stakeholders due to the prescribers' and retailers' preferences for brand named drugs, frequent substitution of drugs in the market, and stakeholders' diverse (contradictory) views regarding the quality of drugs produced in Nepal compared to those imported from India. The vested interest and lack of trust among stakeholders are barriers for the smooth and effective supply of psychotropic drugs in Nepal. Similar findings were reported by Brhlikova and colleagues while tracing three pharmaceutical drugs (Rifampicin, Fluoxetine and Oxytocin) in

South Asia. They found that a lack of trust was a key issue that affected how drugs were produced, stored, distributed, prescribed and consumed. The authors also found that despite the Nepalese government releasing guidelines on the ethical promotion of medicines in 2007, the government was unable to instill confidence in the regulatory process. Consequently, beliefs about the effectiveness of the drugs were dependent on individual experiences and relationships rather than the government's regulatory system itself [15].

In the context of increased competition between companies and numbers of pharmacies (retailers) selling psychotropic drugs, it has become a necessity to strictly implement psychotropic drug related policies and plans. The policy provisions regarding psychotropic drugs are promising, but their implementation is very slow. The non-compliance of legal provisions regarding psychotropic drugs is related to under-the-table economic benefits. Therefore, in order to reduce the misuse of psychotropic drugs, monitoring not only by the DDA but also from other professional entrepreneurial bodies, such as the Nepal Drug Dealers Association, the Nepal Chemists and Druggist Association, and the Civil Society Organization is urgently needed.

"Bonus war": A challenge for quality assurance and sustainability
The system of giving bonuses and gifts to prescribers in Nepal has promoted unethical promotion of drugs and tough competition

amongst companies to replace each other's products. The newer companies influence the doctors to prescribe their drugs over others [9]. Prescribing medication is much more than the mere act of writing the name of a drug on paper, it's a social act, showing power and facilitates social control [8]. Therefore, prescribing is affected by the motives of several stakeholders involved in the production and supply chain. The higher percentage of drugs being prescribed under trade names also indicates how bonuses and commission play a role in psychotropic drug supply chain in Nepal. The drug utilization study conducted by Banerjee and colleagues in western Nepal showed that 88.1% of antipsychotic drugs were prescribed by trade names [16]. The retailers and prescribers we interviewed acknowledged that drug companies try to incentivize them in several ways by offering them gifts, free products and travel [9]. Due to these unethical practices, vested interests and influence of several profit motivated stakeholders, the ethical guidelines on drug promotion released by the Nepalese government in 2007 did not yield much positive results [15]. A review of the promotional brochures used by pharmaceutical companies in Nepal showed that brochures did not follow the WHO's criteria for ethical medical drug promotion but emphasized a more commercial motive [17].

Implications

First, like other drugs, the use of psychotropic drugs has been increasing in Nepal despite the negative attitude of the general community towards psychotropic drugs and psychiatric treatment, and the stigma associated with mental illness [18]. Due to fears of social discrimination many individuals and families hide that they are taking psychotropic medicines and sometimes they even discontinue the drugs to avoid stigmatization. Hence, anti-stigma programs at community, district and national levels are needed to give the message that mental health problems are like any other health problem and the use of psychotropic drugs is similar to the use of medicine for any other physical health problems.

Second, in the context of the government of Nepal's policy of integrating mental health into primary health care [19] and psychotropic drugs being included in the Nepal government's free drug list as well as in the WHO's mhGAP intervention, there is a need for better understanding of how the supply chain of psychotropic drugs is managed, what the barriers are and how such barriers could be overcome. Our study findings suggest that the practice of bonuses and incentives in pharmaceutical products is common in Nepal which encourages unethical corrupt practices and misuse. This indicates that if bonuses and incentives could be regulated and misuse of the drug is controlled, then the current price of psychotropic drugs could be reduced. Cost-effective

strategies such as an emphasis on prescribing generic names and quality monitoring from an independent authority [20] could be helpful in ensuring availability of high quality drugs at affordable prices which could ultimately facilitate the roll out of the mhGAP intervention in primary health care. Secondly, for the mhGAP to be adequately rolled out in community settings, there is a need to revise the current psychotropic drug prescribing authority, from medical officers to the primary health care workers. However, this change in prescribing authority should be accompanied with proper training, supervision and monitoring mechanisms to address possible inappropriate use or misuse of psychotropic drugs by primary health care workers.

Third, our study participants suggested that for the treatment of mental health problems not only drugs but also counseling and social support are necessary. This suggests that the stakeholders involved in the supply chain of psychotropic drugs, especially the prescribers, retailers and the patients need to consider carefully whether the drug they are prescribing, dispensing or using is absolutely necessary or whether a combination of drugs and counseling would be a better treatment approach. Previous studies have shown that when essential psychotropic drugs are provided along with psychosocial management strategies, such as individual and family counseling, the treatment becomes effective and thereby reduces disability and prevents relapse [4]. Drug therapy as well as psychosocial support are effective in treating mental health

disorders such as depression, schizophrenia and alcohol dependence [3]. The importance of medication along with psychotherapy in the treatment of mental illness was evident from a hospital based study conducted in Western Nepal which showed that 51% of schizophrenia cases were given both drug therapy and psychotherapy [16]. As drug cycles start with production and end with consumption, it is important to consider the barriers related to the whole supply chain. The study findings suggest that stages such as prescription, dispensing and use of psychotropic drugs need greater attention when designing programs to address the challenges of psychotropic drug supply chain management in Nepal.

Strengths and limitations

The mix of participants representing the government as well as the private sector involved in psychotropic drug production and supply chain management was a strength of the study. However, the number of participants in each group was fairly small, therefore, group comparisons of the views and perceptions of respondents was not possible. The sample included participants from the capital (Kathmandu), a regional center (Chitwan) and a rural district (Pyuthan) so the findings provide information on these three layers which would be important for future program planning and intervention design. However, the findings should be interpreted with caution as the study sample was not proportionate

representation of members from Kathmandu, Chitwan and Pyuthan. In this study, we included all medicines used for mental health problems using the broadest definition of psychotropic drugs. Consequently, the findings from this study give an overview of psychotropic drugs in general and do not provide information on individual medicines used to treat specific disease conditions, such as anti-depressants or anti-psychotics. The decision to include all psychotropic drugs was due to the lack of research on the supply chain management of psychotropic drugs in general and our belief that a broader approach would help design system level interventions to address the issues facing all kinds of MNS disorders and their respective medicines. Another limitation of the study is that due to inclusion of psychotropic drugs in widest sense, the respondents were not specifically asked to differentiate between psychotropic drugs that pose risk for abuse and that do not. So, this study only provides information for the extent of abuse of psychotropic drugs as a bigger category and it does not provide specific details of drugs with and without abuse potentiality. One of the limitations is that the inter-rater reliability was not explicitly considered as all the researchers worked as a team, from the development of topics guides to the finalization of the coding framework.

Conclusions

Except strict pre-approval processes, quantity restriction and provision of record keeping, all other aspects of supply chain management of psychotropic drugs are similar to that of general drugs in Nepal. Generally, the quality and effectiveness of psychotropic drugs were perceived to be good, although some respondents thought that the drugs from Indian and multinational companies were of better quality compared to the drugs produced in Nepal. Despite having side effects, many respondents thought psychotropic drugs were effective for mental health problems. However, some respondents also stressed that psychosocial counseling and other forms of social support are equally important to increase the effectiveness of psychotropic drugs. It was widely accepted by the respondents that bonuses and commissions were prominent in Nepal's drug supply chain which encouraged inappropriate use or misuse of psychotropic drugs. Although psychotropic drugs should be sold only with a prescription, this was often not implemented in practice. The respondents stated that the misuse of psychotropic drugs takes place by prescribers who over-prescribe, by patients who over-dose, and by retailers who profit from illegal sales. The perceived stigma of mental illness forces patients and their family members to discontinue medicines with a fear that others would know. Therefore, both the social stigma towards people with mental health problems and the perceived stigma among those with mental health problems and

their families need to be addressed to ensure effective use of psychotropic drugs.

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CHAPTER 6

Evaluating the integration of chronic care elements in primary health care for people with mental illness: a longitudinal study in Nepal conducted among primary health care workers

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Abstract

Background: Despite many important developments in the global mental health arena in the past decade, many people with mental health problems still do not have access to good quality mental health care. The aim of this study was to evaluate the perceived impact of a mental health care package (MHCP) in integrating chronic care elements in primary health care for people with mental illness.

Methods: A controlled pre-post study design was used in 20 primary health care facilities in Chitwan, Nepal. We compared 10 health facilities that had implemented a MHCP (intervention group), with 10 health facilities that had not implemented the MHCP (control/comparison group) but provided regular physical health services. We administered the Assessment of Chronic Illness Care (ACIC) tool on a group basis within all 20 health facilities among 37 health workers. Data was collected at three time points; at baseline, midline (at 13 months from baseline) and end line (at 25 months from baseline).

Results: From baseline to end line, we see a notable shift in the level of support reported by the intervention health facilities compared to those in the control group. While at baseline 10% of the intervention health facilities had basic support for the implementation of chronic illness care, at the end line, 90% of the intervention group reported having reasonable support with the remaining 10% of the intervention facilities reporting that they had full support. In

contrast, 20% of the health facilities in the control group at end line still reported having limited support for the implementation of chronic illness care, with the remaining 80% only managing to shift to the next level which is basic support

Conclusions: These findings suggest that training and supervision of primary health care workers in the implementation of MHCP interventions can lead to strengthening of the system to better address the needs of patients with chronic mental health problems. However, substantial financial and coordination inputs are needed to implement the MHCP. The control group also demonstrated improvements, possibly due to the administration of the ACIC tool and components of counselling services for family planning and HIV/AIDS services.

Key words: Chronic care, mental health, Nepal, primary health care, health workers

Background

The past decade has seen many important contributions in the global mental health arena, including the Lancet series 2007 and 2011 on mental health, the Inter Agency Standing Committee guidelines for Mental Health and Psychosocial Support in emergency settings, and World Health Organization (WHO)'s Mental Health Gap Action Program (mhGAP) [1]. Despite this progress, globally the gap between the number of people who have a mental disorder and those who receive treatment for their disorder remains high and is commonly referred to as the 'treatment gap' [2]. In low resourced countries the treatment gap is fast increasing to nearly 90% [3]. The WHO's World Mental Health Survey reported that between 76.3% to 85.4 % of severe mental health cases in less-developed countries received no treatment 12 months preceding participation in the survey [4]. One explanation for this high treatment gap is the lack of trained human resources in mental health. A meta-analysis finds that all low income countries and 59% of middle income countries had far fewer mental health professionals than what was needed [5].

To help bridge the treatment gap, a task-sharing approach has been advocated by the WHO, where non-specialist health workers are trained to provide predetermined packages of mental health interventions and counseling under clinical supervision which is provided by mental health specialists [6]. This collaborative care approach involving generalists and specialists can also yield positive socio-economic and health outcomes for people with mental,

neurological and substance abuse (MNS) disorders [7]. The task-sharing approach has been found to be acceptable and feasible when pre-conditions such as adequate training and compensation to primary health care workers, better access to psychotropic drugs and provision of structured supervision are in place [8].

Mental illness often requires chronic care. Therefore, the focus on perceived quality of care from the chronic care model (CCM) is important for health systems to be able to respond to the needs of patients with chronic mental illness and bridge the gap between the provisions of care and need for treatment. Collaborative care does, however, require coordination of care across providers. The collaborative CCM provides a framework for enabling such coordination as well as enabling the health system to respond to both the acute and chronic nature of MNS disorders. In high income countries, these collaborative CCMs in primary health care settings have resulted in positive patient outcomes for MNS disorders [9]. The CCM involves interventions to support patient's self-management, help service providers to make decisions on treatment plans, link patients and family members to available resources in the community, support the design of systems for health service delivery, organizational structures and clinical information systems [10]. Furthermore, the CCM provides practical strategies for integrated mental health care [11]. The review of research evidence shows that redesigning care using the CCM model improves patient care and yields better health outcomes [12], and reduces health care costs [13]. The CCM has been found useful not only for chronic

disease management in primary care but also for the prevention of risky health behaviors which causes chronic illness [14]. Yet, few LMICs have assessed the need for collaborative CCMs for mental health problems, or reviewed the ways in which integrated mental health care can produce a positive impact on supporting the development of collaborative chronic care.

In Nepal, to the best of our knowledge, a CCM has not yet been applied for the provision of mental health care. However, several initiatives taken by non-governmental organizations in mental health and psychosocial training, service delivery, clinical supervision and mental health and psychosocial research show that some components of CCM have inadvertently been applied [15]. One such initiative is the implementation of the mental health Gap Action Program (mhGAP) based mental health care package (MHCP) which focuses on a task sharing approach. As part of the Program for Improving Mental Health Care (PRIME) project, MHCP was developed and implemented in the Chitwan district by Transcultural Psychosocial Organization (TPO) Nepal and Ministry of Health [7]. While this program did not fully implement the CCM, it contained several interventions that promoted the CCM elements such as decision support for service providers, mental health information system, community linkages, and patient self-care.

Study aims:

- To identify the application and gaps in the organization and implementation of chronic collaborative care for priority

mental disorders (depression, alcohol use disorder and psychosis) at the primary health facility level.

- To assess whether the implementation of the MHCP was a feasible and effective strategy for integrating chronic care elements in primary health care for people with mental illness.

Methods

Study design

A controlled pre-post study design using provider self-report on the organization of the health care system according to the elements of CCM was used.

Setting and sampling

The study sites (n = 20) were primary health care facilities in Chitwan, central Nepal.

In 10 health facilities of Western Chitwan the MHCP was being implemented and piloted hence these health facilities became the intervention group by default. For comparison, we needed another 10 health facilities having similar baseline characteristics but being geographically far from the intervention health facilities to reduce the chances of contamination. These 10 health facilities from Eastern Chitwan (i.e. control group) were selected by district based program staff based on travel distance, accessibility, and population density. The control sites were the health facilities where MHCP was planned

to be scaled up following the completion of all the three measurements (baseline, midline and end line) of the study.

The health facilities in the intervention group implemented the MHCP (described in Table 1) for depression, epilepsy, psychosis, and alcohol use disorders during the study period. The health facilities in the control group did not receive any mental health care support during the study period, but provided regular physical health services (care as usual, which included general outpatient consultation for common physical diseases, antenatal and post natal care, delivery services, immunization services, family planning services and the care for HIV/AIDS and tuberculosis). The details of the MHCP has been published in detail elsewhere [7]. A summary of the activities involved in the implementation of the MHCP as they relate to the elements of the CCM, is presented below.

Table 1: Interventions under the mental health care package categorized as per the elements of chronic care model

Chronic care model elements	Interventions under the Mental Health Care Package (MHCP)
<p>Organization of the Healthcare Delivery System</p>	<p>1) Involvement of clinicians, civil society organization and policy makers in the development of treatment protocol for delivery of mental health services; 2) Participatory process of development of mental health training guidelines and accreditation from National Health Training Center; 3) Policy engagement workshops at the national and district levels; and 4) Managerial supervision by District Public Health Office (DPHO).</p>
<p>Community linkages</p>	<p>1) Anti-stigma program, mass sensitization and awareness through radio program; 2) Home based care by FCHVs; 3) Psychosocial counseling by community based counselors; and 4) Use of Community Informant Detection Tool (CIDT) by community members to identify and refer people with mental health and psychosocial problems.</p>

Self-care management support for patients	1) Psycho-education on self-care management strategies, stress and anger management techniques, common side effects of psychotropic drugs and consequences of inappropriate use of drugs; 2) Individual patient goal setting through counseling; 3) Relaxation exercises; and 4) Peer-support.
Decision support for providers	1) Diagnosis and treatment plan flow chart; 2) Checklist for screening suicidal ideation, depression, epilepsy, psychosis and alcohol use; 3) Monthly clinical supervision to discuss on difficult cases; and 4) Provision of phone contacts to psychiatrist and clinical psychologist for consultation of difficult cases.
Delivery system redesign	1) Appointment system for follow up; 2) Defaulters tracking system; 3) Psychotropic drug supply chain system; and 4) System for supervision/onsite coaching and referral pathways.
Clinical information system	1) Out Patient Department (OPD) card and patient register; 2) Monthly data compilation using data from patient registers; 3) Drug quantification, storage, recording and drug demand and supply tracking system; and 4) Integration of mental health indicators into existing health management information system.

Prescribers (primary health care workers such as medical officers, health assistants and community medical assistants) received nine days of training on basic mental health care such as diagnosis, psycho-education, drug prescription and side effect management based on the mhGAP intervention guide [1]. Non-prescribers (such as nurses and auxiliary nurse midwives) received ten days of training on basic psychosocial support and psychosocial intervention protocols such as the brief version of behaviour activation-based Healthy Activity Program for depression [16]; motivational interviewing-based Counseling for Alcohol Abuse disorders [17]. The community-based health workers known as Female Community Health Volunteers (FCHVs) were trained for 2 days on identification and referral of mental health cases using a Community Informant Detection Tool, which is a structured tool for proactive case detection [18, 19]. The FCHVs were also trained on how to conduct community level mass sensitization and anti-stigma programs and how to support families to ensure treatment adherence through home-based care. The MHCP also included psychological treatment, mainly counseling support (healthy activity program for depression and counseling for alcohol problems) provided by community counselors who visited the clients (patients) in the community and provided psychosocial support. Besides the initial classroom based trainings, regular clinical supervision (of prescribers by the psychiatrist, of non-prescribers and community psychosocial counselors by clinical psychologist and of FCHVs by community psychosocial counselor), case conferences (an opportunity to

observe a senior psychiatrist/psychologist seeing the client in front of the prescribers) and provision of on-site coaching during field visits were implemented to strengthen the MHCP.

The policy engagement workshops and group meetings were organized to orient policy makers and planners about mental health in general and the challenges of developing a system of care for mental illness, in particular. The health facility staff (both prescribers and non-prescribers) were trained on how to do mental health record keeping. A separate mental health register was developed and health workers were trained on how to complete those registers.

Instrument and data collection procedures

The Assessment of Chronic Illness Care (ACIC), a quality improvement tool [10], is generally used to evaluate the strengths and weaknesses of delivery of care for chronic illness. In this study the ACIC was used to assess whether the MHCP was beneficial in integrating chronic care elements in primary health care for people with mental illness. The translation of the ACIC instrument from English to Nepali went through several steps of translation and cultural adaptation by a group of bi-lingual researchers. The ACIC is a service provider (health worker) self-assessment tool which consists of 31 items covering the six domains of the CCM, and a separate component to determine the level of integration of the CCM.

Each domain of ACIC is independent from each other and provides specific health system information. The elements/components of the ACIC include: health care delivery system (4 items); community linkages (4 items); self-management support for patients (4 items); decision support for service providers (4 items); delivery system redesign (6 items); clinical information system (4 items), and integration of CCM elements (5 items). The health care delivery system component assesses the perception at the overall health systems components that play vital roles in supporting the system of care for chronic mental illness. Delivery system redesign component assesses the perception at how roles and responsibilities of team members can be reorganized so that they can work at an optimal level. The community linkages component refers to the coordination with community structures in order to help patients and family members access community resources. The self-management component assesses how patients and carers can be supported to adopt healthy behaviors and be acquainted with locally available self-care strategies. The decision support component covers the mechanisms to optimize service providers' knowledge and skills to provide best possible services to people with MNS disorder. The clinical information systems component assesses the perception at how high quality data can be collected and analyzed to facilitate optimal clinical care and follow up. Finally, the integration of chronic care elements considers how such elements can be integrated into routine health service delivery.

Responses to items on the ACIC requires a score between 0 and 11. Scores of 0-2 are categorized as ‘little support for chronic illness care’, 3-5 indicate ‘basic support for chronic illness care’, 6-8 are categorized as ‘reasonably good support for chronic illness care’ and 9-11 indicate fully developed chronic illness care.

One ACIC form was administered per health facility by a team of experienced researchers with university education and training in mental health research, including the use of the ACIC questionnaire. Two health workers (one with clinical experience and another with administrative experience) per health facility provided one response (i.e. group rating) after discussing among themselves and arriving at a consensus rating for each item of the ACIC. Group response is preferred in ACIC because of its advantage of group reflection and representation of a true picture of the health facility [10]. As the care is not provided in isolation but in collaboration, the group rating was used to incorporate everyone's views in assessing the system of care for mental illness in their health facilities and to evaluate whether MHCP improved the system of care for chronic mental illness. The number of health workers in each interview varied depending on availability but, on an average, two health workers provided collective answers per health facility. The types of health workers involved in answering the questions were: Primary Health Care Doctor (medical officer), Health Assistants, Nurse, Auxiliary Nurse Midwives, and Community Medical Assistants. The ACIC was administered three times (baseline in March 2014, followed by midline in April 2015, and end line in April/May 2016).

Data analysis

The ACIC data was collected on paper forms and entered into SPSS. To verify the consistency of the data entered, we performed checks of all entered data by comparing the values with the paper version. To identify the missing values, the frequency table of each ACIC item was examined. The examination of frequency tables showed that there were no missing values. Descriptive statistics were used to calculate the mean scores and standard deviations of each sub-scale. The sub-scales mean for each domain of ACIC were calculated for the six sections of the ACIC and the overall program score (integration of care) for the baseline, midline and end line data. To determine longitudinal change of the ACIC domains, we performed univariate analysis of variance (ANOVA) with repeated measurements. We used Box's M test to correct for deviations of normality and Mauchly's W test to correct for sphericity.

Results

The health facilities in intervention and control groups had more or less similar baseline characteristics as presented in Table 2.

Table 2: Health facility characteristics at the baseline

Health Facility characteristics	Intervention Facilities	Health	Control Health Facilities
Type of health facilities:	Sub-health post= 5 Health post=4 Primary health care center=1		Sub-health post=3 Health post=5 Primary health care center=2
Health workers categories	Auxiliary health worker= 25 Auxiliary nurse midwives=20 Staff nurse= 2 Health assistant=4 Medical officer=3		Auxiliary health worker= 23 Auxiliary nurse midwives=22 Staff nurse= 5 Health assistant=6 Medical officer=5
Average number of patients seen (daily)	Minimum= 33 Maximum=78		Minimum= 35 Maximum=96

Types of health services available	Primary care consultations and medication for skin disease, minor wounds, headache, fever etc. Antenatal, delivery and post natal care; immunization,	Primary care consultations and medication for skin disease, minor wounds, headache, fever etc. Antenatal, delivery and post natal care; immunization,
Availability of specialized delivery services	Number of birthing centers =3	Number of birthing centers =4
Health facility infrastructure	Old buildings=9 New buildings=1	Old buildings=7 New buildings=3

At baseline, there was no visible difference in ACIC sub-scores between intervention and control health facilities, and both groups fell below the threshold for basic support (score between 3 and 5). The highest sub-scale mean score at baseline for the intervention group was for patient support (3.0). For the control group the highest mean score was for delivery system design (3.2).

The ACIC was repeated at 13 months (i.e. midline) to establish whether there was any change in the mean scores after the implementation of the MHCP intervention. From Table 3, it is evident that at midline the intervention group reported much higher mean scores in all six elements of the ACIC. The most notable change being for decision support for service provider component, which saw a change from 1.1 at baseline to 7.8 at midline. For the control group, there was also an improvement in the mean score on all six ACIC elements, the delivery system design component having the highest mean score of 3.9 (compared to its mean score of 3.2 at the baseline). However, the difference in the mean score from baseline to midline for the control group was minimal when compared to the intervention group.

At end line, conducted at 25 months (after two years of MHCP implementation), the intervention group made further progress in all six elements of the ACIC. The most notable change being for the community linkages component which saw a change from 7.1 at midline to 8.5 at end line. The control group also had some improvements in all six elements of the ACIC. The most notable

change being for the decision support for service provider component which saw a change from 1.7 at midline to 4.7 at end line.

Integration of chronic care model elements

The overall score of the ACIC (Figure 1), which reports the extent of support for the integration of CCM elements, shows that the MHCP had positive and significant effects on strengthening elements of the CCM in primary health care facilities providing mental health services compared to the control facilities.

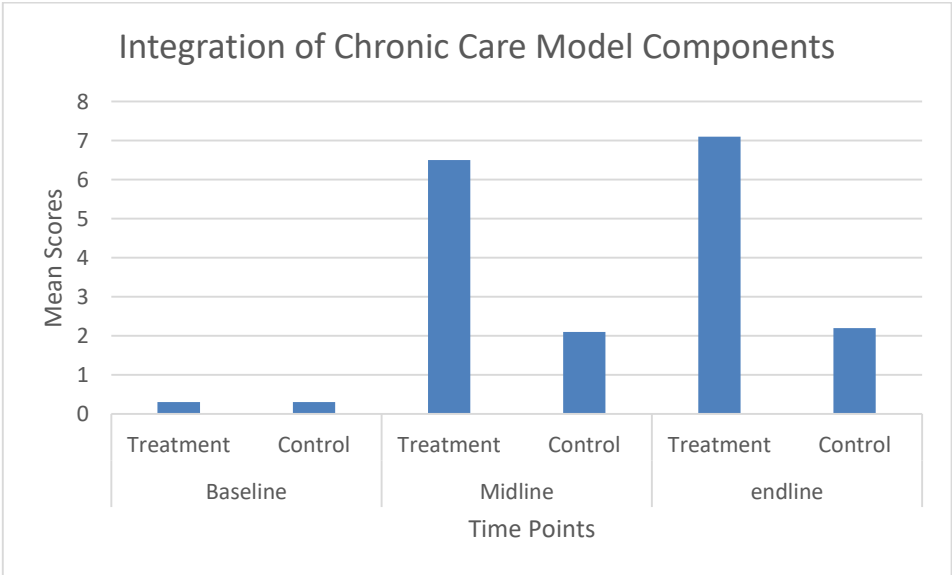


Figure 1: Integration of chronic care model components as a result of MHCP

At baseline both groups scored 0.3 for the integration of CCM elements, which is the lower limit threshold for little support (score between 0-2) of chronic care. These scores indicate that at baseline the health facilities in the intervention and control groups had little support for the implementation of chronic illness care. At midline the intervention group showed remarkable improvements (the mean score changed from 0.3 at baseline to 6.5 at midline) with all health facilities moving from little support to reasonably good support for system of care for chronic mental illness. The health facilities in the control group had some change of scores from baseline (0.3) to midline (2.1) but it was minimal compared to the intervention group; the control group only moved from little support to basic support. At end line, the intervention group showed further improvements in mean score from midline (6.5) to end line (7.1), whereas for the health facilities in the control group, the change was minimal from midline (2.1) to end line (2.2).

When these improvements were categorized as per the ACIC categories (little support, basic support, reasonably good support and full support), using mean of the sub-scale means, it showed that at baseline 90% of the health facilities in the intervention group, and 100% of the health facilities in the control group had limited support for chronic illness care. At end line, 90% of the health facilities in the intervention group showed reasonably good support, and 10% had a fully developed chronic illness care system for mental illness. In the control group, 20% of the health facilities remained in the same category (having limited support to chronic care illness) as in

baseline, while 80% of them moved to the next category (having basic support for chronic illness care).

Table 3 presents the comparison of scores between intervention and control group and demonstrates that a statistically significant effect was obtained for all sub-sections of the ACIC ($P < 0.001$), indicating that the health facilities in the intervention group had made statistically significant improvements in the elements of chronic care service delivery as they pertain to mental illness compared to the control group.

Table 3: System level changes from baseline to end line

Components	Baseline mean (SD)		Midline mean (SD)		End line mean (SD)		ANOVA (df, error time)= F statistic, <i>p</i> -value
	Intervention	Control	Intervention	Control	Intervention	Control	
Part 1: Organization of the Healthcare Delivery System							
	2.4 (1.1)	1.8 (0.6)	6.3 (2.1)	2.5 (1.6)	7.9 (1.1)	3.7 (1.6)	F(2,36)=10.07, <i>p</i> <0.001
Part 2: Community Linkages							
	2.3 (1.6)	1.4 (0.7)	7.1 (1.6)	2.7 (2.3)	8.5 (1.0)	3.4 (2.1)	F(2,36)=11.31, <i>p</i> <0.001
Part 3: Practice Level							
3a: Patient Support							
	3.0 (1.0)	2.6 (0.6)	7.0 (2.0)	3.9 (1.6)	8.1 (1.4)	3.9 (1.1)	F(2,36)=11.58, <i>p</i> <0.001
3b: Decision Support for Service Providers							
	1.1 (1.1)	0.6 (0.5)	7.8 (2.0)	1.7 (1.7)	8.2 (0.7)	4.7 (2.4)	F(2,36)=17.55, <i>p</i> <0.001
3c: Delivery System Design							
	2.9 (1.1)	3.2 (1.2)	7.5 (1.4)	3.9 (2.0)	8.2 (1.3)	4.5 (1.3)	F(2,36)=12.34, <i>p</i> <0.001

3d: Clinical Information Systems	1.8 (1.6)	1.4 (0.9)	7.3 (2.3)	2.7 (1.9)	8.4 (1.2)	2.9 (1.4)	F(2,36)=12.98, p<0.001
Part 4: Integration of Chronic Care Model Components	0.3 (0.7)	0.3 (0.6)	6.5 (2.1)	2.1 (2.2)	7.1 (1.5)	2.2 (1.3)	F(2,36)=16.36, p<0.001

Discussion

The findings show that the MHCP was perceived to have had a positive impact on quality of care systems for chronic mental illness, through the integration of elements of the CCM into routine primary health care. At baseline, health facilities in both groups typically had little support for chronic mental illness care, but after implementation of MHCP, the facilities in the intervention group showed significant improvements on all domains of the ACIC, compared to health facilities in the control group. For example, the higher mean score changes in intervention health facilities shows that essential elements for effective chronic care (such as clinical information system, patient support, decision support for service provider, and integration of care) were strengthened as a result of interventions under the MHCP.

The primary health workers' acknowledgement of greater support for information system showed that training primary health care workers and the availability of mental health registers and proforma indicators improved the patient information system. If the current achievements in the clinical information systems can be sustained, the system will be able to provide quality information that is relevant for policy and practice especially in situations where countries in LMICs do not have reliable mental health information [20].

Another chronic care element that showed a large improvement in health workers' assessment was patient self-care. The higher mean score change in support to patient self-care showed that the

implementation of the MHCP brought about changes in the system of care in relation to how patients were supported at the health facility and linked to the community resources. For this to be sustained, linkages and coordination mechanisms with relevant stakeholders developed through the implementation of the MHCP need to be continued. Cramm and colleagues (2012) in the Netherlands showed that the delivery of chronic care improved due to improvements in coordination among professionals from diverse disciplines [21]. Coordination and collaboration between the health facility and community is vital to address supply and demand issues of mental health care [7]. The findings show that through the MHCP, the system was developed to support the patient self-care component of the CCM. Emphasis on self-care strategies during training and supervision sessions might have motivated health workers to provide information about self-care during interaction with patients. Additionally, regular home visits by FCHVs might have encouraged patients and caregivers to practice better self-care strategies, which are important pillars of a system of care for mental illness.

The higher mean score change for decision support reflects that through the MHCP the system was better organized, and primary health care workers were sufficiently trained and supervised to provide integrated mental health care at the primary health care level based on the CCM model. The availability of mhGAP guidelines in the Nepali language, regular training, supervision and provision of a monthly case conference with senior psychiatrists and psychologists might have helped primary health care workers to make better

decisions in terms of diagnosis, treatment plan, and follow up of patients with mental illness. Sustained improvement, however, will depend up on whether decision support is adopted as part of the integrated support system. The assessment of chronic care for diabetic patients in primary health care settings in South Texas (USA) also found that other aspects of chronic care management needed to be present for the decision support for service provider elements of CCM to be effective [22].

The changes in mean scores for the integration of CCM elements show that at the primary health care level it is possible to develop organizational support structures to assist primary health care workers to provide more holistic integrated chronic care. However, this finding should be interpreted with caution as in this study a fully-fledged implementation of the CCM did not take place, and the assessment only provided the perspectives of primary health care workers on the system of care for chronic mental illness. Nevertheless, the findings show that primary health care workers were ready and willing to integrate the essential elements of chronic care within the existing primary health care. This positive attitude of the primary health care workers opens avenues for the integration of mental health into primary health care in Nepal, including the elements of the CCM [1].

The study also found a trend for positive changes in the control group. The improvements, though small, in health facilities in the control group may be because of some of the CCM components in

physical health programs and the testing effect of ACIC interview process. Although the health facilities in the control group did not receive support as per the MHCP, the usual primary health care for physical health problems was being provided (in both intervention and control health facilities), which had components of counseling, patient information system, inter-sectoral collaboration, and community linkages. The family planning, tuberculosis and HIV/AIDS programs in particular had components of counseling, so the health workers in the control health facilities might have received psychosocial knowledge and skills by participating in the trainings for those programs. The health workers might have applied this knowledge and skills because of the testing effect of the ACIC interview process, which allowed them to reflect on the situation of chronic illness care, identify the areas of improvement and develop collegial relationship by coming up with a group response to ACIC sub-scale items.

Previous studies have found that participatory reflective practice and collegial environments send clear messages to staff about the importance of chronic illness care and thereby, contribute to the improvements in health care practices and patient outcomes [23]. The awareness created by the ACIC interview process among primary health workers about how to make improvements for chronic illness care might have influenced health workers to put efforts in their day-to-day work to improve and this was subsequently reflected in their scoring in midline and end line.

The ACIC is also a useful tool to identify areas that need more focus for improvements [10]. The current study results clearly indicate that in the MHCP, more improvement is needed especially for the system related components of the CCM, such as organization of health care delivery system and delivery system redesign.

Our study also shows that the ACIC tool tailored for the management of mental illness in primary care can be used to assess the level of improvement in quality of care. However, to determine the extent of support for CCM elements in the community and to assess whether care did indeed improve as a result of the intervention, it would be important to administer the patient version of the ACIC tool—commonly referred to as the PACIC, among patients to determine whether the changes in the system have had an effect on their experience of care. This is important because patients and care givers may evaluate the chronic care elements differently to service providers [24]. This study was part of a larger initiative to evaluate the effectiveness of integrating mental health into primary health care. The main evaluation of MHCP is reported elsewhere [26] which also includes patients related outcomes.

The findings show primary health care workers' positive assessment on improvements in chronic care elements as a result of the MHCP. The positive perception and motivation of primary health care workers is a precondition for successful mental health integration in chronic care. The findings derived from ACIC instruments provide useful implementation realities that other LMICs need to consider while implementing MHCP. These findings, however, should be

interpreted in light of substantial financial, technical and coordination inputs provided by the implementing non-governmental organization (NGO), something that might not be feasible for regular government programs. The incentives to health service providers influence their behavior in chronic care [25] so that the sustainability of the achievements gained through the MHCP, would depend on the incentive mechanisms to motivate primary health workers.

Strengths and limitations

A strength of this study was that the ACIC was administered in a group setting allowing for discussion and clarification. The ACIC assessment itself became an intervention as the discussion among the team members helped identify differing views of health workers and explore areas for improvement.

One of the limitations of the study is that due to the transfer of health staffs between baseline, midline and end line, not all the health workers who participated at baseline could take part at midline or end line. Some new health workers who joined the health facilities at midline and end line were included to develop a group response to the ACIC questions. Consequently, the group response might have been affected by the views of the new health workers. Another limitation of the study is that the threshold mentioned in original English version of ACIC might not have reflected the actual threshold limit for Nepali population as ACIC instrument was not validated for use in Nepal.

The possibility of confounders is another limitation of the study as the allocation of health facilities to the intervention and control group was not randomized. All the intervention health facilities were situated in Western Chitwan, and control group health facilities were in Eastern Chitwan, so the control group might be systematically different from the intervention group. Another limitation is the possibility of respondent bias as respondents from the intervention group might be more inclined to give socially desirable responses. In future studies the findings from these ACIC scores could be triangulated with more in-depth qualitative work/ thematic analysis. Another limitation is that the analysis was not controlled for the site characteristics. Likewise, we did not perform a power analysis (eg. sample size calculation) because at the start of the study we lacked essential information to do a reliable power analysis. As this was the first study of its nature in Nepal, we had no indication of the ‘effect size’ of the ‘study intervention’ nor did we have the reference articles to base the sample size calculation and power analysis for this study. Finally, the study has limitations in terms of generalizability of the findings as the data were from only one geographic area (Chitwan district), with a relatively small number of health workers interviewed per health facility. However, this study has novelty as it is the first evaluation of collaborative chronic care for mental illness in Nepal, and its preliminary findings will guide future studies evaluating the process of integrating mental health into primary health care in a low income country setting.

Conclusions

The primary health care workers reported improvements in perceived quality of care systems for mental illness in health facilities that received support under MHCP, compared to those that did not. At baseline there were no statistically significant differences between the intervention and control groups but at midline and end line there was a significant difference in all six elements of the ACIC. Although the health facilities in both groups had improvements from baseline to end line, the health facilities in the intervention group significantly outperformed the control group. This shows that the MHCP (including the training and supervision of health workers) contributed in strengthening the integration of chronic care elements in primary health care.

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CHAPTER 7

Mental health and psychosocial support services in primary health care in Nepal: perceived facilitating factors, barriers and strategies for improvement

*This chapter is based on: **Upadhaya, N., Regmi, U., Gurung, D., Luitel, N. P., Petersen, I., Jordans, M. J., & Komproe, I. H. (2020). Mental health and psychosocial support services in primary health care in Nepal: Perceived facilitating factors, barriers and strategies for improvement. BMC psychiatry, 20(1), 1-13.***

Abstract

Background: The barriers and facilitating factors for integrating mental health into primary health care have been well documented in the literature, but little is known about the perspectives of primary health care workers (who provide integrated mental health care) on barriers and facilitating factors of the health system for scaling up mental health interventions in low and middle income countries. This study aimed to explore these perspectives of primary health care workers within the health system, and identify possible strategies to optimize the integration of mental health in primary health care.

Methods: The study was conducted in the Chitwan district of Nepal with 55 purposively selected primary health care workers representing prescribers (N=35), non-prescribers (N=12) and Female Community Health Volunteers (N=8). Using a semi-structured interview guide, experienced qualitative researchers collected data between September 2016 and May 2017. The interviews were audio-taped, transcribed and then translated into English. The transcripts were coded using Nvivo 10 software and themes were generated for the thematic analysis.

Results: According to the health workers, the facilitating factors for scaling up mental health services in primary health care setting in Nepal included; (1) availability of guidelines, protocols and awareness raising materials, (2) provision of supervision, (3) referral systems being in place, (4) patient record keeping, (5) community

sensitizations and home visits, and (6) provision of psychosocial counseling. The barriers identified included; (1) shortage of psychotropic medicines, (2) lack of private space for counseling, (3) workload and health workers' grievances regarding incentives, and (4) perceived stigma causing dropouts.

Conclusions: The findings suggest that implementation of mental health services through primary health care workers in resource-poor setting is possible when health system level barriers are addressed and facilitating factors are strengthened. In order to address these barriers the health workers suggested a few strategies which included; ensuring dedicated staff available at health facility, allocating dedicated and confidential space for counseling, improving on incentives and motivational benefits to existing health staff, organizing policy level advocacy for mental health, improving medicine supply chain management and strengthening systems for supervision, referral and mental health information management.

Key words: Mental health and psychosocial support, primary health care workers, Nepal, facilitating factors, barriers.

Background

Mental, neurological and substance use (MNS) disorder account for 10.4% of global disability adjusted life years (DALYs) [1]. The global burden of disease study 2015 reported that the depression and anxiety were the third and ninth leading causes of disability respectively [2]. Yet, a small percentage of people who need mental health care have access to mental health treatment, the so-called treatment gap. In low and middle income countries this treatment gap has reached to nearly 90% [3]. A study including 21 countries found that only 1 out of 27 people with major depressive disorder received minimally adequate treatment [4]. To address the unmet need of people with mental health problems, there has been increasing calls to scale-up mental health services which means increasing the coverage of services, the range of evidence-based services and strengthening health systems to facilitate service delivery [5]. In 2008, WHO launched the mental health gap action program (mhGAP) in primary health care to scale-up cost-effective interventions for MNS disorders through the training and supervision of primary health care workers based on a task-sharing approach [6]. This task-sharing approach (mobilizing primary health workers in the diagnosis and treatment of common mental disorders) is perceived to be feasible to implement when other components of service delivery such as supply of drugs, continued clinical supervision by specialists, and clear administrative and governance procedures are put in place [7].

However, several studies also have documented barriers for scaling up mental health services in low- and middle-income countries. Some of those barriers include lack of priority and financial resources for mental health care, absence of decentralization mechanisms for mental health, and the low number of primary health workers trained and supervised in mental health [8]. Other barriers include failure of the primary health care systems to detect people with mental illness, problems in motivating primary health care staff to provide mental health services, the high concentration of mental health services and human resources in tertiary hospitals, lack of mental health and psychosocial interventions in the community and problems providing mental health services at the primary health care settings [9]. Nevertheless, there are also some promising developments for integration of mental health in primary health care in low resourced settings. For example, regular training and mentorship of primary health care nurses in Rwanda and Ethiopia has helped in integrating mental health services at the community level [10, 11]. Similarly, in Nepal, the national mental health policy, Nepal Health Sector Plan and multi-stakeholder action plan for non-communicable diseases, all promote the integration of mental health in primary health care [12].

In the context of integrated mental health care, contrary to disease-focused view, the person focused and population based perspective as suggested by Valentijn and colleagues [39] can link health and social systems, both of which affect/address mental health wellbeing of person and the populations. The decision to access and use health

services is determined by the presence of individual and community level enabling resources [37]. In case of mental health, one of the enabling resources is the organization of mental health care, the way mental health care is organized influences its access and use. Secondly, the health system factors such as health infrastructure, institutional procedures and regulations as well as human and financial resources affect the access and utilization of health services [38].

For our study, the presence of enabling resources at the health facility are the facilitating factors for the integration of mental health into primary health care. Likewise, system level barriers are the lack of enabling resources or lack of their proper management at the health facility. These barriers are responsible for low percentage of realized access (service utilization).

The barriers and facilitating factors for integrating mental health into primary care have been well documented, but mainly at the national level [13, 14]. Little is known about the perspectives of primary healthcare workers (who provide integrated mental health care) on health system level barriers and facilitating factors for scaling up mental health interventions. This information is of critical importance to inform if and how mental health service delivery mechanisms can be scaled up, as these healthcare workers will take on a new burden of care in mental health service provision if a task-shifting approach is used. In rural areas in countries such as Nepal, mental health is highly stigmatized and neglected not only by the government but also by other non-governmental and community

structures [15]. To address this information gap, the present study was guided by the following study aims and research questions.

Study aims:

- To conduct an assessment of health system synergies/implications of integration of mental health into primary health care in low resources setting.
- To identify system level processes, facilitators and barriers for the integration of mental health in primary health care setting.
- To understand interventions/mechanisms put in place to address system level bottlenecks.
- To explore strategies to address barriers and strengthen facilitating factors.
- To understand whether and how integrated mental health services may have increased the burden of care at the primary health care level.

Research questions:

- What are the existing facilitating factors for the integration of mental health into primary health care?
- What are the system level factors or bottlenecks that impede integration of mental health into primary health care?
- What interventions/mechanisms were put in place to address these bottlenecks?

- What are perspectives on whether integrated mental health care has led to a strengthening of the overall provision of chronic care?
- What are perspectives on whether and how integrated mental health services may have increased the burden of care at the primary health care level?

Methods

Study setting and context

Chitwan district is located in Southwestern Nepal. As per 2011 census Chitwan had a total population of 579,984 with 48% male and 52% female. The 27% of the population in Chitwan live in urban areas [16]. Chitwan district is known for its medical facilities, the district headquarter Bharatpur has both government and private hospitals where people from mostly western part of Nepal come for services. Outside of the district capital, however, only government primary health care workers are providing general health services mostly the antenatal and post-natal care, immunization and treatment of common waterborne and seasonal diseases. A community survey conducted in the same district found that 11.2% of the sample screened positive for depression and 5.0% screened positive for alcohol use disorder [17]. Similarly, the health facility based study suggested that nearly 19.6% of females and 11.3% of males had depression [18]. This study was conducted in Chitwan where a district mental health care package was implemented since

2011 in 12 health facilities and scaled-up to all health facilities of Chitwan district in 2016 through a government-NGO pilot mental health project called PRIME (program for improving mental health care) [19], complemented by another project called Emerald (Emerging mental health systems in low and middle income countries)[20]. Through PRIME, three types of primary health workers (prescribers, non-prescribers and Female Community Health Volunteers) were trained on several aspects of primary mental health care. The details of the project components and training programs are published elsewhere [21]. In brief, all health facility staff received 4 days training on basic psychosocial support and stigma reduction while prescribers (medical officers, health assistants and community medical assistants) received additional 5 days training on pharmacological treatment (diagnosis, drug prescription and side effect management) and non-prescribers (nurses and midwives) received additional 5 days of training on specific psychosocial intervention protocols for depression and alcohol abuse. The female community health volunteers (FCHVs) received two days of training on home-based care, mental health community awareness programs, and a community informant detection tool (CIDT) developed for proactive mental health case detection from the community and referral to the nearby primary healthcare center [22-24]. Table 1 provides the types of health workers, training duration and training topics.

Table 1: Training topics and duration

Types of health workers	Training duration	Training topics
FCHVs (female health community volunteers)	2 days	<ul style="list-style-type: none"> ● Anti-stigma program, mass sensitization and awareness raising on mental health and psychosocial problems, referral pathways and available services. ● How to provide home based care for people with MNS disorders. ● How to identify and refer people with MNS disorder with the help of CIDT tool
Non-Prescribers(nurses and midwives)	9 days	<ul style="list-style-type: none"> ● Concepts of basic psychosocial problems and supporting skills. ● Anti-stigma program, mass sensitization and awareness raising. ● Psychosocial counseling-concepts and skills. ● Relaxation exercises and peer support interventions ● Brief protocolized psychosocial interventions such as, Healthy Activity Program (HAP) for depression patients and Counseling of Alcohol Program (CAP) for patients with alcohol problems.

Prescribers (medical officers, assistants and community health assistants)	9 days	<ul style="list-style-type: none"> ● Psycho-education on self-care management strategies, stress and anger management techniques. ● Concepts of basic psychosocial problems, supporting skills and self-care strategies. ● Assessment, diagnosis and pharmacological treatment of MNS disorders as per mhGAP guidelines. ● Common side effects of psychotropic drugs and consequences of inappropriate use of drugs. ● Use of treatment plan flow chart and checklist for screening suicidal ideation, depression, epilepsy, psychosis and alcohol use disorders. ● Monthly data compilation using data from patient registers. ● Drug quantification, storage, recording and drug demand and supply tracking system.
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The Emerald project was implemented alongside PRIME and aimed to improve mental health outcomes by strengthening health system performances specially through capacity building (of primary health care workers, policy makers, researchers and service users/care givers in several aspects of mental health system strengthening in primary health care setting), exploring sustainable financing for mental health, building governance and leadership structures at national and sub-national levels and establishing functional mental health information system within the government's health management information systems.

Sample

All 607 primary health care workers (163 prescribers, 148 non-prescribers and 296 FCHVs) who received training from the PRIME project were eligible to participate in the study because they could provide their experiences and perceptions on opportunities and challenges of scaling up mhGAP based district mental health care package in other districts of Nepal. Of these (607 primary health care workers), the study sample (N=55) was selected purposively, stratified by the above three types of health workers. The prescribers (N=35) included 28 males and 7 females. The respondents for non-prescriber category (N=12) and FCHVs (N=8) were all female as in Nepal these jobs are only for women.

Data collection instruments and process

For each type of health worker, a separate semi-structured interview topic guide was used to collect the information. Based on the literature review and previous study results, the interview guide was first developed in English by the Emerald consortium. The interview guide was translated into Nepali by experienced researcher. Then a group of researchers looked both English and Nepali versions of the interview guide and discussed whether the translation captures the real meaning of the questions. The group made some changes to address the issues related to clarity, relevance and usefulness of the questions. The draft interview guide was piloted with a few health workers in the project location to assess whether the questions are clearly understood or not. After the pilot the language and flow of questions was changed and some probing questions were added. The final interview guide consisted questions related to diagnosis and treatment of MNS disorders, availability of psychotropic drugs, experiences with the integration of new mental health indicators, administrative and logistical challenges of integrating mental health into primary health care, facilitating factors and barriers for scaling up mental health integration in primary health care setting and unintended consequences of adding mental health responsibility to primary health care workers on top of what they are already doing for patients with physical health problems. The data collection took place between September 2016 and May 2017. All interviews were conducted in Nepali and audio-taped by a team of researchers with university level education and minimum two years of experience in

qualitative research. The researchers received training for using the interview topic guides. Each question of the topic guides was discussed among the group of researchers and meaning of each question was explained. Researchers were encouraged to conduct regular self-reflection on their role and critically examine whether knowingly or unknowingly they have influenced the research process during sample recruitment and site selection. They were also encouraged to ask relevant probing questions related to the topic guide, but not to deviate from its overall theme.

Data analysis

The audio-recorded interviews were first transcribed in the original language (Nepali) by the researchers who took the interview. The transcriptions were then translated into English by professional translators and a few sample translations were crosschecked with the original by the supervisor (NU). To identify themes and associated codes within each theme, two researchers from the research team first read and coded 10% of the interviews separately and generated a coding framework for thematic analysis. The two sets of themes and codes generated by two researchers were shared among a group of researchers of the EMERALD project who were familiar with the design of the study and involved in data collection. Based on discussion, the coding framework was finalized and applied to the transcripts uploaded in qualitative data analysis software, NVivo-10. During the coding process in NVivo-10, the themes and codes were further refined and data were summarized and charted. The summary

was exported from NVivo to Excel Spreadsheet and cross-checked for any inconsistencies. When, inconsistencies were found, they were corrected after looking at original transcripts.

To reduce the potential bias of selecting certain types of quotes, two authors (NU and UR) were involved in data analyses which lead to selecting the quotes. We adopted a thematic analysis framework as described by Nowell and colleagues [42] because each stage of thematic analysis establishes trustworthiness. In thematic analysis there are mainly five stages namely familiarization with data set, identifying initial codes, searching for themes, reviewing themes and defining and naming the themes. These stages helped establish trustworthiness of data analysis and interpretation by giving an opportunity to have prolong engagement with data set, sufficient time to reflect on codes/themes and triangulation with data collection modes. These stages also provided opportunities for peer debriefing, researcher triangulation, reflexive journaling, use of coding frameworks, use of diagraming to make connection to several themes. The stages of thematic analysis helped us in determining the hierarchies of concepts and themes, vetting of themes and sub-themes by team members and team consensus on final themes.

Results

The Table 2 provides main result summaries grouped into three themes namely facilitating factors, barriers and strategies for improvement.

Facilitating factors

Availability of the guidelines, protocols and awareness raising materials

The availability of guidelines and awareness raising materials was thought to be a facilitating factor for mental health service delivery as primary health care workers could refer to those documents when confused about diagnosis and treatment procedures. For example, guidelines are available on suicide screening, adverse effect management, treatment for priority mental disorders. A non-prescriber said, *"When we are busy we might forget some of the points [provided during the training] in that case we use those guidelines..... The guidelines help to identify all the signs and symptoms of the person"*.

Although all primary healthcare workers acknowledged the existence of these materials, there were diverse views on their availability, particularly the information, education and communication (IEC) materials for mental health promotion and awareness raising. Some respondents were of the opinion that they were sufficiently available whereas others thought that availability was limited and that this negatively affected efforts to raise community awareness of mental health.

Table 2: Facilitators, barriers and strategies for improvement

Facilitating factors	Barriers	Strategies for improvement
<ul style="list-style-type: none"> • Availability of the guidelines, protocols and awareness raising materials • Provision of refresher trainings, clinical supervision, coaching system • Provision of referral system • Provision of patient record keeping system • Provision of community awareness and linkages 	<ul style="list-style-type: none"> • Frequent transfer of trained staff • Lack of separate space for counseling • Limited number of health staffs/ workload • Shortage of medicines time and again (psychotropic drugs) • Health workers' grievances on incentives/transportation costs 	<ul style="list-style-type: none"> • Develop provisions for dedicated staff available at health facility at all times • Allocate confidential space for counseling • Improve on incentives/motivational benefits to existing health staff to compensate work burden • Organize policy level advocacy for mental health. • Improve overall drug supply chain management

<ul style="list-style-type: none"> • Provision of home based care by FCHVs • Efforts in maintaining privacy and confidentiality. • Provision of psychosocial counseling and other protocolized psychosocial interventions • System level co-ordination • Provision of free treatment 	<ul style="list-style-type: none"> • Defaulters in referral as well as in treatment follow up • Patients not going to the referred places • Stigma for people with mental illness • Lack of data captured in national HIMS • Limited awareness about mental health in the community 	<ul style="list-style-type: none"> • Improve overall training mechanisms and supervision system • Improve the mental health data collection forms (simplifying the language used in the form) • Strengthen the two-way referral system • Increase the engagement of recovered patients and their family member in stigma prevention programs • Focus upon the factors on scale up and sustainability of the program
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Provision of supervision

The provision of regular clinical supervision was perceived to be helpful by all health workers in course-correction and their continued learning. A non-prescriber said, "*We get knowledge on how we should handle cases and if we have missed anything or made any mistakes then we get the chance to learn about it. This [supervision] is very effective*".

During the supervision meetings, the practice of seeing the client in front of primary health care workers was thought to be very effective as this provides opportunity for hands on learning. A male prescriber explained this by saying, "*...the doctor tells us how to diagnose the case, whether we should increase or decrease the dose of medicines of particular cases or not*".

Over time, the supervision system was decentralized from the district to clinical sub-centers, which respondents considered to be beneficial because on site supervision helped to assess the progress in real time and increased the availability of specialist care in primary health care centers, "*This has been helpful because each patient cannot go to Bharatpur [district headquarter], if we conduct meeting in different places, it is easier for them to attend [consultation with psychiatrist]*".

According to the prescribers, the availability of supervisors [psychiatrists] on phone when primary healthcare workers need to consult them further strengthened the supervision system. One of the

female prescribers said, *“In cases where we are confused we can call him [psychiatrist based in Chitwan]. He is available through phone too and he gives us suggestions”.*

Referral system being in place

The formal referral pathway implemented in the district was thought to be a facilitating factor as it provided clear guidelines on how and where referrals can be made. For example, the referral pathway began with the Female Community Health Volunteers (FCHVs) who referred the suspected mental health cases to the primary health care center where the prescribers provided medication and non-prescribers provided psychosocial support. Depending upon the case severity and specific needs of the patients, referral was made to the psychiatric doctors based at district hospital or the community counselors.

There was a widely accepted view among the respondents that the referral system was working well. A prescriber shared his experiences saying, *“It’s very effective. There was one person from Gorkha, her brother was principal of one school in Gorkha but he started drinking from early morning to night. She then brought her brother here and we looked after that case. I thought that the case was little severe and referred it to Doctor [in Bharapur]. Doctor looked at the case and prescribed some medicines. We provided those medicines from health post later. Now that person’s family, everyone is happy with the improvement seen on him. His sister*

comes to us and says that because of our help things are getting better for them".

However, some health workers also said that patients and family members in the beginning complained that the doctors did not give time to referred patients, but that facilitated discussion with doctors and primary health care workers served as a useful facilitating factor to ensure that sufficient care was provided. A male prescriber told: *"at first it was difficult for us to convince them [patients, to seek care]. They used to say: 'why should we go there? We do not have time, money and doctors do not give us time'. Then in monthly meeting we said to the doctors: 'we only send those cases which we found difficult and you have to give them time otherwise it is very hard for us to work at the community level' and then they provided good services to the patients".*

An informal system of back referral took place where the consultant psychiatrist would prescribe those medicines that are freely available at the primary health care facilities and would refer the patients to the health facilities for medicines. Health workers thought this a facilitating factor as patient would not need to spend money to buy the drugs from pharmacy and patients would have more trust on the services provided by primary health care workers. A male prescriber said, *"There are some patients who do not come here and directly go to Bharatpur and Bharatpur hospital refers the patient here".*

Provision of home visits, psychosocial counselling and patient record keeping

Applying home visits by Female Community Health Volunteers (FCHVs) was perceived as helpful as it facilitated treatment adherence by the service users and family members. According to the respondents, the family and community members found it easy to express their problems with FCHVs who were also from the same community. A FCHV said, *“They also said that, they see us (volunteers) as their own family members or their neighbors so they feel easier to share their problems with us.”* The home visit itself turned into an intervention as service users and family members were more cautious with their behaviour and daily practices. A FCHV said, *“those people having severe mental health problems didn't use to obey their family members but as they were informed that we will be visiting them then they have started reducing the consumption of alcohol”.*

The provision of psychosocial counseling within the health facility was thought to be a facilitating factor as it encouraged health workers to reduce the overuse of medication and implement more psychosocial therapies for people with distress related problems. Patients were provided with psychosocial counseling by non-prescribers taking into account the issue of confidentiality. This change was attributed to the increased awareness among the health workers on importance of counseling and other psychosocial support. This was explained by the following interview excerpt of a

male prescriber: *"Before we didn't even have a counseling room. There were problems because of stigma and because we didn't have counseling rooms that time it was difficult to maintain confidentiality. In our health post it's not a problem now. We have counseling room"*.

The focus on privacy and health workers efforts to maintain confidentiality encouraged service users and family members to openly express their problems, without any fear of somebody listening to their conversation. This helped in rapport building, treatment adherence and recovery.

Likewise, the respondents found patient record keeping very useful to complete collected information about the patient and that it was available in a separate mental health register, making it easy to find and use the information during the course of the treatment. A non-prescriber explained why this was useful by saying, *"It is useful because we cannot remember the name of all patients and once we open the register we came to know complete history of that patient with the help of OPD [Out Patient Department] number. It is very good"*.

Community sensitization

The respondents thought that the community sensitization program and home based care helped reduce social stigma and raise awareness about harmful effects of not treating mental illness. According to them, due to this community linkage, the treatment

seeking behaviour improved and more people visited the health post. A female prescriber said, *"We have been able to achieve this because of awareness raised by FCHVs. Because of the FCHVs people with such problems are now coming to health post"*.

The mental health orientation to traditional healers was thought to be a facilitating factor as traditional healers after identifying the sign and symptoms of mental disorders, referred the people to health facility for further treatment. A non-prescriber explained this by saying, *"this program has oriented traditional healers like Dhami, Jhakri of the community as well. Before the implementation of TPO program [pilot mental health project] people used to go to Dhami , Jhakri if they do not have proper sleep, lost the appetite for food, headache; even now though some of the people still practice this behavior but traditional healers send them to the health post which is a great achievement of the program so far"*.

Barriers

Unavailability of trained staff and private space for counselling

Unavailability of sufficient trained health workers in health facility due to their frequent transfers was perceived to be one of the major barriers in mental health service delivery. Legally, the non-prescribers were not authorized to prescribe medication to the patients. Therefore, when there were very few or no trained health workers (prescribers) in health facilities, patients had to be returned

or referred to other mental health service providers. A non-prescriber explained this by saying, *“There are two prescribers now here in our health post. They have received training [mental health] provided by the organization so if they are transferred to some other areas then later, there won’t be human resource who have received such knowledge or who have such experience”*.

In some health facilities, especially those with higher client flow, the lack of private space for counseling was one of the barriers as it was difficult to maintain privacy and confidentiality of patients and family members attending the psychosocial counseling sessions. A female prescriber said, *“If the patient flow is high in the health post and in that condition we have to provide counseling in the OPD [out-patient department] room which is very small and difficult to maintain the privacy of the patient”*.

Shortage of psychotropic medicines

Shortage of medicine came up as one of the biggest barriers as it created mistrust between the health workers and patients/family members. This was explained by a prescriber who said, *“We taught them [patients] to take medicine and provided it free of cost previously but now if they have to buy those medicines they argue with us, so it is being difficult for us to work at the local level”*. The shortage, however, varied across health facilities. The health facilities with higher client flow were the most affected by the stock out of the medicines. Those who spoke about the unavailability of the drugs said, *“It’s really inconvenient for us. There aren’t*

adequate medicines. The patients take around one box of medicine, each time they come here. DPHO [District Public Health Office] gives us two boxes of medicine but the patients in need of medicine are around 60".

Workload and lack of incentives/transportation costs

Workload was thought to be a barrier by some health workers as it gave them extra work and reduced their time for rest. However, the work burden after the introduction of mental health program emerged as a contested issue. Some health workers thought that there was work burden while others said that there was nothing like work burden. Those speaking in favor of work burden argued that mental health patients require more time during consultation so health workers have to work hard to respond to all the patients visiting the health facilities.

A male prescriber alluded, "When patients with mental health problems come, we have to give them time as most of the time they become restless but while we are giving them time, other people[patients with physical health problems]come and disturb and argue with us. So such problem is there. If we try to give priority to these cases, the other person will die as they might be bleeding, or might be in severe condition. It's difficult to manage time".

The lack of sufficient incentives was perceived by some health workers a barrier as it de-motivated health workers to take on extra work related to mental health service delivery. Few health workers

expressed their grievances on the transportation allowances they received during the trainings and supervision meetings. They mentioned that unlike Nepal government's system, from the implementing NGO, they did not receive travel allowances based on the distance travelled.

The health workers perceived the positive response from the community as a good in-kind incentive which motivated them to work better. However, they still expected financial incentives to take on additional responsibility of mental health service delivery, as evident from the interview excerpt with a male prescriber: *"Motivation means refresher training of 1-2 days. We would learn new things and also get incentives. If we get incentives, we would also feel enthusiastic to work"*.

Stigma causing dropouts

The high community stigma towards mental health problems was identified as the key barrier responsible for default and dropouts. A FCHV said, *"Some do not visit health post because of the fear of stigma and discrimination. They feel ashamed to go to health centre since they fear somebody might see them going to health centre for mental health treatment"*.

Stigma (including perceived stigma) was also thought to be a barrier for treatment effectiveness and recovery as people discontinue medicine with the fear of somebody seeing them taking medicine for mental health problems. A FCHV said, *"Though we tell them not to*

discontinue medication, they do not listen to us and do according to their own wish. I don't know whether we are not being able to make them understand or they are being careless?"

Strategies to overcome the barriers

Ensure dedicated staff available at health facility

The health workers were of the opinion that there should be a policy level decision that at least one prescriber need to be available at the health post at all times. A male prescriber said, *"When the DPHO [District Public Health Office] organizes any training, it should be well-managed so that at least one prescriber is present at the health post. They should not be calling everyone at the same time"*.

Some of the respondents also suggested that among the trained primary health care workers, one health worker should be appointed as mental health focal person to support and monitor mental health service delivery. A male prescriber said, *"A focal person should be appointed separately for mental health. If focal person is not appointed by the central level then nobody would work properly. Appointment of the person should be in written form otherwise nobody would fulfill the responsibility"*.

Allocate dedicated and confidential space for counselling

Separate counselling space was suggested by the respondents as a strategy to ensure the privacy and confidentiality of the patients and

their family members. Respondents thought that a dedicated space for counseling would be important for quality psychosocial support as counseling involves intense conversation upon personal issues and problems, that the patients would not want to disclose in public. A non-prescriber said, *“We need medicines, and also we need counselors. We need counseling room as well because of the issue of confidentiality”*.

Improve on incentives and motivational benefits to existing health staff

Health workers were of the opinion that as they were doing extra work for mental health component, the government should consider providing them some financial incentives. A male prescriber said, *“if health workers are doing an additional work not considering even day and night and providing services to the people, they must get some benefits in return like some extra facilities which also include the incentive part as well”*.

For FCHVs the issue of incentives was more of an issue as they were volunteers themselves and had to do more work for mental health. One of the FCHVs expressed this by saying, *“We have to spend a lot of time while dealing with one client. When we go to visit some person's house, it takes 2/3hours for counseling the client.....Therefore, we also feel discouraged to work sometimes since we are not getting anything. Sometimes I feel, I simply wasted my time like” Raat bhari karayo dakshina harayo” [literal*

translation: shouted all night long and lost the collected alms, meaning worked hard all day long but did not get anything].

Organize policy level advocacy for mental health.

For the sustainability of the program the health workers were of the opinion that there should be strong policy advocacy to ensure that government takes the responsibility of implementing mental health programs in primary health care. A male prescriber elaborated this by saying: *"This program [pilot mental health project] will not be effective until it is circulated [included] as one of the prioritized national level program in the policy. Planners and policy makers play a vital role in changing the whole system so they are responsible to bring a change in the field of mental health".*

Some respondents suggested having more involvement of patients and family members in mental health training and advocacy. A FCHV suggested, *"It would be more effective if patients and family members of patients are also provided training on mental health and make them understand about the disease".*

Improve medicine supply chain management

Health workers suggested setting the minimum criteria for keeping the stock of medicines. They also suggested that the exact quantity demanded by the health facilities should be supplied to avoid the problem of stock out. An information system of drug demand and drug availability needs to be implemented as mentioned by the male prescriber who said, *"Prior information should be given. Health post*

has to check the stock timely. The health post should be informed about the stock of medicine". Some of the health workers thought that the whole system of drug supply chain needs to be improved because the unavailability of medicine was not only in the health facilities but also at the district level. A prescriber said, *"When there is no medicine, we have to go and get it. But when we go there [district public health office], it is not available there also".*

Improve supervision system

Some prescribers expected more case discussion during supervision meeting but they did not get as expected. *"Supervision system is all right not perfectly well done; discussion part is found less".* Some respondents wanted more discussion on new and difficult cases. This sentiment was represented by a prescriber who said, *"In that [current] supervision people discuss about the old cases and that's not helpful at all. We should discuss about new cases, about cases that's confusing so that we can correct ourselves, we can learn from it".*

Most of the health workers suggested for monthly supervision, rather than once in two months. A non-prescriber said, *"What I feel is that it must be done in monthly basis like before. We have many other works also so we may forget the cases if we wait for two months for sharing".* The on-the-spot supervision of each health facility was suggested by some health workers. For example, a female prescriber said, *"If they [supervisors] can come to each of our health post and*

look at our cases and provide us feedbacks then it would be even better".

Improve the mental health data collection procedures

Some health workers suggested including follow up cases *"It would have been better if we have included the total number of male–female for follow up for each disorder because there is not always the new case. So in new HMIS it must be added"*. Some others thought that the format of the HMIS form could be similar to the Tuberculosis and leprosy forms. A male prescriber said, *"Data of male and female is clearly mentioned in the present HMIS. However, it should be like the data of TB and leprosy where we can see the treatment outcome and find out whether the patient has completed the treatment or not. If we make it similar to leprosy and TB [forms] we can find out how many people got treatment services and out of them how many cases were defaulter and left the treatment. If we do like this, it would be easier for us to analyze the annual data"*.

Strengthen the referral system

The respondents suggested that the current referral system can be strengthened by making greater coordination with the psychiatrists at Bharatpur Hospital and instituting the process of back referral (referral from Bharatpur Hospital to Primary Health Care Facilities). A prescriber said, *"They [patients/caregivers] complain that they did not find the doctor in the place where we had referred the patient. Therefore, coordination has to be increased I think. The*

relationship should be strengthened so that there won't be problem in referral".

Discussion:

This paper explored factors that affect the implementation of mhGAP based mental health services in primary health care setting in Nepal. The findings indicate that primary health care workers were generally supportive to the components of a newly introduced mental health care package and identified both facilitating factors as well as barriers and provided suggestions on how such barriers could be addressed. Below we discuss main findings and their implications to scaling up mental health services in primary health care setting of low resource countries like Nepal.

The provision of regular training and supervision by the specialists resulted in learning and continuous capacity building opportunities among the primary health care workers. Contrary to one-off trainings the approach of refresher trainings and regular supervision provides the opportunity to practice, ask questions to clarify confusions and get support from specialists to deal with the difficult cases. This builds up the primary health care workers' confidence in the diagnosis and treatment of common mental health problems. The importance of regular training and supervision in maintaining quality of mental health and psychosocial services is well documented in the literature. For example, in Rwanda the training

and regular mentorship of primary health care nurses along with system based improvements was found to be a potential model of integrating mental health into primary health care [10]. A model of decentralization of mental health care was implemented in Ethiopia where nurses were trained and supervised to provide drug prescription as well as initiated community based mental health activities on awareness and education [11].

Our study, however, shows that the full potential of the trained health workers could not be utilized due to frequent transfer of primary health care workers. As a result of transfer system, there was double loss as health workers who were trained in mental health got transferred to other health facilities which did not have mental health services so they could not practice the knowledge and skills they learnt during training and supervision provided by the specialists. This also created capacity crunch at the health facility from which the trained health workers were transferred and replaced by new health workers who did not receive mental health training. This is only a problem now as the integration of mental health care in primary health care has not been rolled out yet across the country. Once, it is done, the staff turnover is not so much of a problem as people transferred from one health facility to the next would be able to practice their knowledge and skills in delivering mental health services. The transfer system was a barrier for providing MH services because mental health training of the new health workers was not always possible due to financial constraints and as a consequence there was more workload for the remaining health

workers. A similar finding of high staff turnover was reported in a study conducted in Africa and Asia, including Nepal [14]. Some of those trained health workers also travel out of the district for official work, training, workshops and sometimes are on long leave, leaving behind a vacuum for the delivery of mental health services. When patients come with expectation of treatment and do not find trained health workers, they lose trust with health facilities and do not return again for mental health services.

The issue of trust in services was clearly impacted by the frequent stock-out of psychotropic drugs in some health facilities. Even after several visits, the patients could not get psychotropic drugs. This resulted into frustration and therefore patients did not return to the health facility. The supply of psychotropic drugs itself and lack of storage facilities were thought to be the challenges in the stock-out of psychotropic drugs. Other studies in Nepal also report unavailability of psychotropic drugs in health facilities [12, 25, 26]. All these findings indicate that there is a need to strengthen overall psychotropic drug supply chain from the national to the health facility level. At the health facility level the delivery, storage and distribution aspect of psychotropic drug supply chain need strengthening. The system of buffer stock at the district level could be one of the options to address the stock-out of psychotropic drugs at the health facilities. The information system on psychotropic drugs demand, supply and availability needs to be further strengthened by a sound monitoring system that collects data on the several levels of the psychotropic drug supply chain and analyzes

data to improve the distribution of psychotropic drugs to health facilities based on the available stock, the client flow and drug demand.

The availability of guidelines, treatment protocols and IEC materials in Nepali language facilitated health workers' effort in providing mental health services. Often in developing countries there is lack of mental health documents published in the local language so the primary health care workers have to refer to documents in English. But, due to limited English language proficiency many primary health care workers do not manage to learn from English documents. Therefore, availability of mental health related documents in Nepali language was a facilitating factor to improve the knowledge, skills and expertise needed to provide better mental health services. Similarly, they felt comfortable educating the patients about mental health because of the pictorial posters, charts and banners available in local language. The availability of culturally appropriate materials in local language was thought to be crucial for addressing stigma and mental health treatment gap [27]. However, our study showed that only availability of the materials did not increase the use of the materials, especially when health workers were not motivated to provide mental health services due to lack of sufficient incentives.

Some health workers thought that after the introduction of mental health services in the health facility, they had to do additional work so they should be compensated through financial or non-financial benefits. The issue of workload came frequently during the interview

which suggests that it might affect the helping relationship between the health workers and people with MNS disorders. Hence, to improve mental health care relationship, there is a need to embrace the quadruple aim of health care as suggested by Bodenheimer and Sinsky [40]. The quadruple aim added one more component (improving the work life of the health workers) to the already existing triple aims (enhancing patients' experience, improving population health, reducing cost). Earlier, triple aim was thought to be the best framework to assess health system performance. But, lately, scholars argued that the fourth aim is a foundational element which helps other aims to be realized [41].

Past studies have also documented the issue of workload. For example, the health workers work burden was one of the main challenges experienced while developing a district mental health care package in Nepal [25]. Similarly, another study from Nepal showed that task-shifting in mental health risks over-burdening the health workers and therefore calls for compensation for all those involved in task-shifting [28]. Therefore, certain level of incentives might need to be put in place. Examples of such incentives could be, improving working conditions, providing financial incentives, social acknowledgment and providing opportunities for career development as suggested by a systematic review on health workers' motivation in low and middle income countries [29]. Improving work environment for health workers and providing an opportunity for them to find joy and meaning in work will, therefore, contribute in achieving the triple aim of health system performance [41], which

will ultimately contribute to integration of mental health into primary health care. Provision of connecting primary health care workers with community structures through community linkages, referral pathways, defaulters tracking system and home based care helped bridge the gap between demand and supply side of mental health service delivery. The engagement of the community and their participation in the detection of potential mental health problems and referral to the nearby health facility was found to be feasible and effective in a study conducted in Chitwan district of Nepal [22-24]. When mental health is integrated in primary care, linkage with community based services is necessary because it aids early identification, referral to appropriate service providers for treatment and community level post-treatment follow up. The study findings also suggest that the macro (system level), meso (organization level) and micro (clinical level) model of integration suggested by Valentijn and colleagues [39] might be helpful in addressing barriers and strengthening the facilitating factors for mental health integration in primary health care setting.

Regular community engagement and educational programs also help in reducing stigma related to mental illness [30]. Despite reduction of stigma due to community mental health awareness program, mental illness is still stigmatized in Nepali communities. In Nepali society mental illness is directly attributed to the “broken mind” and its treatment is thought to be only for the so called “mad people”.[31]. The social stigma was the main factor preventing people from visiting the health facilities for mental health treatment

and follow up. Health workers attributed the increased dropout of mental health service users to stigma associated with patients of mental health problems and their families. A qualitative study from Nepal also showed that stigma and negative cultural norms were responsible for reduced access and demand for mental health services [32]. Along with other anti-stigma programs, the involvement of recovered patients and their family members in mental health awareness raising and advocacy could help bring positive mental health reforms as it did in Zambia [8].

A functioning information system to document patients' demographic and treatment records, stock of medicine and incoming and outgoing referrals was found to be a facilitating factor for integration of mental health in primary health care. Patients' record keeping has enabled the health workers to understand the pattern of symptoms among the patients and eventually track the progress of the treatment process, follow up procedures as well as stock of medicines. However, just setting up information system does not guarantee its success. For example, currently the information is collected at health facility and shared at the district level to report to the health management information system. But, the analysis of the data at the health facility level is rarely done to reflect on trend of patient flow, referrals, treatment adherence and drop outs/defaulters and develop appropriate corrective actions. The flow of data goes only upwards to report the performances as opposed to be used at the health facility level using data driven continuous quality improvement. The quality and usefulness of the system largely

depends up on its proper implementation and maintenance [33]. Therefore, the focus needs to be on the analysis and use of the data at the point of collection [34].

Integration of psychosocial support and counseling in the primary health care facilities contribute to the effects of the treatment of common mental disorders and prevention of day to day distress of patients and family members. However, the lack of private space for counseling in some health facilities compelled health workers to provide counseling services in several open spaces where the privacy and confidentiality could not be ensured. The counseling intervention requires a healing environment that comprise of activities, systems and physical setting [35]. Only a private, safe and pleasant space can provide such healing environment which is a prerequisite for effective recovery from mental illness. A previous study in Nepal has also documented positive results of combining psychotropic medication and counselling services for a complete recovery of people with mental health problems [36].

Strengths and limitations

The strength of the study is that it includes the perspectives of all three categories of primary health care workers involved in mental health service delivery, so the findings are representative for the development and strengthening of the multi layered provision of community based mental health and psychosocial interventions in districts where tertiary mental health services are available. However, the findings cannot be generalized for other rural districts

of Nepal because Chitwan district is much advanced in terms of the availability of mental health care where tertiary care is available from government and private hospitals and primary mental health care is being made available through PRIME project. One of the limitations of the study is that the researchers were from the same organization that provided the mental health training and other mental health system strengthening support, so this might have influenced the primary health care workers to provide socially desirable answers. The research team, however, tried its best to minimize the respondent bias by explaining them that it is not the evaluation of health workers' performance rather the research team was interested to hear the perspectives of health workers on what went well and what did not and what needs to be done in future to improve on the issues/ components that did not go well.

Conclusions

Factors supporting integrated mental health service delivery included availability of protocol and guidelines, provision of regular training, supervision and coaching system, established referral system, system for patients information management, the component of community engagement, provision of home based care and follow up, the provision of psychosocial support along with drugs and various level of coordination with government, non-governmental and community structures. In terms of barriers, health workforce related barriers included the frequent transfer of trained

health workers and arrival of new health workers without mental health training. Patient level challenges included the drop outs, defaulters and not going to the referred places. There were also challenges in terms of private space for counselling, stock of medicine and use of mental health information to improve the quality of mental health services.

To address the barriers for integration of mental health services in primary health care, the strategies suggested by the respondents included; policy advocacy, provision of dedicated space within health facility for counseling services, provision of buffer stock for psychotropic drugs, regular refresher training, clinical supervision and financial benefits to the health workers, strengthened referral pathways, defaulters tracking system, home visits and supervision and feedback system.

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CHAPTER 8

Service user and care giver involvement in mental health system strengthening in Nepal: a qualitative study on barriers and facilitating factors

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Abstract

Background: Service user and caregiver involvement has become an increasingly common strategy to enhance mental health outcomes, and has been incorporated in the mental health policies of many developed nations. However, this practice is non-existent or fragmented in Low and Middle Income Countries (LMICs). Instances of service user and caregiver involvement have been rising slowly in a few LMICs, but are rarely described in the literature. Very little is known about the context of user and caregiver participation in mental health system strengthening processes in a low-income, disaster- and conflict-affected state such as Nepal.

Methods: This study explores (a) the extent and experiences of service user and caregiver involvement in policy making, service planning, monitoring, and research in Nepal; (b) perceived barriers to such involvement; and (c) possible strategies to overcome barriers. Key Informant Interviews (n=24) were conducted with service users and caregivers who were either affiliated to a mental health organization or receiving mental health care integrated within primary care. Purposive sampling was employed. Data collection was carried out in 2014 in Chitwan and Kathmandu districts of Nepal. Data analysis was carried out in NVivo10 using a framework approach.

Results: The involvement of service users affiliated to mental health organizations in policy development was reported to be

'tokenistic'. Involvement of caregivers was non-existent. Perceived barriers to greater involvement included lack of awareness, stigma and discrimination, poor economic conditions, the centralized health system, and lack of strong leadership and unity among user organizations. Increased focus on reducing public as well as self-stigma, improved policy frameworks and initiatives, and decentralization of care are some strategies that may facilitate service user and caregiver involvement.

Conclusions: The study highlighted need for user and caregiver networks free from competing interests and priorities. Improved policy frameworks and decentralization of care may support meaningful service user and caregiver involvement.

Key words: Service user and caregiver; patient involvement; stigma; empowerment; Nepal.

Background

Involvement of service users and caregivers, mainly in advocacy, service planning, service monitoring, and research, has been promoted globally as a strategy to help bolster health and quality of life of service users by improving their mental health. It is also advocated as a method to overcome human rights violations, systematic disempowerment and marginalization of persons with mental disabilities[1-3].The term "user and caregiver involvement"

has become a buzzword that has been embedded in the policy and guidelines of many High Income Countries (HIC)[4-7].

In HICs the service user and caregiver movement stems mostly from dissatisfaction with a paternalistic medical model of care that views patients as passive subjects unable to make their own decisions [8]. Another driver has been the development of consumerist notions of health care that have brought about increased choices and voices for service users [8, 9]. Various theoretical models and frameworks have been used to conceptualize and shape the involvement of service users and caregivers in health services. Arnstein's "ladder of citizen participation" describes different degrees of participation in terms of different rungs, with citizen control at the highest rung followed by delegated power, partnership, placation, consultation, informing, therapy, and finally manipulation at the lowest [10]. Similarly, Choguill's ladder of participation in Low and Middle Income Countries (LMIC)[11], and Hickey and Kipling's participation continuum also explore the extent of service user involvement in decision making [12]. Charles and DeMaio offer a three-dimensional framework that describes the key aspects and goals of lay participation in health care decision making [13]. A more recent model of user involvement, proposed by Tritter and McCallum [14], uses the image of mosaic tiles to represent the complex and dynamic relationships between users and other stakeholders in the involvement process.

The meaning and language of user involvement have also evolved and varied over the years. Rogers and Pilgrims described different conceptualizations of users based on their involvement: 'users as patients' (a traditional view where users are viewed as passive recipients of services), 'users as consumers' (where professionals view users not as objects but as consumers having power to make choices and provide opinions), 'users as survivors' (where users campaign collectively for their human rights), and 'users as service providers' (where users are involved in service delivery and service development) [15].

While the practicalities of achieving involvement of service users and caregivers are still being deliberated, the importance of such involvement for better mental health care outcomes and responsive health systems is now well recognized [16, 17]. Although limited, previous literatures have highlighted the relevance of service user and caregiver involvement in policy making [6], service planning and delivery [18-20], evaluation [21, 22] and research [23-25]. User and caregiver involvement in mental health is deemed crucial, as service users and caregivers are most able to understand the realities of life of other service users and caregivers, for example, with respect to stigma and discrimination, livelihood challenges and economic constraints [26].

The World Health Organization (WHO), in a seminal report [3], lauded the role of consumer and family movements in positively influencing mental health policies and practices. Such involvement

is considered to be especially important in LMICs where weak national mental health systems are pervasive [27, 28]. The importance of user and caregiver involvement was reinforced by the endorsement and ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which calls for equal and full participation of persons with disabilities, including those with mental health conditions, in treatments and in the development of mental health laws, policies, and programs [29].

Despite such high level endorsements, the practice of user involvement in mental health care processes is mostly restricted to HIC [2, 18], whereas in LMIC, it is mostly non-existent or weak and fragmented [30, 31]. Instances of service user and caregiver participation have increased over the years in LMIC with the formation of users' networks, groups, and organizations, as is seen in some African nations such as Uganda, Zambia, Kenya, and Tanzania [32]. However, initiatives of such groups are rarely described in the literature [33]. There are very few studies that delineate the extent and modes of such involvement in LMIC, and even though service user and caregiver involvement is touted by many governments and organizations, examples of best practices remain scattered. As a consequence, very little is known about effective ways to promote service user and caregiver involvement in mental health policy-making, planning, service monitoring, research and evaluation.

In Nepal, service user involvement, mainly in mental health promotion and advocacy, has recently received a boost through the establishment of national level service user organizations [34] and through the signing of UNCRPD and its optional protocols by Nepal in 2008 [35]. However, the experiences of service users and caregivers with respect to involvement, their achievements and struggles, and their views regarding effective ways to promote service user and caregiver involvement remain undocumented. This paper aims to assess the experiences and challenges of service users and caregivers regarding their involvement in mental health system strengthening processes in Nepal, including policy development, service planning, monitoring, and research, and to identify effective ways to enhance service user and caregiver involvement in system level processes.

Methods

Setting

This qualitative study is part of the Emerald programme (Emerging mental health systems in low and middle- income countries) that is being carried out in six countries: Ethiopia, India, Nepal, Nigeria, South Africa, and Uganda. Emerald seeks to identify key health system barriers to, and solutions for, the scaled-up delivery of mental health services in LMIC, and by doing so improve mental health outcomes in a fair and efficient way. One of the thematic areas of the project is to empower, equip and facilitate the

involvement of service users and their caregivers to support mental health system strengthening [36].

This study was carried out in the Kathmandu and Chitwan districts of Nepal. Service users and caregivers affiliated to user and caregiver organizations were mostly based in Kathmandu. Chitwan district was selected as a second site in order to understand the perspective of grassroots level service users and caregivers from rural populations who have no affiliation to user networks or organizations. In Kathmandu district, participants for the study were approached through service user or caregiver organizations, while in Chitwan district, service users seeking mental health services integrated into primary care as part of the Programme for Improving Mental Health care (PRIME)[37, 38] and their family members were recruited.

Sampling and data collection

Our study applied purposive sampling. A total of 24 Key informant interviews were conducted, with the sample comprising service users who are referred as self-advocates affiliated to mental health organizations (n=7), caregiver representative of a mental health organization (n=1), mental health service users not affiliated to any organizations (n=7), and the latter's caregivers (n=9). Seven participants were from Chitwan (4 males and 3 females) and 17 were from Kathmandu (13 males and 4 females). The number of years our study participants had been using mental health services

(medicine and/or counseling) since 5 years (n=9), 1-5 years (n=5), and below 1 year (n=6), while others (n=4) declined to provide the information.

Data collection was carried out in 2014. Prior to the data collection, the research team (comprising of 6 members) received a one week training that included familiarization with the research design, research objectives and ethics, translation of the topic guides from English to Nepali, contextualization into Nepali culture, and interview role-plays.

Semi-structured Key Informant Interviews (KIIs) were conducted in Nepali language. The Interview schedule consisted of demographic information and a topic guide that covered service user and caregiver involvement in four major areas of system strengthening processes: (a) policy making, (b) service planning and development, (c) monitoring, and (d) research. Researchers were mobilized in pairs to conduct face-to-face interviews. Responses were mostly audio-recorded and, in cases where consent for audiotaping was not given, responses were noted manually.

Data Analysis

A framework approach was used for the analysis of the data [39]. The audio-recorded interviews obtained through KIIs were first transcribed. The transcribed data, along with the manually recorded

notes, were then translated into English and crosschecked against the original by the research supervisor.

For the development of a coding framework, two researchers first read and coded 40% of the data separately and identified an initial set of codes and emergent themes. These two separate sets of codes and themes were then compared with each other and discussed among the research team. Based on the discussion, a coding framework was generated, discussed, and finalized. QSR NVivo 10 software was used for indexing and charting of the data.

Results

Current situation of service users and caregivers' involvement

Participants indicated limited involvement of service users in policymaking processes and almost non-existent involvement in other areas of national health system processes (i.e. planning and service development, monitoring, and research). For caregivers, representation or participation in any of the national health system processes was non-existent. Involvement in such processes seemed a foreign idea to many of our study participants, especially among those living in rural areas. They did not understand the meaning of mental health planning and policies, and were unaware of how or why such processes took place. Most participants however, showed interest in taking part in such processes if given opportunity and training.

Any involvement of service users in policy level processes was limited to those affiliated to service user organizations in Kathmandu. However, they too reported that they were being ignored in important decision-making processes most of the time.

"Although there are many programs being organized for policy making, we are not invited. They know we exist, but they don't invite. There are few of us and our voice is not heard. We don't get to participate in the policy drafting." (Service user organization representative, Kathmandu, 34, Female)

The service users who were involved in some of the government policy programs viewed the quality of their involvement as poor. These service users mentioned that although they were invited to group discussions and consultations, they did not have any direct involvement in decision making and reported dissatisfaction with this degree of participation.

"Yes, although they invite us, they don't make us fully participate. For instance, during the drafting of the latest mental health bill it was said that there was some participation of service users. But they never gave those participants chance to express their view. They only used their name. That's why I am saying there is no meaningful participation" (Service user organization representative, Kathmandu, 35, Female).

A service user expressed that such tokenistic involvement had caused service users to be treated as “non-essentials” by the government, as well as by Non-Governmental Organisations (NGOs),

"It is [a] use and throw concept, where service users are called to participate showing token benefits and once they come to the program, they are disregarded. There is no sustainable enrollment." (Service user organization representative, Kathmandu, 33, Male).

In terms of involvement in monitoring of mental health services, the participants voiced that they had no idea about monitoring mechanisms of the government for mental health and, even if such mechanisms did exist, they were not involved. With regard to research, some participants shared that their experience of involvement was limited to that of being research participants. They complained that they were not contacted again after the data collection process and so were not aware how the data were used.

Barriers to involvement of service users and caregivers

Table 1 provides a summary of the barriers experienced by service users and care givers and the strategies they have suggested to facilitate their involvement.

Table 1: Summary of barriers to involvement and strategies to facilitate involvement

Barriers hindering involvement in national health system **Strategies to facilitate involvement processes**

<i>Lack of awareness and information</i>	<i>Raising awareness</i>
<ul style="list-style-type: none"> - Lack of awareness regarding the 'why' and 'how' of involvement among service users, caregivers, and policy makers - Lack of confidence to participate due to lack of information - Ignorance among policy makers that leads to failure to prioritize mental health 	<ul style="list-style-type: none"> - Use of media: documentary/drama, street-plays, posters, pamphlets, radio, TV programs, billboards - Incorporation of mental health issues in school education - Interpersonal interactions among community members - For policy makers- interaction with service users/caregivers, field visits to health centers, awareness workshops

Stigma and discrimination

- Service users and caregivers feel humiliated and don't want to identify themselves or become involved due to stigma
- No space in government positions for service users
- Psychiatrists unwilling to work with service users on equal grounds

Poor economic conditions and competing priorities

- Focus on earning a living, so no time to spare for involvement
- Expectation of free treatments and medicine, involvement in income generating activities rather than system processes

Reduction of stigma

- Through awareness-raising, education, employment opportunities, quota for government positions
- Getting rid of discriminatory words such as 'service users' and 'service providers'

Formation of service user and caregiver groups at grassroots level

- Bottom-up approach: service user/caregiver groups should be established in villages
 - Supports involvement of service users/caregivers from rural areas
-

Centralization of national health system processes

- No access to system strengthening processes for those living in rural areas; health system processes mostly take place in major cities

Lack of strong leadership and unity among service user community

- Disjuncture among service users representing organizations
- A sense of competition among service user organizations

Capacity building

- Training should be conducted by the government
- Training should address basic knowledge of mental illness, its types, and treatments, mental health systems and system strengthening, their needs and roles of service users/caregivers

Selection of representatives

- Selection to represent the population from grassroots level
 - Representation of all demographic, economic and geographical groups needed
-

Methods of involvement

- Conflicting views regarding selection of representatives
 - Lack of consensus on how/to what extent service users should be involved in policy development
 - Involvement should take place at different levels of policy making
 - Monitoring: formation of monitoring committee with service users, caregivers, service providers, government employees as its members
 - Research: involvement mainly in data collection
-

Awareness and information

Lack of education and awareness, compounded by poor economic conditions and being from a rural region, were cited as barriers that hindered users and caregivers' involvement in system strengthening processes. Participants mentioned that these factors lowered their confidence and increased their feeling of inferiority.

"It's scary for a person from a village to go to the city. I think people who live in the city are clever. I fear they will shout at us without really listening." (Non-affiliated service user, Chitwan, 55, Female)

"An uneducated person won't know anything. The educated person can talk and contribute. They [policy makers] will listen to the things said by the educated people." (Non-affiliated service user, Chitwan, 45, Female)

While this was more apparent among study participants from rural parts, where the majority did not have higher education, it was also cited as a barrier by educated participants, as they did not know where to go or whom to meet. They felt that they were ill-equipped to participate in such processes due to lack of technical knowledge about processes relating to policy making, monitoring and evaluation, research designs, and international laws.

Lack of awareness amongst policy makers themselves was cited as a distinct barrier to involvement. Participants suggested that

because policy makers are uninformed about mental health issues and the need for service user and caregiver involvement, they are unable to prioritize mental health in government health strategies or initiate any policy processes to aid user and caregiver involvement. In addition, lack of awareness was also cited as the main driver of stigma towards service users among policy makers.

Stigma and discrimination

For many study participants, their desire to participate in system level processes was overshadowed by their fear of stigma and discrimination. They mentioned that there was no incentive to identify themselves or work in this sector; instead of ‘glory’ or ‘support’, they reported receiving only stigma and discrimination. Due to the presence of stigma in the community, the study participants argued that service users and caregivers feared identifying themselves as people with mental disability.

“They don’t come out due to stigma! How would you identify them? How would you bring them in front? To be honest, these family members of the service users don’t want to be involved at all due to stigma. They say that they don’t know about such problems. They don’t want to get attached to this issue. Due to the stigma, the whole family becomes humiliated and so I don’t see the family members coming forward.”(Service user organization representative, Kathmandu, 32, Male)

The paucity of involvement of service users was also attributed to the stigmatizing attitudes of government and health personnel in the predominantly biomedical health care model. Service users claimed that the government mostly involved psychiatrists to make key policy decisions and felt reluctant to involve service users because psychiatrists viewed service users as their patients and not as equal partners capable enough to work together on the same level: *"There must be some ego issues regarding the power. Or they don't want to change their orthodox view thinking we can't do anything. They don't see the patient as person."*(Service user organization representative, Kathmandu, 35, Female)

Although the government in its recent initiatives acknowledged the need to involve service users, the study participants remarked that service providers and policy makers refused to do so on equal grounds.

"The service providers want to form policies and develop services and seek our token support. They are the ones to decide whether they want to involve us or not. They expect our support but they want the power [to make the decision] too. If they can't create the environment where people sit on equal ground and look straight at each other, then my argument is for whom are they developing their services and programs?"(Service user organization representative, Kathmandu, 33, Male).

Economic condition and competing priorities

Due to poor economic conditions among service users and caregivers, their first priority was to meet the basic needs of the family. Their need, therefore, was for free treatments and medicines, and income generating activities, rather than involvement in system strengthening processes. Participants mentioned that they had to earn their living and so did not have time or money to spare to go to the cities where most of the system level processes took place.

Centralized national health system processes

Centralization of health system processes was recognized as one of the factors limiting access to participation, as most service users live in rural areas while such processes take place in cities such as Kathmandu. *"If I am the service user at the grassroots level, I don't even have the access to the district development level. How can a service user like me have access to the national level?"*(Service user organization representative, Kathmandu, 35, Female).

Some participants reported that the appointment of the Director for the only mental hospital in country as the *de facto* focal point for mental health by the Ministry of Health and Population (MoHP) and lack of district level mechanisms for mental health had resulted in most of the government's initiatives taking place in Kathmandu. The aspirations of service users and the principle of the centralized

mental hospital were at odds, making it difficult for service users to form good working relationships with the mental hospital.

“It is very difficult to build ‘working together relation’ with Mental Hospital in our country. It is because community based mental health does not agree with some of the things in the management of Mental Hospital. So, there is no working together relation.” (Service user organization representative, Kathmandu, 32, Male)

Leadership and unity

The study participants acknowledged that they lacked strong leadership and unity in the service user and caregiver community in Nepal. This was perceived to have inhibited the possibilities of involvement in health system processes, since a collective voice cannot be heard and collaborative work is not common. The disjuncture among service users, especially among those representing different organizations, has allegedly led to disagreement among the small number of service user advocates.

“...Most organizations think that they are the pioneer organizations in this field and everyone should listen to them ...The service users working as advocates feel that they are the only ‘survivors’ and they should be [present] everywhere...They don’t respect each other and they cannot come together.” (Service user organization representative,

Kathmandu, 44, Male)

Some participants hinted that a sense of competition among service user representatives and advocates has led to some of the upcoming service user advocates being ignored by those already established in the field.

"Our organization is not fully established. We are opening a new organization and we need support....But we do not have any knowledge regarding these things. I personally feel that since I started this organization, we have been ignored. We have been told by few others in this field that other organizations are marginalizing us. I even didn't know about the issue of the new policy. I knew only after someone told me that the new policy has been circulated."(Service user organization representative, Kathmandu, 33, Female)

Strategies for increased involvement

Raising awareness

The study participants claimed that improved awareness among service users, caregivers, policy makers, and the general population is needed to foster a suitable environment for their involvement. As mentioned in table 1, involvement of media was thought to be an important method to educate people in the community. Some of the study participants suggested that incorporating mental health topics

in school education would raise awareness in a cost-effective manner. Some also recommended personal means of raising awareness such as interpersonal interactions with neighbors and friends that would help build friendship and promote support among service users.

The participants argued that changing of attitudes was essential for government officers and policy makers as well. They thus proposed awareness classes, field visits (to mental health clinics), and interaction with service users and caregivers to foster greater understanding.

Reduction of stigma and discrimination

The majority of study participants focused on reduction of stigma and discrimination as a major strategy to facilitate user and caregiver involvement. Raising awareness in the community and at the government level was a recurring theme in comments on how to deal with stigma, along with education and employment opportunities for service users, and opportunities to apply to government level positions. Another means of reducing stigma mentioned by some service user representatives and advocates was getting rid of the concept of "service user" and "service provider," as these terms- as well as their equivalent Nepali words '*sewa grahi*' and '*sewa pradayak*'- induced a sense of hierarchy and prevented doctors and patients from standing on equal ground. They proposed that 'survivors' or 'advocates' would be a more fitting term than 'service users'.

"The term of service users alone is stigmatizing. There is a notion of hierarchy in it with the provider as an authority. The identity that you give them after a couple of interactions makes them detached with you. This is the reason why the drop-out rate is high after certain time."
(Service user organization representative, Kathmandu, 33, Male)

Formation of service user and caregiver groups at the grassroots level

Building close-knit service user and caregiver groups in the community was encouraged, as it was assumed to serve as self-help groups, work as advocacy groups, and help to identify representatives for involvement in system strengthening processes. Some caregivers believed that through such support groups, even those residing in rural areas could be involved in system strengthening processes. Participants suggested that the grassroots organizations and the government could conduct meetings at the local level to consult with such groups regarding their issues, views, and suggestions pertaining to mental health plans and policies. They suggested that this would help service user and caregiver groups to contact their local political party members or parliament members and communicate their grievances, issues, and concerns so that these could be relayed to policy makers and government officials at central level.

Capacity building and training

It was emphasized that the best possible way of building capacity of service users and caregivers was for the government to conduct training. Service users complained that although they had participated in training programs, none of the training was conducted by the government. Therefore, participants recommended that such training be conducted by the government using its own training tools, in order to make the government more accountable, and the training, more sustainable. The areas for capacity building and training underscored by study participants are highlighted in table 1.

Representativeness in selection

There was a lack of consensus among study participants regarding selection of service user representatives. Some study participants, mainly caregivers and non-affiliated service users from Chitwan district, mentioned that those with chronic or severe mental illness would not be able to participate and so those having mild form of illness such as general anxiety and depression should be selected as representatives. However, service users working as advocates claimed that there should be representation of all types of mental illness as different types of mental illness are associated with different issues.

Knowledge and experience regarding the system strengthening

process were also set as key criteria for selection of representatives. Study participants put forward strong views regarding representation of all demographic, economic, and geographical subgroups of service users/caregivers, particularly poor people from rural areas. For example, one caregiver cautioned,

“The one who is from the rich family perceives mental health differently than the one whose economic condition is low, and the one who cannot afford for his medicines. The issues of both the groups should be addressed properly and representation should be done from all sectors... We should not involve only selected service users whom we already know. Representation of all should be there.”(Non-affiliated caregiver, Kathmandu, 28, Male)

Methods of involvement

Most service users affiliated to an organization argued that greater involvement in drafting of policy and their inclusion in drafting committees was a must to make their participation more meaningful. Some caregivers and service users, however, differed in their opinions. They believed that service users and caregivers should be involved, but not directly:

“Rather than involving them directly in the policy making, what we can do is, in a loose forum we can discuss a questionnaire which can address their problems. They can

give their view on it. Service users won't be making the policy but at least we can take their view in the policy making. We can take loose data from them and 'concretely and strategically' develop the data into policy."(Non-affiliated service user, Kathmandu, 29, M)

Some conceived that service users should be involved only in later phases because a working committee (consisting of individuals selected to draft policies) should have 'expert stakeholders' who are experienced, while participants from rural community believed that policymaking was the role of the government and policymakers, and that they should be the ones making the policies instead of service users and caregivers.

Discussion

This study set out to explore experiences of service user and caregiver involvement in national mental health system strengthening processes and assess the barriers to, and strategies for, facilitating such involvement. The findings of this study show limited involvement of service users and caregivers in policymaking and health system strengthening processes in Nepal. Framed within Arnstein's ladder of involvement, in policymaking, service users were *informed* and/or *consulted* on the draft policies. Service user involvement in Nepal, although present, is mainly limited to service users affiliated to organizations.

For caregivers, involvement in national mental health system strengthening is simply non-existent. This could be because both service providers and service users consider the caregiver's role to be 'less important and realized' [40]. Nevertheless, the importance of caregiver involvement has been highlighted[3, 17, 41]. Caregivers are a vital part of the service system and often have different viewpoints from those of service providers and service users [42]. A study conducted in Iran showed that caregivers could become effective case managers when provided with training[43]. This study also shows the need for governmental and non-governmental organizations to take the initiative in promoting caregiver involvement in health system processes along with that of service users in Nepal.

Levels of involvement varied among non-affiliated service users and users affiliated to mental health organizations. The service users affiliated to mental health organizations, who also tended to be based in the capital city, reported more experiences of involvement compared to non-affiliated service users from rural areas. Building user groups and networks at village and district levels, as suggested by study participants, could be one strategy to involve other interested service users. Studies conducted in other countries also show that building user and caregiver group networks is necessary to support collective user action (for example, see [6, 14, 44]). However, some study participants warned against '*NGO-isation*' of such groups and networks as this might alter the objectives and priorities of the organizations to compete in

the donor driven market. The limited number of service user organizations, mostly concentrated around major cities and vying for increased funding and recognition, appeared to lead to narrow representation of service users and their issues at the grassroots level. This may be one of the reasons underlying the sense of mistrust and reservations towards NGOs repeatedly expressed by our study participants. Although NGOs have played a pivotal role in advocating for the rights of service users in mental health and lobbying for their involvement, the lack of consensus among NGOs has been identified as a key challenge to development of the mental health sector in Nepal [45]. Hayward and Cutler[46] also warn that competition and mistrust among NGOs is a major barrier to grassroots civil society. In contrast, grassroots groups such as self-help groups, with broader representation from mental health service users and caregivers, have been shown to foster empowerment, reduce stigma, and create a favorable environment to advocate for the rights of service users [47].

Among the most recurrent barriers to involvement mentioned were low economic status and lack of awareness, information, and education. The majority of study participants from rural areas mentioned that economic constraints and accompanying time constraints were major barriers to becoming involved or to being interested in participating in system strengthening processes. Our participants' demand for financial incentives resonates with findings of McDaid's study [48], which indicated that disparities in economic resources between service users and other participants in

mental health policy and planning processes was one of the major barriers to equal participation of users. This suggests organizations and government that plan to engage service users and caregivers may need to provide stipends or other forms of economic support [49-51].

Internalized self-stigma and within-group stigma among the service users and caregivers was also reported by participants in our study. Some believed that users with severe mental illness would not be able to participate and hence should not be selected as representatives, and some even stated that they themselves would not be able to contribute much in the system strengthening processes due to their illness. This may be, to some extent, due to self-stigma among service users, although this was not overtly expressed. Self-stigma has been linked with lower levels of empowerment and fear of disclosure among service users [52]. Nepal's government has tried to promote inclusiveness and tackle stigma through the creation of a disability quota for government positions. However, due to stigma, persons with mental disabilities fear disclosing their disability, and thus are often unable to compete for employment through the disability quota. This situation illustrates the complexity of confronting stigma and discrimination; in the anti-stigma programs of the government and mental health organizations, it is essential to address not only public stigma but also self-stigma. Highlighting the stories of service users who have disclosed their mental health problems and giving examples of their roles in system strengthening processes might be one effective

strategy. Diversity and representativeness in service user involvement is a long standing issue that has been discussed in previous studies [18, 53]. Our findings too indicate the need for increased diversity among service user representatives in terms of types of illness and demography. Decentralization of mental health services and promotion of community-based care could provide additional opportunities for service users from diverse demographics to participate in local processes. Community participation in decision-making, user empowerment and self-help, and a focus on public needs have been emphasized as characteristics of community based care [54]. With the decentralization of power to communities, the voices of different community groups can be heard and a collective agency can be established to deal with problems [27]. Similarly, integration of mental health into primary health care systems could also ensure some level of representativeness at local level by involving service users in the existing management committees of the primary health care centers. As integration of mental health in the public health system is being initiated in some districts by NGOs and government [34], it is timely to consider ways of adapting approaches to service user/caregiver involvement to facilitate effective integration and strengthen the national mental health system.

Government initiative to reform policies was mentioned as another strategy to support service user and caregiver participation. Existing national documents on mental health refer to partnership

among the government, International NGOs, and researchers, but do not mention involvement of service users and caregivers [55, 56]. Many of our study participants complained that they had been invited to participate in trainings and research programs run by NGOs, but never in government-led programs. This lack of governmental initiatives to involve service users and caregivers and exclusion of this issue in policy documents contrasts with health sectors such as Human Immuno-deficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) and tuberculosis, where service users are considered to be important actors of system development, and their inclusion is not only emphasised in policy documents, but also practiced [57, 58]. This could be a result of high prioritization of these problems by the government in its national health strategy, and due to the existence of dedicated centers for these problems in the MoHP. Mental health, by contrast, lacks a separate unit in the MoHP, and there is ambiguity in the appointment of a focal point for mental health related activities, due to which any effort to coordinate with the government has resulted in confusion among mental health civil societies [34]. The establishment of a coordinating body has been suggested as a way to facilitate the role of mental health NGOs in Nepal [45], and this may also help service users and caregivers to raise their issues directly with the government.

Limitations

Findings of this exploratory study reflect the views of a relatively small group of service users and caregivers and therefore may not be representative of the entire user and caregiver population of the country. This is mainly because there are very few service user organizations and caregiver organizations, and a limited number of user and caregiver advocates working in Nepal. Use of convenience sampling may have led to participants who were more outspoken and easily accessible being represented in the study. This study also addresses the issue of service users and caregiver involvement in system strengthening processes in Nepal through the perspective of service users and caregivers only; to provide a complete picture of the issue, further inquiry is necessary with multiple stakeholders including policy makers and service providers.

Conclusion

This study shows that meaningful involvement of service users in Nepal is lacking, while involvement of caregivers is simply non-existent. Among service users, experiences and attitudes towards involvement varied between those who were non-affiliated service users and those affiliated to mental health organizations. Self-stigma and within-group stigma, although not mentioned explicitly, was a recurrent theme in the data collected and is one of the major barriers to their involvement. Establishment of user and caregiver

networks free from competing interests and priorities (such as those faced by NGOs) was underscored as a strategy to enhance involvement. Improved policy frameworks and improved initiatives (such as those that have been implemented for HIV/AIDS in Nepal) and decentralization of care may support meaningful service user and caregiver involvement.

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CHAPTER 9

Epilogue: Key findings/learning from Nepal for strengthening mental health systems in low and middle income countries

Background

The chapters in this dissertation explore the strategies for strengthening mental health systems within and outside the responsibility of the Ministry of Health (MoH) by using the building blocks of the World Health Organization (WHO) Health System Strengthening (HSS) conceptual framework. In this concluding chapter, I synthesize the findings of the different studies on strengthening mental health systems in Nepal and discuss how insights/findings from this research can be used as a model for strengthening mental health systems in other low and middle income countries.

This dissertation attempts to answer the main research question, “What are the challenges and opportunities for mental health system strengthening in the context of low resource settings like Nepal?” The chapters in this dissertation are organized according to the WHO Health System Strengthening (HSS) framework which consists of six building blocks; (1) health financing; (2) health information; (3) service delivery; (4) medical product vaccine and technologies; (5) health workforce; and (6) leadership and governance.

This dissertation has 9 chapters. Chapter 1 provides an overview of literature on mental health system strengthening organized as per the six health system building blocks. Chapter 2 presents the situation of mental health and psychosocial support in Nepal and describes the role of non-governmental organizations in mental health system strengthening and service delivery, especially during conflict.

Chapter 3 provides the mental health system governance matrix based on Siddiqui's Health System Governance Framework [1] and explores the policy level challenges and facilitating factors for mental health system strengthening in Nepal. Chapter 4 provides a situation analysis of mental health data collection, compilation, analysis and use for policy and practice in six low and middle income countries including Nepal. Chapter 5 explores the perspectives of stakeholders involved in the supply chain management of psychotropic drugs, including people involved in the production, manufacturing, procurement, import, transport, storage, prescription, administration and uses. Chapter 6 explains how the regular training and supervision of primary health care workers on mental health contributed to strengthening the integration of chronic care elements into primary health care. Chapter 7 explores the real life challenges faced by primary health care workers in providing mental health services through primary health care facilities. In particular, it explores the system level facilitating factors and barriers for the scaling up mental health gap action program (mhGAP) based district mental health care package. Chapter 8 provides the perspectives of mental health service users and their caregivers on their level of involvement for mental health system strengthening in Nepal. Chapter 9 (this discussion chapter) reflects on how mental health systems can be strengthened in low resource settings like Nepal and provides key actions of policy and practice relevance.

The chapters included in this dissertation are based on research studies that were part of a multi-country mental health system project known as ‘Emerging Mental Health Systems in Low and Middle Income Countries’ (Emerald) (<https://www.centreforglobalmentalhealth.org/emerald-emerging-mental-health-systems-in-low-and-middle-income-countries>). The Emerald project had several thematic work packages; 1) coordination and collaboration, 2) mental health capacity building of primary health care workers, service users/care givers, policy makers, planners and mental health researchers, 3) identifying health system resources and financial mechanisms to support universal coverage for persons with a mental health disorder, 4) identifying policy and system level barriers for the integration of mental health into primary health care, 5) development and implementation of an information system for mental health within the government Health Management Information System (HMIS) and 6) dissemination and publication of study results to relevant stakeholders at the community, district, national and international level. In this concluding chapter, first, I will briefly summarize the mental health system strengthening efforts in Nepal carried out by Transcultural Psychosocial Organization Nepal (TPO Nepal) in collaboration with the Ministry of Health (MoH) through two research projects called “Emerging Mental Health Systems in Low and Middle Income Countries (Emerald) and the Program for Improving Mental Health Care (PRIME). Second, I will highlight key findings from the research in Nepal that can be used for strengthening mental health

systems in other low and middle income countries. Third, I will discuss and reflect on possible modifications of WHO's Health System Strengthening framework.

Strengthening the Mental health system in Nepal based on outcomes of the EMERALD and PRIME research projects.

During the implementation period of both the EMERALD and PRIME projects several efforts contributed to the strengthening of mental health systems in Nepal. These efforts and their outcomes are presented below and are discussed for each of the six building blocks of WHO HSS model using the following format: 'what was done', and 'what was learned'.

Building Block: Service Delivery

What was done? As described in chapter 6, the mhGAP based district mental health care package (MHCP) was implemented in the study area. The MHCP included pharmacological treatment, psychosocial counseling support, protocolized psychosocial interventions, and home based care and community awareness. To facilitate mental health service delivery, a treatment protocol was developed through a process of stakeholder consultation. In addition, to increase early identification and timely referral to the primary health care facilities, the community informant detection tool (CIDT) was developed, tested and used [2]. To trace the defaulters, a follow up defaulter tracking system was developed and

used by Female Community Health Volunteers (FCHVs) during the community awareness sessions and home based care (Chapter 7).

What was learned? First, the findings from chapter 6 indicate that the mental health service delivery mechanism should involve both community systems for initial impetus of service seeking and later on continued medication and follow up, with health services starting from village health workers to specialist mental health service providers. Mental health service delivery is a combined task and can best be performed when these community and health systems are well connected and communicate on a regular basis. Second, the clear role division among the three cadres of community health workers (prescribers, non-prescribers and FCHVs) facilitated service delivery with no confusion of “who does what”. However, communication among these cadres sometimes created problems, as patients referred by FCHVs could not be attended by the prescribers or non-prescribers because of their workload/or absence (Chapter 7). Third, the home based follow up care provided by FCHVs showed positive results in terms of treatment adherence and regular health facility visit. This shows that with minimum training and a small incentive package, appropriate home based care for mental illness can be provided in the community (Chapter 6 and 7). Fourth, almost all the Non-government Organizations (NGOs) in Nepal depend upon external funding which are mostly of short duration so there are issues with the sustainability of the services initiated by NGOs (Chapter 2). Therefore, the provision of counseling services by NGOs-employed community counselors was challenging in terms of

their sustainability after the phase out of the NGO supported project. Hence, organizations trying to integrate psychosocial counseling and other psychosocial support interventions need to advocate for positions within the government structures. Fifth, the involvement of community members and community linkages through the anti-stigma program, the radio-based awareness program, the home-based support by FCHVs and use of the CIDT tool were helpful not only during the treatment but also during the recovery phase as they helped in facilitating community support for people with mental, neurological and substance abuse (MNS) disorders and their families (Chapter 6).

Building Block: Health Workforce

What was done? Three types of primary health care workers were trained in mental health and psychosocial support: 1) prescribers, 2) non-prescribers and 3) FCHVs (Chapter 7). The prescribers (medical officers, health assistants and community medical assistants) received two weeks of training on diagnosis of MNS disorders and prescription and management of side effects of prescribed psychotropic drugs. The non-prescribers (nurses and midwives) were trained for two weeks on basic counseling skills and providing protocolized psychosocial interventions for depression and alcohol use problems. The community based FCHVs were trained on case identification and home based follow up care. The community psychosocial counselors were trained for six months to provide counseling services for patients referred by these three types of

primary health care workers. The prescribers received regular refresher training and clinical supervision by psychiatrists and non-prescribers received training and clinical supervision by psychologists. The FCHVs received refresher training and supportive supervision by community counselors. Administrative supervision to the health facilities was provided by the District Public Health Office (DPHO) staff on how to account for and what procedures to use. Primary health care workers were trained on mental health information recording and reporting and their perception on feasibility and utility of newly introduced indicators was assessed [3]. The training focused on the meaning of each mental health indicator and how mental health information should be recorded in the mental health register. The service users and caregivers were trained on mental health and psychosocial problems, the rights of people with mental illness, the benefits provided by the government and level of service users and caregivers' involvement in mental health system strengthening. Short engagement sessions with policy makers were organized to orient them on the situation of mental health and the overall health benefits of prioritizing and treating mental illness [4].

What was learned? First, our findings show that a task-sharing approach in mental health can only be sustainable with the provision of regular training, supervision, administrative support to the primary health care workers (Chapter 7) and a coordination mechanism to manage several mental health activities to deliver a comprehensive mental health service package (Chapter 2). The lack

of specialist supervisors willing to travel and supervise in rural areas was a challenge for successful task-sharing as there were few psychiatrists and they were primarily concentrated in urban areas. Furthermore, the primary health care workers in Nepal saw the mental health component as an added responsibility to their usual work so they complained of the work burden and demanded financial incentives for the additional mental health work (Chapter 7).

Second, as the provision of mental health services was not scaled up across the country, the retention of trained health workers in certain health facilities which provide mental health services was a challenge due to the government's frequent transfer system (Chapter 3). Another finding was that trained health workers were frequently transferred to health facilities which did not provide mental health services and new health workers without mental health training arrived to the health facilities that were providing mental health services. In addition, organizing regular mental health training of new health workers appeared to be logistically and financially difficult (Chapter 7). So, efforts need to be focused more on the provision of pre-service mental health training rather than in-service training. During in-service training, clinical supervision and on site coaching are useful to sharpen and revise knowledge and skills of the primary health care workers.

Third, there was no consensus among psychiatrists about task-sharing: not all senior psychiatrists agreed that primary health care workers should be allowed to prescribe psychotropic medicine

(Chapter 5). There was however, a positive attitude of psychiatrists towards the counseling services provided by primary health care workers and community based mental health promotion and follow up by FCHVs (Chapter 5). Fourth, our experience showed that mental health service delivery is effective when the service delivery model is team based and is implemented as a team effort (Chapter 2). A team of psychiatrists, psychologists, medical officers, health assistants, counselors, nurses, social workers, community mobilizers and FCHVs would be ideal for community based mental health service delivery, but our experience showed that due to government mechanisms and lack of financial resources this is not going to be possible at least for 5 to 10 years. So, external support for the interim period would be needed to support the government's initiative of integration of mental health into primary health care. Fifth, mental health training alone (without any follow up) for primary health care workers is not enough. The class-room training needs to be followed up with clinical supervision, onsite coaching and regular refresher training.

Sixth, in Nepal, specialist supervisors do not like to, or manage, travel to rural areas for clinical supervision and most of the time, supervision visits are costly. Our pilot using a telephone for supervision, appeared successful in the Nepali settings (Chapter 7). Hence, a structured tele-supervision system could address the gap related to professional mental health supervision of primary health care workers.

Building Block: Health Information System

What was done? A situation analysis of existing mental health information systems in six low and middle income countries was carried out to understand current best practices of collection, management and dissemination of mental health information (Chapter 4). Similarly, with an aim of developing consensus on mental health indicators to be included within existing government Health Management Information System (HMIS), a consultation round with HMIS experts and mental health experts was carried out through a Delphi study [5]. Based on the findings of the Delphi study, an initial set of mental health indicators were developed and shared during a HMIS workshop conducted in the Kathmandu and Chitwan districts. The HMIS experts, mental health experts and service user/care giver representatives provided feedback on the initial set of mental health indicators. The final set of indicators was defined after incorporating the feedback of HMIS workshop participants. In collaboration with the HMIS section of the Department of Health Services (DoHS) and the HMIS section of the District Public Health Office, Chitwan, the developed indicator set was pilot tested in primary health care facilities of Chitwan district. The out-patient department (OPD) booklet was revised to include the mental health section. A separate mental health register was developed and used to record patients' details, treatment regimes and follow up dates. The performance of the mental health indicator was evaluated by analyzing mental health registers and exploring

whether or not mental health data were correctly collected in a timely manner and appropriately used [3].

What was learned? First, findings from chapter 4 suggest that although the mental health data was collected through mental health registers and reported to the district level, the data was not analyzed at the health facility to develop corrective actions. This was due to the workload of the health workers and lack of experience in analyzing the mental health data. So, it is recommended that in each health facility, one of the trained health workers should be appointed as mental health focal point and be responsible for recording and analyzing data, and implementing corrective actions to improve data quality. Second, there were inadequate policies, human resource and infrastructure to support effective collection, reporting and dissemination of mental health information (Chapter 4). Hence, there is a need to develop specific plans and policies for the governance and implementation of a mental health information system within the national HMIS. Third, continued training and supervision on mental health data collection forms, meaning of each indicator, the process how each indicator needs to be recorded/analyzed/disseminated should be planned and implemented. This will increase the understanding, acceptance and implementation of the mental health forms. Fourth, efforts to improve mental health information systems by developing and pilot-testing a new set of mental health indicators should be explored. A pilot study conducted in six low and middle income countries successfully demonstrated good performance and perceived utility for a new set of mental health indicators [3]. Hence,

these indicators can be incorporated within the existing HMIS to monitor coverage of mental health care in primary health care settings of low resource countries.

Building Block: Medical Products, Vaccines and Technology

What was done? At the beginning of the program (research projects PRIME and EMERALD) the NGO procured psychotropic drugs which were handed over to the District Public Health Office (DPHO) for distribution to the health facilities where government-NGO pilot mental health projects (PRIME and Emerald) were being implemented. The health facilities, based on their client flow, filled in the demand form for the quantities of psychotropic drugs needed and submitted these to the DPHO. The DPHO dispatched the drugs after verifying the demand forms. In the meantime the NGO lobbied the Ministry of Health to allocate budget for the procurement of psychotropic medicines. After repeated visits, and exchange of formal letters, the Ministry directed the DPHO to buy some psychotropic drugs from the government budget. Subsequently, the government could not continue procuring psychotropic drugs due to budget insufficiency. To understand the challenges in the psychotropic drug supply chain, a qualitative study was conducted among stakeholders involved in the production, import, procurement, transportation, storage, prescription, administration and use of psychotropic drugs (chapter 5). Formal and informal lobbying and advocacy were conducted for the inclusion of

psychotropic drugs in the free drug list and revision of essential drug list to include new generation psychotropic drugs.

What was learned? First, when there was lack of budget from the government systems to procure psychotropic drugs, the implementing NGO procured the psychotropic drugs and handed the drugs over to the District Public Health Office (DPHO) for storage, recording and distribution to the primary health care facilities. This handing over of drugs to the DPHO built trust with the DPHO and improved its systems and capacity for proper storage, recording and distribution of psychotropic drugs. Second, when a budget was made available to the DPHO to procure psychotropic drugs, the DPHO could only procure drugs that were listed in the national essential drug list. The essential drug list included old generation psychotropic drugs with more severe side effects compared to the new generation drugs available in the market. Hence, the NGO collaborated with other stakeholders to update the list of psychotropic drugs to include new generation drugs. This was a lengthy and intense process but it proved to be helpful as the government changed the list and included new generation drugs. Third, frequent transfer of senior government officials contributed to the difficulty in convincing DPHO officials to allocate on a regular basis budget for psychotropic drugs. During this research the NGO filled the gap by providing the psychotropic drugs. It is therefore recommended to continuously lobby for the availability of drugs to the government and at the same time call NGOs to contribute to the implementation of the program by reserving an additional budget for

back-up drug procurement. Fourth, the findings of the qualitative study (Chapter 5) show that stakeholders throughout the supply chain give priority to their own interest and thereby promote the practice of bonus and commission. Such vested interest of the stakeholders involved in the supply chain contributed to the misuse of psychotropic drugs. There were several impacts of the vested interest, such as the bonus and commission practice increasing the cost of medicine, only certain branded drugs were prescribed, some drugs were sold without prescription and therefore were misused. The loop holes in the government system and lack of human resources for proper supervision were some of the reasons for failure to address the misuse of psychotropic drugs (Chapter 5). Hence, there is a need for education, awareness and strict monitoring and supervision from government bodies to control vested interest and misuse of psychotropic drugs (Chapter 3).

Building Block: Health Financing

What was done? The cost of implementation of the mhGAP based MHCP was borne by the implementing NGO while the government provided some financial resources for the psychotropic drugs (but later stopped citing budget insufficiency). The Mental, Neurological and Substance abuse (MNS) component of WHO's One Health Tool (OHT) was populated in Nepal in consultation with Nepalese mental health professionals. A situation analysis and qualitative study on mental health financing was carried out. Finally, a household survey

was conducted among people with MNS disorder and people with other physical health problems.

What was learned? First, although the government agreed to partner with the NGO to provide primary mental health services, the formal commitment of the government (in terms of regular financing for procurement of psychotropic drugs) could not be fulfilled as officials who signed the Memorandum of Understanding (MoU) were transferred and replaced by new officials. However, the formal engagement with the government and continuous lobbying for mental health and psychosocial support facilitated, for example the support for disaster mental health financing during the 2015 Nepal earthquake. This shows that getting financial support from the government is not easy but organizations should not be discouraged and discontinue the lobby and advocacy efforts with the government. Second, the results of the study using the MNS component of WHO OHT shows that in four of the study countries (Ethiopia, India, Nepal and Uganda), the cost of delivering key interventions for psychosis, depression and epilepsy at existing treatment coverage was estimated at US\$ 0.06-0.33 per capita of total population per year [6]. This shows that with some additional resources for training and procurement of psychotropic drugs the community based mental health care can be provided by primary health care workers in low resource settings like Nepal. These findings can be used for lobbying and advocacy for greater mental health financing in community based mental health care in other low and middle income countries. Third, the household survey findings showed that households with a

family member with MNS disorder spent more on health care and compensated by selling assets and borrowing money. Compared to non-MNS households, the households with MNS disorder have higher catastrophic health expenditure [7]. This shows that some level of financial protection is needed for families with MNS disorder. Such financial protection could include subsidies in medicine and reimbursement of hospitalization costs. The most important strategies to ensure such financial protection for people with MNS disorder is inclusion of mental health in national health insurance schemes[8].

Building Block: Leadership and Governance

What was done? Several policy engagement activities were conducted with national and district level policy makers and planners. Support was provided to consultation meetings on the draft mental health act, revision of the national mental health policy, development of mental health indicators to be included within the HMIS, development of the treatment protocol and revision of the list of psychotropic drugs in the national essential drug list. There was strong interaction between policy makers and international mental health experts during the consortium meeting of Emerald and PRIME projects held in Kathmandu. Policy makers from Kathmandu and district level were invited to visit the project implementation sites to observe the implementation realities and provide feedback. A formal MoU with the Ministry of Health was signed for Government-NGO collaboration in implementing mental

health services through primary health care facilities. A separate MoU was signed with the National Health Training Center for the development of the mental health training curriculum for primary health workers. A qualitative study was conducted among policy makers and planners to explore the legal and policy context as well as systems-level facilitating factors and barriers for the integration of mental health into primary health care. Siddiqi and colleagues' health system governance framework was used to report on the mental health system governance matrix (Chapter 3).

What was learned? First, although the program was run with an official MoU with the Ministry of Health, the health workers referred to the program as, “this NGO run program” (Chapter 7). This raises questions of ownership and sustainability of the program after the NGO project ends. Despite challenges in coordination with government systems and structures, the government-NGO model mental health program is appropriate and NGOs should not be implementing mental health programs in isolation from the government. The regular interaction between government officials and NGO staff helps in identifying and accepting the burden of mental health, development of system and structure within the government primary health care framework and raising mental health awareness at the policy and implementation levels. Second, the barriers in Nepal are not necessarily related to policy, but more importantly on the implementation of existing policies and plans (Chapter 3). Therefore, there is a greater need for research and debate on why the policy and programs are not implemented as planned and

why the implementation strategies and guidance do not enter into the policy documents. Third, for the pilot project (PRIME/Emerald), the money was made available through a research fund led by Universities outside of Nepal. Such pilot projects are good to generate evidence and inform policies but regular mental health service delivery cannot be sustained through pilot research projects. Therefore, regular funding from donors and the government is needed. However, traditional donors supporting health sector development in Nepal do not prioritize mental health so mental health does not receive the attention it requires. Currently mental health funding in Nepal is very limited and NGOs compete for scarce resources (Chapter 2). Until and unless major health sector donors for Nepal take up mental health as a priority area and provide regular funding, the achievements gained by NGOs through pilot projects of short duration, cannot be sustainable (Chapter 2). Therefore, it is advisable to have simultaneous lobbying and advocacy with donors and the government, because governments in many LMICs are less likely to prioritize mental health without donors' support and influence.

Key learning from the Nepal case study for strengthening mental health systems in other low and middle income countries

Based on the findings of the studies in this dissertation, I would like to highlight five key areas to which mental health stakeholders can and should contribute in order to strengthen mental health systems in LMICs.

First, capacity building in mental health is not only needed for the service providers but also for family members, community groups, local government officials and national policy makers. Each of these groups play an important role in improving the psychosocial wellbeing of people with MNS disorders but they require different and specific information on mental health because of their different positions, roles and responsibilities. Regular interactions between these stakeholder groups would promote their own understanding of mental health and perspectives of others on how addressing mental health issues in fact also contributes to achieving their sector specific goals such as better school performance, less poverty, more productivity and greater participation to community development. The Nepal experience shows that mental health capacity building programs and any other mental health system strengthening efforts in LMICs should include the local culture, illness epistemologies and supportive local cultural structures/mechanisms for psychosocial wellbeing. Cultural traditions, norms, socio-economic inequities and expectations influence the health explanatory models and help-seeking behavior of the person and family. In every local context, the accomplishment of social expectations is a key indicator for psychosocial wellbeing, while on the other hand, mismatch between social expectation and an individual's choice and ability brings about tension and gives rise to mental health and psychosocial problems. Such problems can better be addressed through a comprehensive and multi-stakeholder approach. As mental health is cross-cutting and involves many implementation spaces in socio-political and cultural

spheres as well as in many thematic areas (such as health, protection, livelihoods); mental health promotion, advocacy and capacity building should also be cross-cutting.

Second, the Nepal experience shows that active participation of service users and caregivers is vital for mental health system strengthening efforts, not only at the policy level but also at the practice level in the community. Mental health system strengthening efforts in Nepal are mostly led by mental health practitioners or staff of government and NGOs. There is virtually no, or very little, involvement of local service users and their caretakers. As patients and family members, who are experts by experience, their rich experience needs to be properly mobilized for strengthening mental health systems in LMICs. As family members have faced challenges both in the health institutions and in the community, they know feasible ways to address those challenges. Hence, empowerment of service users and care takers and their mobilization in lobbying and advocacy is vital for successful mental health system strengthening in LMICs.

Third, the findings from Nepal show that strengthening the mental health infrastructure within the government, especially at the Ministry of Health is a pre-requisite for scaling up mhGAP based mental health interventions through primary health care centers. For example, establishment and operationalization of a mental health focal unit within the Ministry of Health and its departments active on regional and district levels as well as in other relevant ministries

is urgently needed to strengthen mental health systems in LMICs. The unit at the Ministry of Health should be the main coordination unit to liaise with stakeholders within its departments as well as with state and non-state actors outside of health systems. If there is no budget available for a separate mental health unit, an existing department, such as the non-communicable disease (NCD) department, could be assigned as a focal unit for mental health. The NGOs and other non-state actors should help a mental health unit through technical and logistical support.

Fourth, a national level multi-sectoral mental health coordination group should be formed, the leadership of which can either be the Ministry of Health or it can rotate among the relevant and capable stakeholders. The mental health focal unit at the Ministry of Health would provide technical documents, evidence and data to this group for national level lobbying and advocacy. In any mental health system strengthening efforts, the coordination group should also take into account the impact of major national events on the local context and landscape of mental health. For example, in Nepal the 10 years long armed conflict, Bhutanese and Tibetan refugee crisis, flooding and the 2015 earthquake each had major impacts on how mental health advocacy was carried out, how policies and programs were formulated and how funding was made available. The national level coordination group should be guided by a systems approach for strengthening mental health systems in LMIC because a systems-approach increases the feasibility and sustainability of health systems due to shared costs and facilitates adjustment and

cooperation between several aspects of providing primary health care and community development. As the treatment for mental health problems requires both medical and social interventions, such a comprehensive system should include health and community oriented development professionals during development, implementation and up-scaling or strengthening the health system.

Fifth, there is a need to develop and implement a mental health research agenda focusing on capacity building, service delivery designs, system strengthening, knowledge management and documentation of evidence (case studies) at all levels. The lack of documentation of successful mental health interventions and policy relevant data are some of the biggest barriers in mental health lobbying and advocacy. Hence, a simple format of mental health data collection and a procedure for mental health knowledge management would greatly contribute to efforts in strengthening mental health systems in LMICs.

Besides the five key actions cutting across health system building blocks, the findings from Nepal also suggest other key actions for strengthening mental health systems in low and middle income countries which are presented in table 1. All these actions would require financial resources, so the government and NGOs need to work together to lobby for resources and implement the key actions on several phases based on the current need and priority of the country.

Implementation Space	Key Actions	Expected Outcome/Goal
Within MoH	<p>Service Delivery</p> <ul style="list-style-type: none"> ● Promote a community based socio-medical model of mental health service delivery including culturally relevant psychosocial interventions and a multidisciplinary team of service providers. ● Ensure involvement of service users and care givers in improving service delivery and patients experience at the health facility. 	Health system strengthening to improve mental health system performance (reducing mental health treatment gap through expansion of mental health systems and services).

	<p data-bbox="156 1079 185 1317">Health Workforce</p> <ul data-bbox="238 707 548 1266" style="list-style-type: none"> <li data-bbox="238 786 377 1266">● Standardize the training program, accreditation and licensing mechanisms for the mental health workforce. <li data-bbox="406 707 548 1266">● Emphasize on service provider self-care strategies to reduce health worker's burden and facilitate quality of care. 	
	<p data-bbox="600 1090 630 1317">Health Financing</p> <ul data-bbox="683 695 822 1266" style="list-style-type: none"> <li data-bbox="683 695 822 1266">● Develop financial risk protection mechanisms to reduce catastrophic health expenditure. 	

	<ul style="list-style-type: none"> ● Develop a clear flow of funding mechanisms and ways to monitor the use of the available funds. 	
	<p>Medicine and Technology</p> <ul style="list-style-type: none"> ● Identify and address loop holes in the supply chain management of psychotropic drugs to ensure regular availability of medicines. ● Promote a culture of buffer stock to avoid stock-out of psychotropic drugs at the health facilities. 	
	<p>Health Information</p>	

	<ul style="list-style-type: none"> ● Promote a culture of data analysis and use to improve mental health systems, services and policy formulation/revision. <p>Leadership and Governance</p> <ul style="list-style-type: none"> ● Identify and understand existing barriers and facilitating factors across the six health system building blocks. ● Identify collaborative actions needed for mental health system strengthening. ● Conduct a mapping of key actors, programs, interests, political ecosystem and relative influence and hierarchies of the stakeholders. 	
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	<ul style="list-style-type: none"> ● Start working on the exit strategy and sustainability plan from the beginning of the mental health project implementation. 	
<p>Outside of MoH</p>	<p>Stakeholders relevant to mental health and their roles</p> <ul style="list-style-type: none"> ● Understand major actors (which are needed for mental health collaborative action) and their political ideology. ● Identify interests and key approaches of the relevant stakeholders to mental health. ● Identify and address conflict of interest among stakeholders. 	<p>Non-health sector strengthening to improve mental health and psychosocial wellbeing (reducing the treatment gap through strengthening psychosocial service provision and its quality by capitalizing on resources scattered outside the ministry of health).</p>

	<ul style="list-style-type: none"> ● Define roles and responsibilities for each stakeholder group based on thematic preference and expertise. <p>Build partnership and consolidated mental health advocacy</p> <ul style="list-style-type: none"> ● Frame the mental health agenda in a strategic manner keeping in mind the existing socio-political context. ● Identify and strengthen existing structures to support mental health system strengthening efforts. ● Grab any crisis moment to lobby for mental health. 	
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	<ul style="list-style-type: none"> ● Develop mental health leadership at all levels. If possible, look for a rotational system of leadership so that everyone gets the chance to lead. ● Develop and sustain public private partnership in mental health. 	
	<p>System of communication and coordination</p> <ul style="list-style-type: none"> ● Develop a proper system of communication, coordination and reporting among stakeholders. ● Strengthen intra- NGO, intra-government and inter-agency coordination and learning mechanisms. 	

	<ul style="list-style-type: none"> ● Institute a system of coordination and collaboration with the legal and judicial system for the management of suicide and forensic psychiatric cases. 	
<p>In the community</p>	<p>Community and cultural groups</p> <ul style="list-style-type: none"> ● Orient community groups such as youth clubs, child clubs, mother's group, sports clubs, school teachers, and other cultural and religious groups such as Bhajan Mandali (group of singers), traditional healers and traditional dance groups on mental health and psychosocial problems. 	<p>Community system strengthening to improve mental health awareness, attitude and behavior towards people with mental illness (reducing the treatment gap by reducing the number of people needing mental health services through community based engagement and prevention programs).</p>

	<ul style="list-style-type: none"> ● Collaborate with such groups to develop mental health awareness materials, conduct awareness sessions and identification and referral of people with mental illness. 	
	<p>Community based local government</p> <ul style="list-style-type: none"> ● Involve local level government bodies such as municipalities and village development committees while designing and implementing community based mental health and psychosocial programs. ● Lobby with local government to contribute cash or in-kind support for 	

	<p>the implementation of community based mental health and psychosocial support programs.</p> <p>Involvement of service users and care givers</p> <ul style="list-style-type: none"> ● Promote involvement of recovered mental health service users as role models for community based mental health awareness programs. ● Involve service users and care givers in the design and implementation of community based mental health and psychosocial support programs. 	
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Critique on WHO Health System Strengthening Building Blocks framework

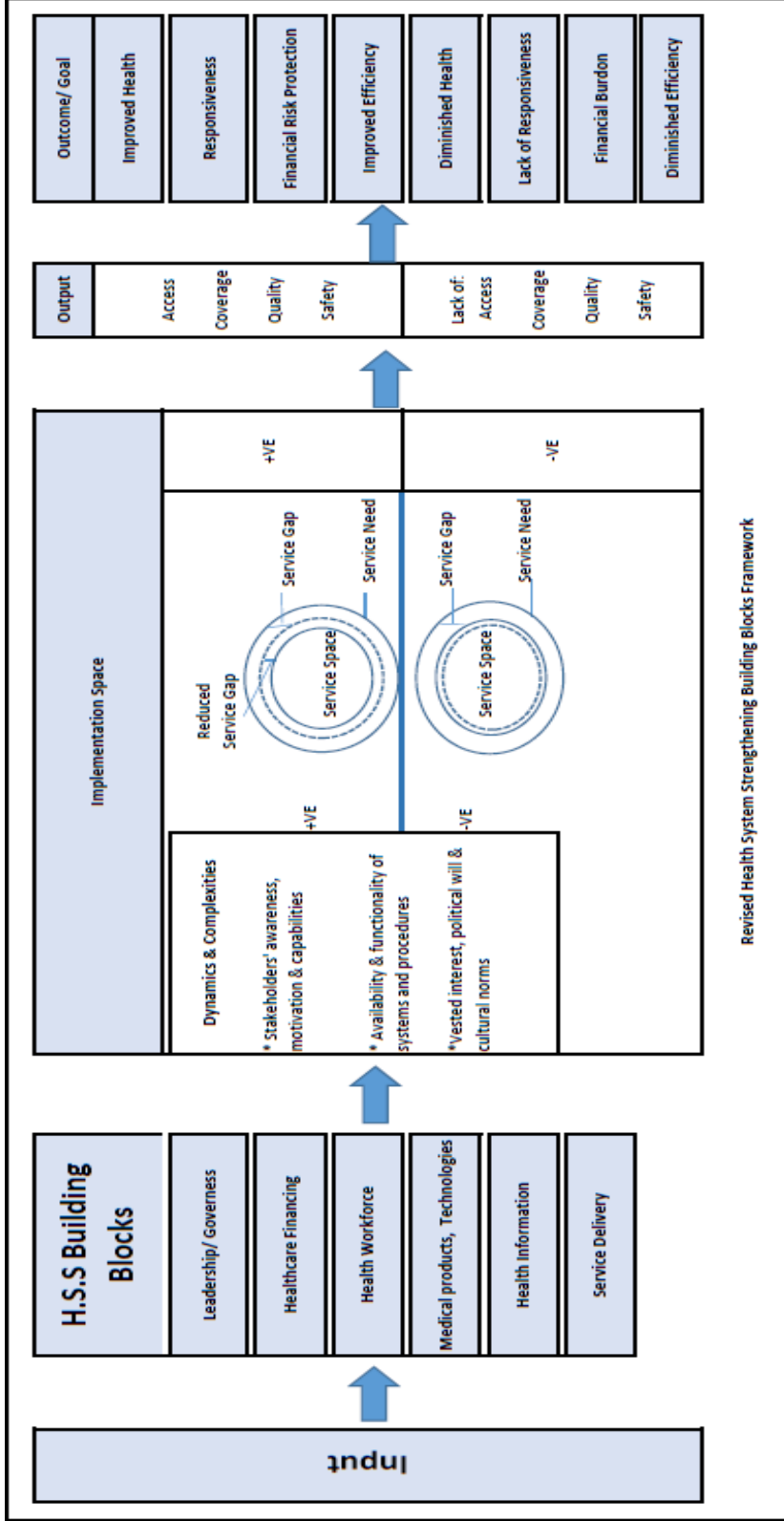
The WHO HSS framework is not without imperfections, the framework has been critiqued. Mounier-Jack and colleagues [9] concluded that the WHO six building blocks framework has limitations such as: it provides equal weight to all six building blocks, there is no explanation of interconnectedness between the building blocks and the dynamic process of the health system is not captured in this framework. De Savigny and Adam [10] have also raised issues regarding the dynamic nature of the health system as any intervention in one building block can affect outcomes in any of the other building blocks. The research presented in this dissertation reveals additional limitations in this model as it assumes that inputs in the six building blocks will automatically bring about desired outcomes. The framework does not sufficiently explain the processes and mechanisms by which inputs result in outputs and outputs result in outcomes. My conclusion is that, outcomes are affected and influenced by the implementation space where several stakeholders with vested interest interact and influence each other. Secondly, this framework does not explain which factors are responsible for the amplification effects or diminishing effects of inputs to the outcome. In other words, this framework does not tell which factors facilitate or impede the potentiality of inputs to achieve desired outcomes. Therefore, I conclude that there is currently a 'black box' between input and outcome which needs to be unravelled to explain and understand underlying assumptions and

mechanisms that drive inputs to outcomes and how outcomes are determined by decisions and actions of stakeholders within the ‘black box’. Based on the findings of the studies included in this dissertation, I try to describe this black box as the “implementation space” and provide a model to systematically address some of the limitations of the WHO HSS framework. The critique on HSS framework does not mean that it has no value. On the contrary, the framework has great value but needs to be expanded to make the framework more coherent and hence, effective. I propose an “implementation space model” presented below as an additional component to the existing framework to address and rebut some of the critiques on the WHO HSS framework.

An implementation space model to address the critiques on WHO Health System Strengthening Building Blocks

An “implementation space model” as shown in Figure 1 is proposed to address the need for unpacking the black box that exists in WHO’s HSS building blocks. The model assumes that a complex set of dynamics and complexities among the stakeholders determines whether a positive or negative result is achieved in terms of reducing the mental health treatment gap. The implementation space is comprised of many individual elements such as the mental health service need, the current provision of services, the treatment gap and reduced treatment gap (through better health system performance and community based awareness and prevention programs). Within an implementation spaces, there are several stakeholders with

mainly three dynamics and complexities; 1: vested interest, political will and cultural norms of stakeholders, 2: the awareness, motivation and capacities of stakeholders and 3: availability and functionality of procedures and systems. Each of these dynamics interact and influence the output of the investment made (input). The inputs will bring about the intended outputs only when the stakeholders interacting in these implementation spaces are able to reconcile and work with one another to put in place the systems and procedures needed to bring expected output. Their continued and sustained support is needed for outputs to bring expected outcomes.



Revised Health System Strengthening Building Blocks Framework

For example, when acceptable, feasible and affordable health system interventions are available as inputs, their uptake to policy and practice depends upon characteristics such as awareness about effective health system interventions, the motivation to take these into policy and practice, the capacities of individuals to provide and receive interventions and the structures to translate the interventions into policy and operation; and political will and readiness to implement mental health system interventions. Not only do the inputs (interventions defined in HSS building blocks) but also the implementation space (the dynamics and complexities in terms of vested interest, political will and cultural norms of stakeholders, the awareness, motivation and capacities of stakeholders and availability and functionality of procedures and systems) determine the level of access, coverage, quality and safety of health care which ultimately impact the overall outcome of the health interventions. Implementation realities (interest and motives of stakeholders during policy formulation and implementation, availability and use of systems and procedures for policy and practice and socio-cultural and political opposition to certain inputs) trigger both positive as well as negative impact on health systems performance. The positive impact provides impetus for better health system functioning thereby increasing better patient outcome (improved health). The negative impact results in barriers and inefficiencies in the health system bringing poor health system performance which ultimately gives rise to poor patient outcome (health). There will be a positive output of the intervention (eg, improvement of client, improved access to care,

coverage, quality and safety) if the stakeholders, systems and socio-cultural norms within the implementation space support the ideology of the intervention and act together. If these processes in the implementation space are in conflict with the ‘theory of change’ of the intervention or if there are competing interests, then there will be non-intended (or even negative) outputs of the intervention. This could include no improvement or even reduction in access, coverage, quality and safety. For example, though the mhGAP intervention in Nepal has been successful in bringing some changes at the patient level, its sustainability is questionable due to lack of government funding for mental health and a lack of awareness about the effectiveness of mhGAP interventions among policy makers and planners and health care managers. The competing priorities with limited resources, physical health problems getting more attention and lack of political will to move the mental health agenda forward are some of the realities of the implementation space which determine whether an effective mental health system intervention will be implemented as needed.

In the case of mental health systems, among several realities in the implementation space, some of the prominent concerns are a lack of knowledge about mental health, stigma related to mental health, stakeholders’ interest in political gain in lobbying for mental health and the existence of pressure groups interested only for their own benefits. Based on the findings of this research project, I conclude that only providing funding (inputs) for evidence based interventions impacting the health system building blocks is not sufficient to

achieve the planned outcomes of health system strengthening activities. These activities work through processes and we need more understanding and evidence on how these processes function within the implementation space; that is decisions made by actors and institutions based upon the health system and community context. I also conclude that the desired or planned effects of health systems interventions are reduced in LMIC settings due to the lack of capacity in the health systems to optimize health activities to the context and specific needs. The research findings from studies included in this dissertation show that lack of capacity can be compensated by optimizing the implementation space. This includes implementing interventions to address the factors that negatively affect the desired outcome of health system interventions.

The research findings from this dissertation also show that community mental health interventions, such as mhGAP, will only be effective when factors responsible for facilitating or blocking their effectiveness in the implementation space are adequately identified and addressed. Health systems focus on optimizing the provision of care through structured implementation and, it seems, through a unidirectional linear approach. While in the implementation space the providers, clients/ service users and their families interact with, and influence each other, in a non-linear approach. So, I argue that there is a need to shift from dichotomous thinking to dimensional thinking when it comes to mental health system strengthening. The conventional dichotomous thinking answers whether the intervention is working or not while using the

implementation space we can also answer where we are between working and not working in a continuum of care.

The dissertation describes the WHO Health Systems Building Blocks as a conceptual framework with specific activities to unpack the hidden box (black box) between ‘the input leads to output concept’ of the health system framework by introducing the implementation space model. This model aims to describe and explain how inputs entering the black box lead to the planned or expected outputs and outcomes. With the implementation space model one can concretize both latent and manifest variables and processes that determine how the inputs result in the planned or achieved outcomes. These unintended and unexpected variables and processes are for instance the group dynamics and complex interactions between and within these variables and processes that define the implementation space and determine the final outcome.

Based on the findings of several papers included in this dissertation and personal experiences during the research project 2013-2018, a model of “implementation space” is proposed to facilitate effective and efficient implementation of mental health system strengthening activities in low resources settings like Nepal. This dissertation focused on the “implementation space” within the Ministry of Health and across six building blocks of health systems strengthening. But, for the mental health wellbeing of the populations, we also need support from other sectors who have the potential to influence mental health promotion, policy formulation and service delivery.

Hence, this implementation space model can be extended to non-health sectors and community structures as presented in Table 1. Such extension should, however, be linked to each other by three interwoven strategies: 1) strengthening health system performance (within the Ministry of Health structures), 2) strengthening non-health sectors (outside of Ministry of Health structures) that influence mental health wellbeing of the population and 3) strengthening community systems that play a vital role in individuals' social acceptance, belonging and psychosocial wellbeing. As implementation spaces are not static but dynamic and change over time and context, due to changes of policy/ political context and changes in adjoining social and cultural environments, the implementation space model needs to be regularly updated and revised to secure that the implementations of the project activities result to the planned outcomes.

Consideration for further research

First, as mental health and psychosocial issues cut across implementation spaces of many systems (health, social, cultural, legal, protection, livelihood etc.), further mental health system research on the continuum of care across several inter-connected systems is needed to understand the complex nature of the underlying causes of the lack of attention to mental health and psychosocial issues, and to develop strategies to overcome barriers to mental health system strengthening in LMICs. Further research is

needed to answer questions around why mental health does not get the attention it deserves, using Shiffman and Smith's framework which has four components: actor power, ideas, context and the characteristics of the issue [11].

Second, the empowerment of service users, family members and community structures plays an important role in the rehabilitation and recovery of people with MNS disorders. But, very little research has been done on this subject in many LMICs including Nepal. Chapter 8 in this dissertation found that despite stressing the importance of service users and care givers' involvement, sparse or token involvement is the practice. For other LMICs aiming to start mental health system strengthening, efforts should be taken to sufficiently research around service users and care givers' involvement and provide enough space and budget to realize their true involvement. This is important because the contextual factors and behaviors of close friends and relatives of people with mental illness burdens the individuals suffering from mental illness and impedes their recovery process. Therefore, future research should have active involvement of service users and their care takers in the design and implementation of research to answer questions such as perceived challenges from social networks and health sector response to address stigma and discrimination for people visiting health services for MNS disorders.

Third, introducing mhGAP based mental health interventions in primary health care settings, without taking into consideration the

perceived or actual workload of health workers, risks overburdening health workers and thereby increases their distress level (Chapter 7). The distress level of health workers also increases when they have doubts in diagnosing cases and have difficulties handling prescription and side effects of psychotropic drugs. Further research is needed to understand provider self-care strategies and culturally relevant mechanisms to reduce distress of service providers.

Fourth, the quality control of mental health services provided by primary health care (PHC) workers is another area where further research is needed. Chapter 6 in the dissertation captured the perspectives of PHC workers on perceived impact of mhGAP based mental health interventions on quality of care and system development, but rigorous research on actual quality of services is needed.

Fifth, although the standardization of training materials was initiated and endorsed by the government, there is still a lack of minimum requirements of mental health service delivery and a system of licensing of mental health and psychosocial care provided by non-specialist health workers and community members. Further research is needed on health workers' competency in providing pharmacological treatment and psychosocial support to people with MNS disorders.

Concluding remarks

The goal of this dissertation was to provide insights from research from Nepal on existing challenges and opportunities for mental health system strengthening and provide guidance on how such a knowledge-base can be implemented in other low resource settings. In Nepal and many LMICs, the integration of mental health into primary health care is relatively new. This means that WHO's health systems strengthening model requires adaptations and improvements to fit these new contexts. Based on the findings included in this dissertation I have proposed a "implementation space model" which aims to unpack the mechanisms of change for WHO's health system strengthening model.

Finally, though this dissertation started with a focus on strengthening mental health systems, during the course of the study it became evident that a broader perspective was needed. This meant looking at the wider political and socio-cultural dimensions of mental health and not merely focusing on the individual's psychopathology and treatment, and looking at synergies between several stakeholders outside of ministry of health as opposed to only focusing on stakeholders within the ministry of health structures. Ultimately, such integrated systems thinking approaches are crucial to close the treatment gap that exists for mental health.

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Samenvatting in het Nederlands

Psychische en neurologische stoornissen en stoornissen ten gevolge van het gebruik van verslavende middelen zijn verantwoordelijk voor 10,4% van de wereldwijde ziektelast. Dit percentage is een onderschatting omdat zelfmoord en zelfverwonding afzonderlijk worden geregistreerd en persoonlijkheidsstoornissen niet worden meegerekend onder de psychische stoornissen. Als deze stoornissen allemaal worden gecombineerd, zou het totale percentage hoog worden. Ondanks de hoge ziektelast krijgen veel mensen met deze stoornissen niet de behandeling die ze nodig hebben: dit wordt behandelkloof genoemd. In lage- en middeninkomenslanden bedraagt deze behandelingskloof bijna 90%. Vanwege deze grote behandelkloof en het gebrek aan specialistisch personeel in de geestelijke gezondheidszorg heeft de Wereldgezondheidsorganisatie in 2008 het ‘Mental health gap action program’ (mhGAP) richtlijn gelanceerd. Deze richtlijn was bedoeld om het gebruik van *evidence-based* interventies door niet-gespecialiseerde gezondheidswerkers in eerstelijns-gezondheidszorginstellingen te vergemakkelijken. Hierbij wordt een benadering gebruikt die algemeen bekend staat als ‘taakverschuiving’, waarbij psychiaters en psychologen een trainings- en superviserol innemen en eerstelijns-gezondheidswerkers geestelijke gezondheidszorg verlenen.

Echter, om de op mhGAP gebaseerde interventies succesvol te laten zijn, moeten de interventies op het niveau van het gezondheidssysteem tezamen worden geïmplementeerd en

geëvalueerd. Dit is niet het geval vanwege de wereldwijde lage prioriteit en vanwege het feit dat er zelden onderzoek naar geestelijke gezondheidssystemen wordt gedaan en er weinig kennis is over de successen en uitdagingen bij het versterken van de geestelijke gezondheidssystemen in lage- en middeninkomenslanden. In dit proefschrift worden pogingen ondernomen om de belangrijkste onderzoeksvraag te beantwoorden: "Wat zijn de uitdagingen en kansen voor het versterken van het geestelijke gezondheidssysteem in de context van een land met een gebrek aan middelen, zoals Nepal?" Dit wordt gedaan door de volgende deelvragen te beantwoorden; 1) wat zijn de nieuwste inzichten met betrekking tot het versterken van de geestelijke gezondheidssysteem ?, 2) welke factoren die van toepassing zijn op het gezondheidssysteem vergemakkelijken of belemmeren de versterking van de geestelijke gezondheidszorg in een omgeving met weinig middelen ?, 3) hoe denken belanghebbenden over het beleid met betrekking tot de geestelijke gezondheid , over het voorraadketenbeheer van psychotrope geneesmiddelen en over de verdeling van taken bij geestelijke gezondheidszorginterventies die plaatsvinden in de lokale gemeenschappen?, en 4) wat zijn de bepalende acties die moeten worden ondernomen om de geestelijke gezondheidszorgsystemen in lage- en middeninkomenslanden te versterken?

Het proefschrift is gestructureerd rond het 'Health System Strengthening (HSS) building blocks' raamwerk van de Wereldgezondheidsorganisatie. In dit raamwerk wordt een

gezondheidssysteem onderverdeeld in zes bouwstenen, namelijk: 1) financiering, 2) informatie³) dienstverlening; 4) medische producten, vaccins en technologieën; 5) gezondheidszorgpersoneel; en 6) leiderschap en bestuur. Het raamwerk gaat ervan uit dat versterking van deze zes bouwstenen de toegang, dekking, kwaliteit en veiligheid zal verbeteren en daardoor zal leiden tot betere gezondheid en tot een systeem dat beter reageert, beter beschermd is tegen financiële risico's en een verbeterde efficiëntie heeft.

Hoofdstuk één (het inleidende hoofdstuk) geeft een korte beschrijving van geestelijke gezondheid wereldwijd en specifiek in Nepal, belangrijke ontwikkelingen in de wereldwijde geestelijke gezondheid in de afgelopen twee decennia en een samenvatting van literatuur over systemen voor geestelijke gezondheidszorg met behulp van het 'building blocks' raamwerk van de Wereldgezondheidsorganisatie. Dit hoofdstuk bevat de beschrijving van de setting waar het onderzoek is uitgevoerd, de onderzoeksthema's, het conceptuele kader dat voor de studie is gebruikt, de onderlinge verbondenheid van de verschillende hoofdstukken in het proefschrift en tot slot een persoonlijk verhaal van de promovendus.

Hoofdstuk twee presenteert de bijdrage van Nepalese niet-gouvernementele organisaties (NGO's) op het gebied van geestelijke gezondheid en psychosociale ondersteuning. Aan de hand van de 4W (wie doet wat waar en wanneer) methodologie, beschrijft het hoofdstuk de stand van de geestelijke gezondheid en de

psychosociale ondersteuning in Nepal en de rol van niet-gouvernementele organisaties bij het versterken geestelijke gezondheidssystemen en het verlenen van geestelijke gezondheidszorg, vooral tijdens conflicten en rampen. De bevindingen tonen aan dat Nepalese ngo's hebben bijgedragen aan de preventie en behandeling van geestelijke gezondheidsproblemen en psychosociale problemen. Training van het personeel, het verlenen van geestelijke gezondheidszorg en voorlichting waren de belangrijkste aandachtsgebieden van de meeste NGO's, terwijl sommige ook betrokken waren bij onderzoek naar geestelijke gezondheid en bij wetenschappelijke publicaties. De NGO's waren instrumenteel bij de ontwikkeling van een op de gemeenschap gebaseerd psychosociaal zorgsysteem en de integratie van mentale gezondheid in de primaire gezondheidszorg. De geloofwaardigheid van NGO's en hun diensten werd echter negatief beïnvloed door het gebrek aan accreditatie voor hun trainingen en het ontbreken van voorzieningen voor het monitoren en het vergunnen van hun diensten. (bijv. voor counseling).

Hoofdstuk drie bevat de bevindingen van een kwalitatief onderzoek onder beleidsmakers en planners in de gezondheids Het presenteert een matrix voor het bestuur van een geestelijk gezondheidssysteem gebaseerd op Siddiqui's 'Health System Governance' Framework' en onderzoekt de uitdagingen en faciliterende factoren op beleidsniveau om het geestelijke gezondheidssysteem in Nepal te versterken. Uit het onderzoek blijkt dat , ook al zijn er sommige faciliterende factoren zoals de aanwezigheid van het beleid met

betrekking tot geestelijke gezondheid, deelname van NGO's aan training en zorgverlening en een eerste betrokkenheid van cliënten / verzorgers bij het beleid en de planning van geestelijke, ontmoet het geestelijk gezondheidssysteem veel uitdagingen en heeft het behoefte aan meer inbreng van hulpmiddelen en leiderschap om deze uitdagingen te boven te komen. De belangrijkste uitdagingen waren het ontbreken van wettelijke kaders voor geestelijke gezondheidszorg (De ontwerpwet met betrekking tot geestelijke gezondheid is nog steeds niet goedgekeurd) en het niet invoeren van bestaand beleid vanwege het ontbreken van leiderschap bij het ministerie van Volksgezondheid en het ontbreken van bestuursmechanismen met betrekking tot geestelijke gezondheidszorg. Evenzo waren het gebrek aan opgeleid personeel, frequente overplaatsingen van opgeleide gezondheidswerkers, ontoereikende budgetten, onvoldoende infrastructuur, slechte administratie en stigma met betrekking tot geestelijke gezondheidsproblemen enkele van de belemmeringen die moeten worden aangepakt door middel van goede bestuursmechanismen op nationaal en districtsniveau. Ten slotte zijn de bestuursprincipes met betrekking tot transparantie, verantwoording, ethiek, reactievermogen en een rechtvaardige verdeling nog onderontwikkeld en verdienen zij meer aandacht.

Hoofdstuk vier biedt een situatieanalyse met betrekking tot het verzamelen, compileren, analyseren en gebruiken van gegevens over geestelijke gezondheid voor beleid en praktijk in zes lage- en middeninkomenslanden, waaronder Nepal. De bevindingen toonden

aan dat de zes landen zich in verschillende stadia bevinden met betrekking tot het ontwikkelen van een HMIS (Health Management and Information System) bevinden en in het verzamelen en rapporteren van indicatoren met betrekking tot geestelijke gezondheid, terwijl de uitdagingen en kansen in alle landen vergelijkbaar waren. Uitdagingen op het gebied van personeel, infrastructuur en software kwamen veel voor. In alle landen ontbrak een sterk beleid en strategische visie op het verzamelen van gegevens over geestelijke gezondheid binnen het HMIS. Het HMIS in Nepal verzamelde weinig gegevens over geestelijke gezondheid en er was behoefte aan het toevoegen van indicatoren met betrekking tot zorgbehoefte, dekking en gebruik. HMIS experts waren maar zeer beperkt beschikbaar en daarom werd het grootste deel van het werk gedaan door junior personeel zonder expertise en ervaring.

Hoofdstuk vijf geeft het resultaat van een kwalitatief onderzoek onder belanghebbenden die betrokken zijn bij het voorraadketenbeheer van psychotrope geneesmiddelen, waaronder mensen die betrokken zijn bij de productie, de inkoop, de import, het transport, de opslag, het voorschrijven, de administratie en het gebruik. De bevindingen toonden aan dat, afgezien van strikte processen die nodig zijn voor goedkeuring, beperkingen in de hoeveelheid en het bijhouden van gegevens, alle andere aspecten van de voorraadbeheerketen van psychotrope geneesmiddelen vergelijkbaar waren met die van algemene geneesmiddelen in Nepal. Over het algemeen werden de kwaliteit en effectiviteit van

psychotrope geneesmiddelen als goed ervaren, hoewel sommige respondenten van mening waren dat geneesmiddelen geproduceerd door Indiase en multinationale bedrijven van betere kwaliteit waren dan medicijnen die in Nepal werden geproduceerd. Ondanks hun bijwerkingen, werden psychotrope geneesmiddelen als effectief beschouwd voor psychische problemen. Sommige respondenten benadrukten echter dat psychosociale counseling en andere vormen van sociale ondersteuning even belangrijk zijn als psychotrope geneesmiddelen, omdat ze gezamenlijk tot een hogere effectiviteit leiden. De respondenten waren het er in het algemeen over eens dat bonussen en beloningen prominent aanwezig waren in de geneesmiddelenketen van Nepal, wat ongepast gebruik of misbruik van psychotrope geneesmiddelen aanmoedigt. Het stigma dat wordt geassocieerd met psychische aandoeningen dwingt patiënten en hun familieleden om te stoppen met medicijnen uit angst dat anderen het te weten komen.

Hoofdstuk zes presenteert de bevindingen van een gecontroleerde voor- en nameting onder eerstelijnsgezondheidswerkers. Het legt uit hoe regelmatige training en supervisie van eerstelijnsgezondheidswerkers met betrekking tot geestelijke gezondheid en de implementatie van het op mhGAP gebaseerde pakket voor geestelijke gezondheidszorg hebben bijgedragen aan een versterkte integratie van chronische zorgelementen in de eerstelijnsgezondheidszorg. De bevindingen toonden aan dat de eerstelijnsgezondheidszorgers in gezondheidsinstellingen die steun

kregen vanuit dit pakket verbeteringen rapporteerden in de kwaliteit van zorg voor psychische aandoeningen, vergeleken met zorginstellingen waar dit pakket niet aangeboden was. Bij de voormeting was er geen statistisch verschil tussen de gezondheidsinstellingen in de interventie- en controlegroep, maar bij de tussentijdse meting en bij de eindmeting was er een significant verschil in alle zes ACIC (Assessment of Chronic Illness Care) elementen in de gezondheidsinstellingen in de interventiegroep. Hoewel de gezondheidsinstellingen in beide groepen verbeteringen vertoonden tussen de voormeting en de nameting, presteerden de gezondheidsinstellingen in de interventiegroep aanzienlijk beter dan die in de controlegroep. Hieruit blijkt dat het pakket voor geestelijke gezondheidszorg (inclusief de opleiding en begeleiding van gezondheidswerkers) heeft bijgedragen aan een versterkte integratie van chronische zorgelementen in de eerstelijnsgezondheidszorg.

Hoofdstuk zeven verkent, door middel van een kwalitatief onderzoek onder drie groepen eerstelijnsgezondheidswerkers (voorschrijvers, niet-voorschrijvers en *female community health volunteers*), de dagelijkse uitdagingen waarmee eerstelijnsgezondheidswerkers worden geconfronteerd bij het verlenen van geestelijke gezondheidszorg via eerstelijnsgezondheidszorgvoorzieningen. Het onderzoekt met name de bevorderende factoren en barrières op systeemniveau voor de opschaling van een op het mhGAP gebaseerde pakket om op districtsniveau geestelijke gezondheidszorg te verlenen. Factoren die

de geïntegreerde levering van geestelijke gezondheidszorg bevorderen zijn de beschikbaarheid van protocollen en richtlijnen, het aanbieden van regelmatige training, supervisie en coaching, een duidelijk omschreven verwijzingssysteem, systemen voor informatiebeheer van patiënteninformatie, aandacht voor betrokkenheid vanuit de gemeenschap, de beschikbaarheid van zorg aan huis, en follow-up van patiënten, de beschikbaarheid van psychosociale ondersteuning en geneesmiddelen en de aanwezigheid van coördinatie op verschillende niveaus met overheden, niet-gouvernementele organisaties en gemeenschapsstructuren. Het eerste type belemmeringen zijn de personele belemmeringen: frequente overplaatsingen van opgeleide gezondheidswerkers en de komst van nieuwe gezondheidswerkers zonder opleiding in de geestelijke gezondheidszorg. Belemmeringen op patiënten-niveau zijn onder meer patiënten die stoppen met de behandeling of die niet naar de instellingen gaan waarheen zij doorverwezen zijn. Daarnaast zijn er ook uitdagingen op het gebied van een afwezige privéruimte voor counseling, een onvoldoende medicijnvoorraad en onvoldoende gebruik van informatie over de geestelijke gezondheid om de kwaliteit van de geestelijke gezondheidszorg te verbeteren. Om de belemmeringen voor de integratie van geestelijke gezondheidszorg in de eerstelijnsgezondheidszorg weg te nemen, werden door de respondenten de volgende strategieën voorgesteld; beleidsbeïnvloeding, het aanwijzen van speciale ruimte binnen de gezondheidsfaciliteit voor counselingsgesprekken, het aanleggen van een buffervoorraad van psychotrope geneesmiddelen,

regelmatige bijscholing, klinische supervisie en financiële voordelen voor gezondheidswerkers, een verbeterd verwijssysteem, een volgsysteem voor patiënten die met de behandeling stoppen, het afleggen van huisbezoeken en de aanwezigheid van een supervisie- en feedback system.

Hoofdstuk acht presenteert een kwalitatief onderzoek onder gebruikers van geestelijke gezondheidszorg en hun zorgverleners en richt zich op hun betrokkenheid bij de versterking van het geestelijke gezondheidssysteem in Nepal. De bevindingen toonden aan dat gebruikers van geestelijke gezondheidszorg niet daadwerkelijk betrokken waren , terwijl betrokkenheid van zorgverleners eenvoudigweg niet bestond. De ervaringen en standpunten onder gebruikers van geestelijke gezondheidszorg ten aanzien van betrokkenheid bij hun behandeling varieerde: sommigen hadden zich niet aangesloten bij zelfhulporganisaties, terwijl anderen dat wel hadden gedaan. Alhoewel niet expliciet vermeld, waren zelfstigma en stigma binnen de groep een terugkerend thema in de verzamelde gegevens en was dit een van de grootste belemmeringen voor hun betrokkenheid. Een strategie, die genoemd werd om de betrokkenheid van gebruikers en zorgverleners te vergroten, was het opzetten van gemeenschappelijke netwerken zonder botsende belangen en prioriteiten (zoals die waarmee NGO's te maken hebben). Verbeterde beleidskaders en initiatieven (zoals die ook geïmplementeerd werden voor HIV / AIDS in Nepal) en

decentralisatie van zorg kunnen ook de betrokkenheid van gebruikers en zorgverleners bevorderen.

Hoofdstuk negen (het discussiehoofdstuk) geeft een overzicht van de uitgevoerde activiteiten en geleerde lessen in elk van de zes 'Health system strengthening building blocks'. Het geeft ook weer hoe geestelijke gezondheidszorgsystemen kunnen worden versterkt in landen met weinig voorzieningen (zoals Nepal) en het presenteert belangrijke beleids- en praktijkacties. Ten slotte geeft het kritiek op het WHO 'HSS building blocks' raamwerk en stelt het voor dit raamwerk te herzien door de toevoeging van een model voor de implementatieruimte. Het huidige raamwerk gaat ervan uit dat *inputs* in de zes bouwstenen automatisch het gewenste resultaat opleveren. Het raamwerk verklaart echter onvoldoende de processen en mechanismen die plaatsvinden vanaf het moment dat de *input* wordt gegeven tot het moment dat de gewenste resultaten worden bereikt. Met andere woorden, dit raamwerk vertelt niet welke factoren de potentie van *inputs* vergemakkelijken of belemmeren om de gewenste resultaten te bereiken. Daarom concludeert dit proefschrift dat er momenteel een 'black box' is tussen input en uitkomst die moet worden ontrafeld om onderliggende aannames en mechanismen tussen input en uitkomst alsmede de invloed van beslissingen en acties van belanghebbenden binnen de 'zwarte doos' te verklaren en te begrijpen. Op basis van de bevindingen van de onderzoeken in dit proefschrift beschrijft dit proefschrift deze black box als de "implementatieruimte" en biedt het een model om systematisch

enkele beperkingen van het WHO 'HSS building blocks' raamwerk aan te pakken. De kritiek op het HSS 'building blocks' raamwerk betekent niet dat het geen waarde heeft. Integendeel, het raamwerk is van grote waarde, maar moet worden uitgebreid om het raamwerk coherenter en dus doeltreffender te maken. De "implementatieruimte model" wordt gepresenteerd als een extra component van het bestaande raamwerk om enkele kritiekpunten op het WHO 'HSS building blocks' raamwerk aan te pakken en te weerleggen.

Summary in English

Mental, neurological and substance use (MNS) disorders account for about 10% of the global disease burden. This percentage is an underestimate however, because suicide and self-injury are categorized separately and personality disorders are not included in the MNS disease burden calculations. When all these are combined, the percentage is significantly higher. Despite this high disease burden, many people with MNS disorders do not receive the treatment they need, resulting in a treatment gap. In low and middle income countries (LMICs) this treatment gap has reached nearly 90%. Given the large unmet need and lack of specialist human resources in the mental health sector, the World Health Organization (WHO) launched the mental health gap action program (mhGAP) guidelines in 2008. The guidelines aimed to facilitate the delivery of evidence-based interventions by non-specialized health workers in primary health care settings, adopting the approach commonly known as “task-shifting” where psychiatrists and psychologists take on training and supervision roles and primary health care workers provide mental health services. For mhGAP based interventions to be successful, health system level interventions need to be implemented and evaluated simultaneously. This is not the case however, due to several factors, including: mental health is a low priority within the health sector globally; research on mental health systems is rare; and there is limited knowledge about the successes and challenges of mental health system strengthening efforts in LMICs.

Through this dissertation, attempts are made to answer the question, “What are the challenges and opportunities for mental health system strengthening in the context of low resource setting like Nepal?” This broader question can be addressed by considering the following sub-questions; 1) what is the current state of mental health system strengthening efforts?, 2) what health system level factors facilitate or impede mental health system strengthening in low resource setting?, 3) what are the perspectives of stakeholders on mental health governance, supply chain management of psychotropic drugs, and task-sharing for community based mental health interventions?, and 4) what are the key actions to be undertaken for strengthening of mental health systems in LMICs?

This dissertation is structured around the World Health Organizations’ (WHO) Health System Strengthening building block framework. In this framework, the health system is organized into six building blocks consisting of: 1-financing; 2-information; 3-service delivery; 4-medical products, vaccines and technologies; 5-health workforce; and 6-leadership and governance. The framework assumes that inputs in these six building blocks will improve access, coverage, quality and safety, and thereby yield better health, responsiveness, financial risk protection and improved efficiency.

Chapter one (the introductory chapter) provides a brief description of the situation of mental health globally, and specifically in Nepal; important developments in global mental health in the past two decades; and a summary of literature on mental health systems using

WHO's six building blocks approach. This chapter includes a description of the setting where the research was conducted, research themes, conceptual framework used for the study, interconnectedness of several chapters included in the dissertation, and finally a personal narrative of the Ph.D. candidate.

Chapter two focuses on the contribution of Nepali non-governmental organizations (NGOs) to the field of mental health and psychosocial support. Using the 4Ws (*who* is doing *what where* and *when*) methodology, the chapter provides an overview of the situation of mental health and psychosocial support in Nepal and describes the role of non-governmental organization in mental health system strengthening and service delivery, especially during conflict and disasters. The findings show that Nepali NGOs have contributed to awareness raising, prevention and treatment of mental health and psychosocial difficulties. Human workforce development, service delivery, and awareness raising were the areas of focus for most NGOs, while some were also involved in mental health research and scientific publication. The NGOs were instrumental in the development of community based psychosocial care systems and integration of mental health into primary health care. However, the credibility of NGOs and their services were negatively impacted by lack of: accreditation for training courses; provisions for monitoring of services; and licensing of services (e.g., counseling services).

Chapter three provides findings from a qualitative study of policy makers and planners. It also presents a mental health system

governance matrix based on Siddiqui's Health System Governance Framework, and explores the policy level challenges and facilitating factors for mental health system strengthening in Nepal. The findings suggest that, despite availability of mental health policy, participation of NGOs in training and service delivery, and beginning of service users/caregivers involvement in mental health policy and planning, mental health systems governance in Nepal faces many challenges. Greater resource inputs and leadership to overcome these challenges is required. Main challenges include the lack of legal provisions for mental health (the draft mental health act has not yet been endorsed), and non-implementation of existing policies. These difficulties appear to be due to both an absence of leadership at the Ministry of Health and a lack of governance mechanisms for mental health. Likewise, the lack of trained human resources, frequent relocation of trained health workers, inadequate budget allocation, insufficient infrastructure, poor record keeping, and stigma related to mental health were some of the barriers which need to be addressed through proper governance mechanisms at the national and district level. Finally, the governance principles related to transparency, accountability, ethics, responsiveness and equity are still underdeveloped and need greater attention.

Chapter four provides an overview of mental health data collection, compilation, analysis and use for policy and practice, in six low and middle income countries, including Nepal. Findings indicate that the six countries are at different stages in the development of Health Management Information System (HMIS), as well as in the

collection and reporting of mental health indicators, but the challenges and opportunities are similar across countries. Workforce, infrastructure, and software-related challenges were common to all. In addition, strong policies and strategic visions for mental health aspects of HMIS were lacking in all countries. The current HMIS in Nepal has only collected limited mental health data and there is a need to add indicators related to service needs, coverage and utilization. Very few HMIS experts are available and therefore the bulk of the work is being done by junior staff without expertise or experience.

Chapter five provides result of a separate qualitative study among stakeholders involved in supply chain management of psychotropic drugs, including people involved in the production, manufacturing, procurement, import, transport, storage, prescription, administration and uses. Findings indicate that except strict pre-approval processes, quantity restriction and provision of record keeping, all other aspects of supply chain management of psychotropic drugs were similar to that of general drugs in Nepal. Generally, the quality and effectiveness of psychotropic drugs were perceived to be good, although some respondents thought that the drugs from Indian and multinational companies were of better quality compared to the drugs produced in Nepal. Despite having side effects, psychotropic drugs were perceived to be effective for mental health problems. However, some respondents also stressed that psychosocial counseling and other forms of social support are equally important to maximize effectiveness of psychotropic drugs. In addition, it was

widely accepted by the respondents that bonuses and commissions were prominent in Nepal's drug supply chain which encouraged inappropriate use or misuse of psychotropic drugs. Furthermore, the perceived stigma of mental illness results in patients and their family members choosing to discontinue medicines out of fear that others may find out that they are being treated for a mental health concern.

Chapter six presents findings from a controlled pre-post study among primary health care workers. It explains how the training and supervision of primary health care workers on mental health and implementation of mhGAP based mental health care package (MHCP) contributed to strengthening integration of chronic care elements into primary health care. Results indicate a difference in primary health care workers' perception of quality of care systems for mental illness in health facilities that received support under MHCP compared to those that did not. At baseline there was no statistical difference between the health facilities in intervention and control groups, but at midline and end line there was a significant difference between the two groups in all six elements of Assessment of Chronic Illness Care (ACIC). Although the health facilities in both groups reported improvements from baseline to end line, the health facilities in the intervention group significantly outperformed the control group. This shows that the mental health care package (including the training and supervision of health workers) contributed to strengthening the integration of chronic care elements in primary health care.

Chapter seven, through highlighting a qualitative study among three cadres of primary health care workers (prescribers, non-prescribers and female community health volunteers), explores the real life challenges faced by primary health care workers in providing mental health services through primary health care facilities. In particular, it explores the system level facilitating factors and barriers for the scaling up of mhGAP based district mental health care packages. Factors supporting integrated mental health service delivery included availability of protocol and guidelines, provision of regular training, supervision and coaching system, established referral system, system for patient information management, community engagement, provision of home based care and follow up, the provision of psychosocial support along with drugs, and various levels of coordination with government, non-governmental and community structures. Health workforce related barriers included the frequent transfer of trained health workers and arrival of new health workers without mental health training. Patient level challenges included drop outs, defaulters and not following through on referrals. There were also challenges in terms of lack of available private space for counselling, limited medicine stocks and inadequate use of mental health information to improve the quality of mental health services. To address the barriers for integration of mental health services in primary health care, the strategies suggested by the respondents included: policy advocacy, provision of dedicated space within health facilities for counseling services, provision of buffer stocks for psychotropic drugs, regular refresher

trainings, clinical supervision, financial benefits to the health workers, strengthened referral pathways, defaulter tracking system, home visits, supervision and feedback systems.

Chapter eight, provides results from a qualitative study among mental health service users and their caregivers, investigating their level of involvement in mental health system strengthening in Nepal. Findings indicate that *meaningful involvement* of service users in Nepal is lacking, while involvement of caregivers in any capacity is simply non-existent. Among service users, experiences and attitudes towards involvement varied between non-affiliated and affiliated service users of mental health self-help organizations. Self-stigma and within-group stigma, although not mentioned explicitly, was a recurrent theme in the data and appeared to be a major barrier to involvement. Establishment of user and caregiver networks free from competing interests and priorities (such as those faced by NGOs), was emphasized as a strategy to enhance involvement. Improved policy frameworks and initiatives (such as have been implemented for HIV/AIDS in Nepal) and decentralization of care may support meaningful service user and caregiver involvement.

Chapter nine is a discussion chapter that summarizes activities implemented and lessons learned in each of the six health system strengthening building blocks. The discussion focuses on how mental health systems can be strengthened in low resource setting like Nepal and provides recommendations for actions with policy and practice relevance. Finally, this chapter provides a critique of

WHO's Health System Strengthening (HSS) building block framework and proposes a revision of the framework by adding an implementation space model. The current building blocks framework assumes that inputs in six building blocks will automatically bring about the desired outcomes. It does not however, sufficiently explain the processes and mechanisms that happen from the time inputs are given up to the time desired outcomes are achieved. In other words, this framework does not indicate which factors facilitate or impede the potentiality of inputs to achieve desired outcomes. Therefore, this dissertation concludes that there is currently a 'black box' between input and outcome which needs to be unpacked to understand underlying assumptions and mechanisms linking inputs to outcomes. Furthermore, how outcomes are determined by decisions and actions of stakeholders within the 'black box' needs to be better understood. Based on the research in this dissertation, the black box can be considered as the "implementation space", providing a model to systematically address some of the limitations of the WHO HSS building blocks framework. The critique of the HSS building blocks framework is not meant to call into question the value of the framework. On the contrary, the framework has great value, but needs to be expanded in order to be more coherent and effective. An "implementation space model" is presented as a compliment to the existing framework to address and rebut some of the critiques of the WHO HSS building blocks framework.

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Nawaraj Upadhaya

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Curriculum Vitae

Nawaraj Upadhaya was born in Simkhada village of Jumla district in Nepal, and is a public health researcher and medical anthropologist. He holds a Master's degree in Medical Anthropology from University of Amsterdam, the Netherlands. In 2005, he joined Transcultural Psychosocial Organization (TPO) Nepal as program officer and in 2007 assumed the role of Executive Manager/Director until 2010. In last quarter of 2011, he moved to Afghanistan to work with HealthNetTPO as technical advisor to support mental health and psychosocial support projects. He also supported Community System Strengthening (CSS) and Public Private Partnership (PPP) projects. Later on, he worked as Public Health Advisor supporting the delivery of primary and secondary health care.

From 2013 to 2015, he worked as project coordinator/research fellow for Emerging Mental Health Systems in Low and Middle Income Countries (Emerald) Project in Nepal. In 2016, he again went to Afghanistan and provided support to public health, mental health and Gender Based Violence related projects. In 2017, he was transferred to HealthNetTPO country office in South Sudan where he was involved in the development and pilot testing of Women and Girls Friendly Spaces (WGFS) guidelines, implementation of GBV and psychosocial support projects, malaria prevention and coordination of multi-country research project (Post Research Ethics Analysis- PREA) on research ethics in humanitarian crisis. In the year 2019, he served as Country Director for HealthNetTPO

in South Sudan and supervised projects related to primary health care, hospital-based services, community-based prevention of malaria, community engagement and mobilization, institutional capacity building, mental health and psychosocial support and research on nodding disease. Since January 2020 he has been working in Burundi, supporting program implementation and research on health, mental health and psychosocial support, livelihoods and community development.

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