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Participatory planning of a primary care service for people with severe mental disorders in rural Ethiopia

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ABSTRACT

Little is understood about the feasibility and acceptability of primary care-based models of task-sharing care for people with severe mental disorders (SMDs) in low- and middle-income countries (LMICs). A participatory planning approach was adopted in preparation for the transition from hospital-delivered psychiatric care for SMD to a primary care-based, task-sharing model in a rural Ethiopian community. In this article, we present findings from community consultation meetings ($n = 4$), focus group discussions ($n = 7$) and in-depth interviews ($n = 11$) with key stakeholders (healthcare administrators and providers, caregivers, service-users and community leaders) which were carried out over a 2-year period in the context of ongoing dialogue with the community. The principle of local delivery of mental health services was agreed upon by all stakeholder groups. Key reasons for supporting local delivery were increased access for the majority due to proximity, reduced cost and reduced stress related to transportation. However, acceptance of the new service was qualified by concerns about the competence of staff to deliver a comprehensive and dependable service of equal quality to that currently provided at the hospital. Adequate training and support, as well as ensuring consistency of medication supply were identified as key components to ensure success. Encouragingly, our results suggest that there is significant support for the service change and an interest for the mobilization of community resources to support this. One of the study strengths was that we were able to present the different perspectives of multiple stakeholder groups. By nesting the study in an ongoing community-based cohort of people with SMD we were able to interview a more representative and empowered group of caregivers and service users than is often available in LMICs. Despite this, the extent to which service-users are able to express their opinions is likely limited by their marginalized role in rural Ethiopian society.

Key words: Task-sharing, severe mental disorders, primary care, Ethiopia, low-income settings, qualitative research, community participation in healthcare planning

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Key Messages

- Stakeholders agree primary healthcare service for severe mental disorder is desirable and achievable
- Key concerns include: skills gap, continuity of medication supply and social support
- Healthcare workers express willingness to mobilize resources to support change
- Community-based care not perceived to be associated with additional stigma

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Introduction

Fewer than 1 in 10 people living with severe mental disorder (SMD) (psychotic disorders, bipolar disorder, severe depression) in low-income country settings ever receive treatment for their illness (Kebede *et al.* 2003). A lack of mental health services is the primary driver of this treatment gap (Group mEW 2010). Specialist infrastructure and human resources for mental health are low and likely to remain very limited (Kakuma *et al.* 2011). In the absence of specialist services, task-sharing, whereby lay or non-specialist health workers are trained to carry out aspects of mental health care, has been promoted as the best strategy to rapidly expand access to treatment (Prince *et al.* 2007; WHO 2008a,b). The delivery of mental health services by primary healthcare workers has potential to improve physical healthcare of people with SMD (WHO/WONCA 2008).

Despite successful and expanding psychiatry and psychiatric nurse training programmes, coverage of mental health services in Ethiopia is likely to stay low in coming years (Fekadu and Thornicroft 2014). There is currently 1 psychiatrist per 2 million of the population and 0.68 mental health professionals per 100 000 people, with services concentrated in urban centres and hospitals among a population that remains largely rural (Abera *et al.* 2014). Task-shared delivery of mental health services within primary care is being rolled out in Ethiopia as part of the country's new mental health strategy to close the treatment gap. Training primary health staff to successfully identify and treat people with mental illness using an mhGAP approach targeted at priority disorders and adapted for local use is at the heart of this plan. The latest Health Sector Development Programme set a target for the integration of mental health care into 50% of healthcare settings by the end of 2015 [WHO/WONCA 2008]. Although government commitment to mental health is an excellent starting point for scale-up, a number of unanswered questions remain regarding implementation and delivery of these new services.

A recent systematic review concluded that there was a lack of evidence for the feasibility and acceptability of mental health task-sharing interventions in low- and middle-income countries (LMICs) and that detailed data were required in order to maximize the likelihood of successful implementation (Padmanathan and De Silva 2013). An emerging evidence base suggests that non-specialist workers may be effective in delivering psychological interventions for common mental disorders (WHO 2010, van Ginneken *et al.* 2013), but task-sharing has been less commonly tested in the context of management of SMD. In particular, very little is known about the feasibility and acceptability of task shared care for SMD from the perspectives of all relevant stakeholders, including service-users, caregivers and healthcare staff. In previous published studies from Ethiopia (Abera *et al.* 2014, Mendenhall *et al.* 2014), respondents did not have experience of receiving any form of mental healthcare, thus limiting their ability to critically reflect on the potential benefits and disadvantages of introducing a new service model. Task-shared care for mental has been adopted by a number of national

governments and is in the process of being scaled-up in a number of settings. Although acknowledging the potential of task-shared care to close the gap for mental disorder, it is important to remember that task-shared services delivered in primary care are unlikely to be a panacea for the complex problems commonly faced by people with SMD in LMICs. For example: primary healthcare systems are not designed to address the structural and social problems which are closely associated with mental disorder (Mendenhall *et al.* 2014). Differences in conceptualizations of problems between healthcare workers and service-users and their families are another potential limitation to a successful therapeutic relationship (Mendenhall *et al.* 2014, Burgess 2015).

TaSCs (TAsk-Sharing for the Care of Severe mental disorders in a low-income country) is a non-inferiority trial that is seeking to investigate the impact upon patient outcomes of switching from centralized management of SMD by hospital-based psychiatric nurses to local, primary care-based management and care delivered by non-specialist healthcare workers. Participants in TaSCs will be recruited from the Butajira Study—a large population-based cohort study of people with clinician-confirmed SMD, who have been followed-up for >10 years, have an ongoing need for care and are under active follow-up at a psychiatric nurse-led clinic (with two weekly psychiatric outreach clinic) (Kebede *et al.* 2003, Fekadu *et al.* 2006, Alem 2009). Modern psychiatric treatment of SMD is unusual in rural Ethiopia, but free consultation, medication and follow-up were offered as benefits to participants in the cohort study (Teferra *et al.* 2013). As a consequence, the Butajira study offers a more representative and informed sample of mental health service users than would otherwise be available in a setting where fewer than 10% of people with SMD are usually able to access care.

The aim of this study was to engage key stakeholders in participatory planning for a shift to mental health care integrated into primary care, and to explore their perspectives on acceptability and feasibility of the change. We identified four key concerns that warranted exploration: (1) Would primary healthcare workers be personally prepared to take on the additional burden of delivering a mental health service? (2) Would healthcare workers feel prepared to work with people living with SMD? (3) Would people living with SMD and their careers have confidence in the quality and competence of a service led by primary healthcare centres? Although there is some evidence that increasing contact between mental health service users and the community can reduce stigma (Lund *et al.* 2012), results from previous studies carried out in rural Ethiopia suggest that stigmatizing attitudes versus people living with SMD are common (Girma and Tesfaye 2011, Girma *et al.* 2013). It is likely that accessing services from Butajira town hospital provides relatively anonymity as compared to visiting primary care in the heart of the communities where people with SMD live. We therefore wanted to assess whether community-based delivery of mental health services be expected to increase stigma among people living with SMD?

Community-based participatory research provides a research framework which integrates community concerns and priorities,

aiming to ensure that the voices of stakeholders are heard and ultimately promoting 'mutual credibility and trust' (Mosavel *et al.* 2005) between research teams and the communities in which they work. Petersen *et al.* (2012) suggest that community participation in the development of mental health services may have diffuse beneficial effects upon healthcare workers, service-users and their families: empowering them to speak out about their experiences, supporting the development of social inclusion and reducing stigma and discrimination (Petersen *et al.* 2012). Given the current lack of involvement of stakeholders in service planning and development of mental health services in LMICs, any move towards greater participation is to be welcomed. However, debates around the degree to which different levels of 'participation' lead to genuine transformation and empowerment must be recognized (White 1996; Hickey and Mohan 2005).

Materials and methods

Study design
Our study can be considered as having a 'nominal', uni-directional participatory approach, wherein the views of different stakeholder groups were sought in order to legitimize and contribute to refinement of the proposed new model of mental health care (White 1996). The study comprised of a series of consultative workshops and ongoing dialogue with service-users, caregivers, healthcare workers, local healthcare administrators, officials and community leaders combined with a formal qualitative study using in-depth interviews (IDIs) and focus group discussions (FGDs).

Setting
The study was carried out in Butajira town and the surrounding districts, located 135 km south of Addis Ababa, the capital of Ethiopia, in the Gurage Zone of the Southern Nations, Nationalities and People's Region. As is the case in much of rural Ethiopia, the majority of the population are subsistence farmers, with urban dwellers relying on trade as a key income generating activity. At the time of the study, the psychiatric nurse-led outpatient unit at the Zonal hospital in Butajira, and a two weekly outreach clinic held in Enseno town, were the only mental health services available for a population of around 2 million people. The psychiatric outpatient unit was first opened at Butajira Health Centre in 1997 in collaboration with a mental health research project which had completed a survey for common mental disorders, substance abuse and suicide in the Butajira Demographic Surveillance Site. When Butajira Hospital became operational in 2001, the unit moved from the health centre to the newly built Hospital. Two psychiatric nurses run the service at this unit, which serves a larger population than the 0.5 million people living in the neighbouring districts. The nearest in-patient mental health service is in Addis Ababa. There are 13 primary healthcare facilities ('health centres') staffed by nurses (2–3 years training) and health officers (3–4 years training) in the area. Medical doctors are only available in the zonal hospital in Butajira town. Community-based health extension workers (HEWs) are attached to each health centre. HEWs are female, paid, non-specialist workers who receive 1 year training in health promotion and illness prevention. HEWs are recruited from the local area and are tasked with being the primary care interface with the local community. Two HEWs work together to serve 1000 households (around 5000 people). The proposed roles for PHC workers in the new task-shared service are summarized in Table 1.

A series of consultation meetings was convened with health care administrators, health care workers, community leaders, caregivers and service users in October 2012 (two meetings, including group discussions; $n = 100$). In April 2014 and August 2014 two further consultative meetings were held (healthcare administrators; $n = 8$; health facility board members comprised of health facility heads and local officials, respectively).

Meetings were all held in Butajira town and were facilitated by senior psychiatrists linked to the TaSCS study (co-authors A.A., T.S., A.F.) who had been carrying out mental health research in Ethiopia for over 10 years. Each meeting started with awareness-raising about mental health and illness, feedback of findings from the previous Butajira mental health studies, an overview of the National Mental Health Strategy plans to integrate mental health into primary care and discussion. Small groups were then convened to discuss in detail about the acceptability of the new model, the acceptability of shifting from psychiatric nurse-led care and how a task sharing model of mental health care in primary care could be implemented in the three districts. Initial consultation meetings were conducted in tandem with the qualitative study, but later meetings drew on the qualitative study findings to explore particular issues with the planned service change.

Interviews and focus groups
A sample of key local stakeholders (service-users, caregivers, primary healthcare centre workers- nurses, health officers, HEWs) was selected purposively. Service-user participants in this study were under active follow-up through the service provided at Butajira hospital psychiatric clinic (or Enseno health centre outreach). FGDs were carried out with healthcare workers ($n = 2$ primary healthcare workers; $n = 2$ HEWs) and caregivers ($n = 3$). IDIs were carried out

Table 1. Proposed roles for PHC workers in the new task-shared service

Component of primary care	Human resource	Planned roles in ongoing mental health care for people with SMD
Health centre	Health officers Nurses (BSc and Diploma level)	• Providing regular follow-up • Monitoring response to treatment and adjusting medication as necessary • Managing side effects of medication • Knowing when to refer for specialist review
Health posts and community	HEWs	• Supporting engagement with care and providing outreach to those who drop out of care • Providing psychoeducation • Raising awareness and countering stigma • Knowing when to refer

Table 2. Characteristics of participants in IDIs and FGDs

	IDIs with service-users (n = 11)	FGDs with caregivers (n = 3, 27 participants in total)	FGDs with HEWs (n = 2, 15 participants in total)	FGDs with health centre workers (n = 2, 10 participants in total)
Gender	n (%)	n (%)	n (%)	n (%)
Female	5 (45.5)	15 (55.6)	15 (100)	7 (70)
Male	6 (54.5)	12 (44.4)	0 (0)?	3 (30)
Age (years)				
Mean	38.5	37.2	25.4	28.9
Range	34–65	18–65	22–32	22–42
Educational level	n (%)	n (%)		n (%)
Less than fourth grade (<4 years of primary education)	6 (54.5)	16 (59.3)		0 (0)
Fourth to eighth grade (4–8 years of primary education)	5 (45.5)	7 (25.9)		0 (0)
Ninth to eleventh grade (8 years of primary education, some secondary education)	0 (0)	2 (7.4)		0 (0)
Twelfth grade (completed primary and secondary education)	0 (0)	1 (3.7)		0 (0)
Higher education—diploma	0 (0)	1 (3.7)		4 (40.0)
Higher education—degree	0 (0)	0 (0)		6 (60.0)
Occupation	n (%)	n (%)		
Farming	9 (81.1)	23 (85.2)		
Unemployed	0 (0)	1 (3.7)		
Other occupation	2 (18.2)	3 (11.1)		
Duration working			Years	
Mean			5.7	
Range			1–8	
Diagnosis	n (%)			
Depression	3 (27.3)			
Bi-polar	5 (45.5)			
Schizophrenia	3 (27.2)			
Duration of treatment (years)				
Mean	13.1			
Range	8–20			

with service-users (n = 11). See Table 2 for characteristics of participants.

FGDs were carried out in primary healthcare centres, the Butajira mental health research office or the psychiatric unit in Butajira hospital, depending on which location was most convenient for the participants. Every attempt was made to ensure that the FGDs were homogeneous with respect to the type of participant (see Table 1). Each FGD had two facilitators, including senior psychiatrists and Masters-level research assistants with experience in qualitative research. One facilitator led the discussion while the other took notes and contributed follow-up questions where relevant. The facilitators ensured that every member of the FGD had an opportunity to express their view and sought to encourage discussion between respondents. The FGDs were all audio-recorded, with the permission of the participants.

IDIs were carried out in the psychiatric unit in Butajira hospital. In all cases privacy was assured. With the permission of the participant, the interview was audio-recorded. Refreshments were provided for the FGDs. For both the IDIs and FGDs, participants were given small remuneration for their travel expenses and time.

A topic guide was used for both the FGDs and IDIs. In each case the proposed change to the service model was described and participants were invited to give their perspectives on the benefits and disadvantages of the new (task-sharing) approach, as well as their views of the benefits and limitations of the existing centralized, psychiatric nurse-led model. Participants were then asked about

feasibility concerns and how these might be addressed to make the new service model workable. Finally, respondents were asked about their willingness to be randomized to one model or the other in an attempt to understand the strength of any preference for one service model over the other.

Data analysis

The audio-recordings of IDIs and FGDs were transcribed in Amharic and translated into English by interviewers prior to coding. English summaries of community consultative meetings were written close in time to the conduct of the meetings. The data were managed using Open Code 4.0 qualitative software (University of Umeå S 2011). A framework approach was used (Smith and Firth 2011). Transcripts were read and re-read by C.H. and R.M. in order to ensure familiarity. RM used the topic guide as the basis for the development of the coding framework. The coding framework was developed in an iterative way. RM and CH met over a 2-week period to discuss codes and then applied them to the data independently. Codes were either: derived from the topic guide or new codes that emerged from the data. Once consensus was reached codes and the framework were finalized and data coded, CH and RM met to discuss salient themes emerging from the data. In order to ensure that interpretation was true to the data and to provide input on patterns and themes, A.T., who carried out all of the service user interviews, participated in this meeting. Finally, R.M. and C.H.

interpreted the meaning of these themes and applied them to the context of the change from centralized, specialist-delivered care for SMD to local delivery by non-specialist healthcare workers in rural Ethiopia and to the ongoing roll-out of task-shared delivery of mental health in other LMICs.

Ethical considerations

Ethical approval was obtained from the author's institute. Participants were informed about the study and subsequently provided voluntary, written consent.

Results

Any mental health care

In general, none of the groups of key stakeholders, including caregivers, mental health service-users, healthcare administrators, community leaders, primary health centre workers and HEWs, expressed a strong preference for either health centre-based management of people with SMD or for the existing model of hospital-based care. Amongst respondents there was a sense that 'any mental health care' was something to be grateful for, compared with the experience before the Butajira psychiatric nurse unit was opened. As a consequence, most respondents were prepared to accept changes as long as this did not jeopardize continuation of a service and, in particular, the ongoing provision of medications. Caregivers in particular spoke warmly about the positive and dramatic changes they had seen in their family member living with SMD. For example, caregivers described how, prior to accessing care, their lives were characterized by violence and the threat of violence due to the untreated illness of their relatives. They attributed the relief of these problems to access to biomedical mental health care:

> We have had to endure being hit by a rock, stabbings; it's thanks to this [medication] that we have regained hope. They would try to break out of the house, set fire on us, fall into a pit, try to kill someone with a stone. This was the extent of our troubles, but thanks to the medication...—Caregiver, FGD 3

A widely expressed view among respondents in all groups was that the service change was an inevitable development. For service-users, an opinion on the way in which the service was delivered was felt to be well outside of their knowledge and usual concerns. Even when assured by interviewers that their opinions about the proposed change were important, they often responded by saying 'what can I do? [about the change]'or by asserting that changes were the responsibility of those better equipped to decide, including the research team and the government.

Support for primary care delivery

The principle of local delivery of mental health services was agreed upon by caregivers, primary health centre workers and HEWs, participants in community consultative meetings and also endorsed by some service users. Key reasons for supporting local delivery were ease of access, reduced cost and reduced caregiver burden. Having a local service was associated with easier access to services: caregivers felt that this would make regular follow-up more achievable, that emergency access would be more feasible and that visits would be less stressful, requiring fewer people to accompany the service-user to appointments:

> Some patients are very strong, which makes it hard for the caregiver to take charge and take the patient to the health provider. There are instances where their legs are chained with shackles,

some patients can't even be contained with the help of one or two people. For these reasons some caregivers may not even consider bringing them to the health provider.—Caregiver, FGD 2

Three of the service-users interviewed agreed that local provision would be convenient because they could travel by foot and go to work after appointments. Primary healthcare workers and HEWs endorsed health centre delivery as a means of improving access to mental health care. There was clear recognition of unmet need from primary healthcare workers:

> As a matter of fact I think it's in peoples' best interests to have services brought here. There have actually been instances where we have turned away people who came seeking these very services—Primary Healthcare Centre worker, FGD 4

Beyond the advantages associated with the convenience of a local service, reduced costs were considered to be significant. This included spending less transport for shorter distances (e.g. Horse-driven cart rather than minibus or other motor vehicle) or being able to walk to the service, and reduced indirect costs due to less time out from other activities:

> It would be good to have it [mental health service] in our localities because the maximum amount of time a person would have to spend on the road is no more than 30 min. This way the caregiver and even the patient will be able to get back to work. So not only will this help us to save money but also to be more productive. The impact this will have on reducing costs for people will be tremendous—Caregiver, FGD 2

HEWs acknowledged that they were well-placed to deliver mental health services to their community, both because of their physical location within the health posts but also because they are a part of the communities in which they work:

> All the tasks that the government proposed to be performed at the primary healthcare level can be performed because we know each other among the community. We live and work here. We are from this community and we are familiar to each other—HEW, FGD 1

Primary healthcare workers agreed that because of their extensive experience working in the local area, HEWs would be best placed to 'reach' people with SMD deliver mental health care.

Concerns about the shift to primary care delivery

Acceptance of the planned new service was qualified by concerns about change and disruption to a familiar service that was seen to be working well. Amongst the key concerns were adequacy of staff competence, consistency of supply of medications and whether or not service users would be treated respectfully in the primary healthcare centres. Caregivers were concerned about whether health centre staff would be sufficiently knowledgeable and skilled to be able to correctly prescribe and monitor medications. This concern was illustrated by examples of perceived improper management of other health conditions in the health centre setting:

> A son of my uncle's was sick this last August...he lives around Bamo. He had malaria. They [the Health Centre workers] give him three pills he was not supposed to take. And he ended up passing out due to overdose...When we got him checked in here at the hospital; we learned that the medication which we gave him was wrongly prescribed—Caregiver, FGD 1

Caregivers were concerned that health centre workers would not be able to handle the more complex and severe cases of mental illness

as well as the hospital-based psychiatric nurses. They were also unsure whether or not the PHC staff would have the skills or knowledge to be able to provide the counselling and advice that they were used to receiving. They were somewhat sceptical about the effective management of follow-up. Healthcare workers shared some of these concerns about their own ability to do a good job and the impact that this might have upon patient's and caregiver's use of the local health services:

> If we tell them to come here but fail to administer the services properly, it will further erode their [patients & caregivers'] faith in the health system. They may even resort to alternative methods of treatment. We have to do everything in order to prevent this— Primary healthcare worker, FGD 4

Three of the eleven service-users interviewed indicated clearly that their only concern in relation to service change was that their medication supply was uninterrupted. Caregivers shared this concern:

> if they were to say that they have run out of medication, it will be like playing with people's lives. Like I have said earlier, it will be a great loss if something was to be broken or if a life was to be lost as a consequence of this negligence— Caregiver, FGD 1

This concern was justified with examples. Focus group participants cited occasions when health centres had run out of medications for other conditions. It was suggested that this was due to staff negligence rather than issues with supply. There were also concerns that rural facilities would lack the capacity to store medications adequately.

As described previously, in general, service users did not express a clear preference for either hospital or health centre-based care. However, when prompted regarding whether the change to health centre delivery was likely to be problematic in any way, four of the service users interviewed described aspects of the current model that they viewed as advantageous. These included, the familiarity of the service, the respectful and caring way in which they were treated at the hospital and the lack of waiting time for appointments:

> we have been adapted to this place and also with the works like father and child. It is a treatment which we began from the beginning. Therefore we are very happy if we stayed here—Service-user, IDI 15

Relationship of primary care to traditional and faith healing

One HEW expressed the concern that they may face some resistance from the community during the implementation of locally delivered mental health services, related to the treatments currently provided at holy water and religious sites. However, this was felt to be an obstacle that could be overcome through persistence. HEWs in the other focus group felt that the issue of treatment with holy water should be addressed explicitly as part of the community awareness campaign:

> There was one of our staff who had a mental illness. But there is a priest who knows that her problem is a mental illness. Though he knows that she gets well when took her medication, he keeps her with him saying that the solution is holy water. He kept her away from her family even up to now. Therefore what is needed from religious leader is to know about the mental illness and treatment clearly. This practice shouldn't be stopped. It should be told in the church that a mental illness couldn't be healed by a holy water

Focus group facilitators asked caregiver participants whether seeking help for their family member's mental illness within the local community would cause them any difficulty or discomfort, e.g. due to stigma. Respondents indicated that an untreated person with SMD was difficult to hide and so the location of treatment had little bearing on such issues. Treatments carried out according to the recommendations of traditional healers were also visible and may involve the assistance of community members. The lack of impact of traditional treatments and the impact of modern intervention were also apparent. Therefore accessing services within primary care was felt to be unlikely to incur any additional stigma:

> Everyone would know about the mentally ill person. I don't think anyone would share this view [that it is difficult to seek care in local community]. For example, I have slaughtered many [stock] for the traditional healer [...]when he [traditional healer] tells us to slaughter megasa burqa [a particular type of sheep] I always followed his orders: I washed him [his son] with the carcass's blood when I was told to do so[...]After all my efforts, nothing worked. Finally he regained his peace of mind when he got this pill...So what I am trying to say is that this is not the kind of illness you can hide from people. How can you even manage that? It actually requires the involvement of other people— Caregiver, FGD 3

Overcoming concerns
Training
Primary health centre staff, HEWs and participants in community consultation meetings were in agreement about the importance of training in determining the success of local delivery of care. For caregivers, provision of appropriate training and 'refresher trainings' for primary healthcare centre staff and HEWs was identified consistently as the key intervention needed to overcome concerns about staff competence, supply of medications and treating service-users with respect. Healthcare workers acknowledged that their very limited baseline knowledge about mental health meant they were currently ill-equipped to address mental illness:

> I know what the problem is but I just don't know how to treat it. There is misconception in the community that mental illness is caused by evil spirits etc. I have, through my training, come to learn that these problems are treatable but there is nothing in my scope of expertise that I've been able to do so far—Primary healthcare worker, FGD 4

However, primary healthcare workers and HEWs were mostly enthusiastic about receiving training and expressed confidence that, with the right training, they would gain the knowledge and skills to deal with mental illness effectively in their communities. The consensus among primary healthcare workers was that all clinical staff working within the primary healthcare unit (HEWs, nurses and health officers) should receive the mental health care training. Reasons for this related to ensuring availability of the service at all times: to reduce delays for service users and their families and to prevent disruption due to staff turnover, sickness, annual leave and transfer to other health centres. However, a minority of primary healthcare workers and health centre heads (at a community consultation meeting) raised the idea of training a specialist workforce of motivated and gifted individuals, to ensure that those treating mental health problems were prepared for the perceived difficulty and complexity of the task.

HEWs were keen to understand the limits of their training and their role in managing SMD. Understanding when to refer service-users to a health centre was identified as an important aspect of this

component of training. Once again, the establishment of good working relationships with service-users and their families was felt to be essential to building the necessary trust to make referral pathways work. Experiences and received narratives of the violence, threat of violence and aggression associated with (untreated) SMD in the community meant that ensuring personal safety was a concern for HEWs. It was recognized that training on how to approach people with SMD and how to manage aggression was essential to enable the development of the effective working relationships needed to deliver mental health care:

> Unless we are capable enough without being shy and fear, we can't help the patients. We should get enough training to build a relationship which qualifies for treatment, and there to do awareness creation and behaviour change to the caregivers and community appropriately and with full confidence—HEW, FGD 11

HEWs recognized the role of family/caregiver relationships in determining the outcomes of service-users and also the difficulties associated with living with someone with SMD and were keen to learn how to work effectively with families as well to provide a holistic service that supported recovery:

> The other thing is supporting patients who recovered from the illness, to be functional and productive in their life. In order to support them, we will use the community in the kebele [sub-district], the safety net and different organisations which works in relief to enable these people by doing better work..'—HEW, FGD 11

Monitoring and demonstrating equality of service with that provided at Butajira Hospital

Caregivers in all three FGDs and one service user stated that evidence to suggest that the quality of the service provided in primary care was equal to that provided at the hospital would enable them to overcome concerns about primary care delivery.

The importance of monitoring progress was mentioned in two of the three caregiver focus groups, one of the primary healthcare worker focus groups and in one of the service-user interviews. The caregiver participant who raised the issue suggested that the research team would be best placed to carry out the monitoring whilst the service-user suggested an 'external' body and the primary healthcare worker suggested that healthcare workers may need to go into the community to speak to defaulters. One participant noted that despite their own scepticism about other services delivered in the health centres, the only way to know whether the new service was 'up to standard' would be to use it.

Community awareness

Healthcare workers, in particular, HEWs emphasized the importance of developing community awareness as a pre-requisite for the successful transfer of services from hospital to primary care delivery:

> There is nothing that can't be changed if proper relationship is created with the community. We implement many activities through building relationship with the community. We usually work on the sixteen health extension packages in the same way—HEW, FGD 11

Community awareness was conceptualized as provision of information about the service to key stakeholders in the community, including leaders at the kebele (sub-district) level, development workers, teachers and religious leaders. HEWs noted that community awareness-raising would require the support and input of community leaders. The idea of having a named person at the district level

who would be a mental health advocate was raised by health professionals at the community consultation meetings.

HEW, FGD 11

Discussion

Legitimacy of primary care delivery model

Our findings indicate that researchers and stakeholders (caregivers, service-users, primary healthcare administrators and providers, HEWs and community leaders) understand and agree upon the potential advantages of delivery of primary care-based treatment for people with SMD in rural Ethiopia. The established and on-going programme of research, treatment and community participation in mental health in Butajira district has provided a strong foundation for community engagement with service change. There is widespread support for this common goal in the context of some shared concerns about potential barriers to implementation. Encouragingly, our results indicate that there is a significant appetite for the mobilization of healthcare and community resources in order to give the change of service delivery the best chance of success. The detailed information about training needs and ideas and the necessity of community engagement indicated by our findings will be used to refine the implementation of the new model of service delivery.

A particular strength of the study was the inclusion of the perspectives of all relevant stakeholders, including service users and caregivers, on an important change to mental healthcare delivery. Among some of the voices presented, a sense of ownership and momentum for further social change may be detected. This was particularly salient among HEWs and caregivers, in relation to community awareness raising, access to treatment and reduction of stigma. In addition to strengthening legitimacy and helping to ensure appropriateness of planned changes for the populations served, community participation may encourage ownership of services and empowerment of disadvantaged groups (Kleintjes *et al*. 2010). The inclusion of the perspectives of service users and caregivers is a step forward for mental healthcare planning and development in low-income settings. However, it should be acknowledged that our approach to participation was nominal (White 1996), constrained by resources and by the scope of the project described here. The extent to which this work conveyed empowerment is difficult to assess but likely to be modest. In future, further efforts should be made to support a higher level of participation. Who participates in such consultation warrants additional consideration. As the development of new mental health services in low and middle income settings continues apace, it would be useful to evaluate the effectiveness and impact of different strategies to encourage participation in health service planning.

Another strength of our approach was that mental health service users and caregivers were recruited from a population-based study of SMD (Kebede *et al*. 2003; Fekadu *et al*. 2006; Alem *et al*. 2009) and were not subject to the selection biases towards higher education and socio-economic status which are commonly encountered in facility-based studies. The mental health service users and caregivers had experience of a model of mental health care delivered by psychiatric nurses and supported by project outreach workers. This meant that respondents were able to compare the planned new service model to a good quality and functional example of the existing model of decentralized mental health care in Ethiopia. This contrasts to other studies of acceptability and feasibility of task sharing where respondents have had limited experience of any mental health care.

Ensuring preparedness for change

Adequate preparation of teams and communities before implementation is essential to successful transition from hospital to primary care delivery, as underlined by our findings. Further community awareness-raising about available services was seen to be a pre-requisite for utilization. Because of the tangible impact pharmacological treatment has been seen to have upon people's lives, the consistent provision of medication was clearly identified as being central to the value placed on the existing service. In FGDs, negative experiences of healthcare were linked to mistrust and seeking alternative services elsewhere. Any disruption to medication supply would engender mistrust of the service and would subsequently constitute a serious threat to the success of the transition from hospital to community-based care. Training should therefore aim to equip staff to deliver this essential component of the service well from the start. On-going supervision and support is necessary to ensure sustainability. Chains of supply and distribution must be reliable and it must be ensured that health centres have the capacity to store and manage medications.

What should a primary care delivery of a service for people with SMD look like?

In common with findings from other studies carried out in Ethiopia, we found that healthcare workers were starting from a very low knowledge base, with very little understanding of evidence-based interventions for SMD, but an appetite to learn more. This discrepancy between the self-reported skills-gap among healthcare workers and the prioritization of faultless medication supply by service-users and caregivers further underlines the importance of training and supervision in this area. In contrast to other studies, where healthcare workers have recognized the importance of integration of mental health care within primary care without necessarily endorsing being personally involved in the delivery (Abera *et al.* 2014; Mall *et al.* 2012; Mwape *et al.* 2010), HEWs in our study recognized the importance of primary care delivery and expressed confidence that with appropriate training, they were well-placed to deliver the proposed service.

Support received from hospital and research staff and the respect with which service-users were treated were highly valued characteristics of the existing service. There was anxiety, particularly among service-users, that the change of service delivery model and personnel may lead to the deterioration of these attributes. In fact, HEWs demonstrated enthusiasm and ambition to address broader needs of service-users and their families. It therefore seems plausible that HEWs may be able to fulfil and develop the supportive role played currently by psychiatric nurses and research workers. As recognized by the HEWs themselves, their closeness to the local community may lead to a shared approach to dealing with problems, which may be advantageous in terms of perceived acceptability (Padmanathan and De Silva 2013; Chibanda *et al.* 2011; Petersen *et al.* 2012) and successful community engagement. This may, in turn, ultimately be an important contributor to the success of the transition to primary care delivery. HEW's emphasis on working with families to treat SMD are a good fit with the collectivist approach commonly held in many communities in LMICs, where the smallest autonomous unit is held to be the family rather than an individual (Hanlon *et al.* 2010).

Providing training to all staff within primary care centres so that everyone is equipped to deliver care for people with SMD was endorsed by the majority of healthcare workers. An advantage of this approach would seem to be that this may ensure that caregiver concerns about consistency of access and availability of the service in an emergency were met. However, a minority of healthcare workers in FGDs and health professionals at community consultation meetings raised the possibility of training a new cadre of specialist mental health workers selected for their motivation and particular skills. Perhaps because primary healthcare workers have yet to take on the role of delivering care for people with SMD, participants did not express the concerns about the additional burden this would bring that have been identified elsewhere among those already involved in the delivery of task-shared care (Padmanathan and De Silva 2013; Mendenhall *et al.* 2014; Petersen *et al.* 2011). This debate taps into ongoing questions about the limitations of task-sharing and the extent to which non-specialist workers in primary care may be expected to integrate mental health into their role whilst delivering high quality care to people with SMD (Hanlon *et al.* 2014; Lund *et al.* 2012).

Stigma and the enacted roles of service-users in rural Ethiopia

Our findings suggest that a person living with SMD is already identified as such to other members of these small, inter-reliant communities. Being treated within the community was not, therefore, anticipated to incur any additional disadvantage in terms of disclosure or stigma. Although healthcare workers were concerned about their personal safety when dealing with people with SMD, they endorsed a problem-solving, training-based approach that they believed would resolve their concerns. We found no evidence to suggest that healthcare workers held the kind of pervasively stigmatizing views about people with SMD held by healthcare workers in other settings (Kapungwe *et al.* 2011). On the contrary, HEWs believed that they could provide a bridge between traditional practices and stigma and endorsement of more effective modern medicine.

Healthcare workers, service-users and caregivers shared many of the same views about the potential advantages and pitfalls of management of SMD within primary care. However, one of the advantages of our study design was that it enabled us to examine the feasibility and acceptability of the change in service delivery from different perspectives. Despite overlap in many areas (e.g. all three groups recognized the economic advantages to caregivers and service-users of local delivery), prioritization of concerns differed between groups. For example, the primary concern of caregivers was ensuring high-quality medication management. The primary advantages of primary care delivery were perceived to be ease of transport and convenience of a locally delivered service. For service-users, medication interruption was clearly linked to relapse and subsequent suffering and was therefore something to be feared but it was also clear that the supportive nature of the service they had received up until now was highly valued.

As it is estimated that 90% of people with SMI in Ethiopia never receive mental health care (Kebede *et al.* 2003), the inclusion of relatively more experienced and empowered caregivers and service users in our study increased the likelihood that the responses tapped into the real concerns of these stakeholders. However, it is important to note that whilst caregivers seemed to endorse their role as experts invited to be involved in service development, service-users were reticent in expressing preferences and seemed unused to being asked for their opinions and stating their views. Data from service-user interviews therefore need to be interpreted with care. Although caregiver and service-user narratives conveyed vast improvements in functioning and participation (attributed to medication), the role

people living with severe SMD play in their communities is circumscribed by their diagnosis. Further research is necessary to disentangle to what extent this role limitation may be due to stigma and discrimination, ongoing symptoms or other factors in the context of Ethiopia. However, it seems likely that the limited opinions expressed by service users in interviews may be reflective of these wider restrictions on the way in which the lives of people with SMD are lived. These difficulties in obtaining data from service-users may impede the development of services that truly meet their needs. Researchers, service-providers and policymakers should be mindful of the differences in perspectives between caregivers and service-users and make efforts to involve both these groups in ongoing research and service development (Petersen *et al.* 2011).

Ethical approval

Ethical approval for this study was obtained from the Institutional Review Board of the College of Health Sciences, Addis Ababa University.

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