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"Restoring the person's life'': a qualitative study to inform development of care for people with severe mental disorders in rural Ethiopia

Running title: Care for severe mental disorders in rural Ethiopia

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Abstract

Aims

In low-income countries, care for people with severe mental disorders (SMDs) who manage to access treatment is usually emergency-based, intermittent or narrowly biomedical. The aim of this study was to inform development of a scalable district-level mental health care plan to meet the long-term care needs of people with SMD in rural Ethiopia.

Methods

The study was carried out as formative work for the **Pr**ogramme for **I**mproving **M**ental health Car**E (PRIME)** which seeks to develop, implement and evaluate a district level model of integrating mental health care into primary care. Six focus group discussions and 25 in-depth interviews were conducted with service planners, primary care providers, traditional and religious healers, mental health service users, caregivers and community representatives. Framework analysis was used, with findings mapped onto the domains of the Innovative Care for Chronic Conditions (ICCC) framework.

Results

Three main themes were identified. Theme 1) focused on 'Restoring the person's life', including the need for interventions to address basic needs for food, shelter and livelihoods, as well as spiritual recovery and reintegration into society. All respondents considered this to be important, but service users gave particular emphasis to this aspect of care. Theme 2), engaging with families, addressed the essential role of families, their need for practical and emotional support, and the importance of equipping families to provide a therapeutic environment. 3) Delivering collaborative, long-term care, focused on enhancing accessibility to biomedical mental health care, utilising community-based health workers and volunteers as

an untapped resource to support adherence and engagement with services, learning from experience of service models for chronic communicable diseases (HIV and Tuberculosis) and integrating the role of traditional and religious healers alongside biomedical care. Biomedical approaches were more strongly endorsed by health workers, with traditional healers, religious leaders and service users more inclined to see medication as but one component of care. The salience of poverty to service planning was cross-cutting.

Conclusions

Stakeholders prioritised interventions to meet basic needs for survival and endorsed a multi-faceted approach to promoting recovery from SMD, including social recovery. However, sole reliance on this over-stretched community to mobilise the necessary resources may not be feasible. An adapted form of the ICCC framework appeared highly applicable to planning an acceptable, feasible and sustainable model of care.

Key words:

Chronic care model, primary health care, schizophrenia, mental disorders, sub-Saharan Africa, community-based rehabilitation, recovery, social inclusion.

Introduction

The treatment gap for severe mental disorders (SMD), comprising psychotic disorders (e.g. schizophrenia) and bipolar disorder, is substantial in low- and middle-income countries (LMICs). In Ethiopia, it is estimated that around 90% of people with SMD never receive effective treatment (Kebede *et al.*, 2004). Furthermore, the care received by the minority who do access treatment is mostly emergency-based, intermittent and narrowly biomedical. The consequences of inadequate care for people with SMDs in LMICs are substantial, including prolonged mental ill-health for the affected individual, premature mortality(Teferra *et al.*, 2011), under-nutrition (Lijalem *et al.*, 2003), loss of productivity and functional impairment (Kebede *et al.*, 2006, Mogga *et al.*, 2006), economic and caregiver burden (Shibre *et al.*, 2003, Zergaw *et al.*, 2008), stigma, discrimination and abuse (Shibre *et al.*, 2001).

Compelling arguments have been made for making care for people with SMDs an essential component of emerging initiatives to achieve universal health care in LMICs (Patel, 2015). The World Health Organization (WHO) launched the mental health gap action programme (mhGAP) to improve access to care by integrating mental health into primary care services (World Health Organization, 2008). The mhGAP Intervention Guide provides evidence-based, packages of care for prioritised mental, neurological and substance use disorders (Barbui *et al.*, 2010, World Health Organization, 2010). However, at present, mhGAP does not address the issue of how these packages of mental health care can be delivered to people with SMD who have ongoing needs for care Furthermore, mhGAP has limited focus on how to achieve social and functional recovery in addition to clinical improvement. A systematic review of evaluations of community-based mental health care in sub-Saharan Africa revealed the paucity of data available to inform service development and implementation of care for people with SMD in LMICs (Hanlon *et al.*, 2010).

For long-term health conditions more generally, a 'chronic care model' of service delivery has been associated with improved outcomes (Wagner *et al.*, 1996). This model has been adapted for LMICs in the Innovative Care for Chronic Conditions (ICCC) framework (Epping-Jordan *et al.*, 2004). The ICCC framework incorporates the health system elements that support patient-centred care at micro, meso and macro levels (see Table 1). Recent interest in the integration of mental health care into existing chronic care models in LMICs (e.g. for HIV/AIDS or tuberculosis (TB)) has focused on depression and alcohol use disorders due to the high levels of co-morbidity and evidence for the effectiveness of task shared care (Patel *et al.*, 2013). However, this strategy may not meet the needs of people with SMD in LMICs. Integrated models for people with SMD in high-income countries have included resource-intensive specialist multidisciplinary teams which are unlikely to be feasible in LMICs (Lehtinen and Taipale, 2001). Contextual differences between HICs and LMICs, for example in terms of community poverty levels, literacy and social connectedness, need also to be considered. To the best of our knowledge, the ICCC framework has not been applied previously or evaluated with respect to the care of persons with SMDs in LMICs.

The Programme for Improving Mental Health Care (PRIME) (Lund *et al.*, 2012) aims to produce high quality evidence about how to implement mental health care within primary and maternal health care services in five LMICs (Ethiopia, India, Nepal, South Africa and Uganda). In this paper we present data from formative work from the PRIME study in rural Ethiopia. Our objectives were (i) to identify the key components of a model of long-term mental health care integrated into primary care for people with SMD in this setting, and (ii) to explore the acceptability, feasibiity and sustainability of potential strategies to achieve long-term care with the goal of achieving recovery and social reintegration.

Methods

Study design

A qualitative study employing individual in-depth interviews (IDIs) and focus group discussions (FGDs) (Lambert and Loiselle, 2008).

Study setting

The study was carried out in Sodo district of the Gurage Zone, in the Southern Nations, Nationalities and Peoples Region of Ethiopia, located around 100km south of the capital city, Addis Ababa. Sodo has a population of around 160,000 adults(Central Statistical Authority (CSA), 2008). The area is predominantly rural. The majority of people engage in subsistence farming.

At the time of the study, there were no mental health services within Sodo district. The nearest mental health service was a psychiatric nurse-led out-patient unit located in the General hospital in the neighbouring district of Butajira, between 30 and 50km away. The nearest in-patient psychiatric care is available in Addis Ababa. In Sodo district there are eight health centres delivering primary health care, mostly staffed by nurses and health officers. There are no medical doctors or hospital facilities. Linked to each health centre are paid, community-based, health extension workers (HEWs), who form the primary health care interface with the community. HEWs are all women, high school completers who are recruited from the local area and have received one year of training in health promotion and illness prevention. Most HEWs have little or no training in community-based mental health care. There is also a community network of health volunteers mobilised for health education (Donnelley, 2011).

Population and sample

A sample of key stakeholders was selected purposively, covering each of the planned levels of the PRIME mental health care intervention; health service organisation (n=4 IDIs from the District Health Office and Federal Ministry of Health), health facility (three FGDs with PHC frontline workers and supervisors of HEWs) and community (one FGD with HEWs, one FGD with health volunteers, one FGD with families of persons with mental and developmental disorders, and IDIs with family members (n=3) and mental health service users (n=8), traditional and religious leaders (n=5), community leaders (n=3), and representatives from non-governmental organisations active in the area (n=2). Characteristics of the participants are summarised in Table 2. FGDs were used whenever it was feasible to convene a relatively homogeneous group of respondents (e.g. primary care workers, health volunteers, family members) in order to elicit additional information about the manner in which the respondents spoke about the topic in front of one another as well as their perspectives on the topic. In-depth interviews were used when the informants were more heterogeneous or difficult to access or, in the case of mental health service users, to avoid the potential stress of a group discussion.

Research process

All IDIs and FGDs were conducted in Amharic, the official language of Ethiopia, by three experienced Masters' level research assistants. The FGDs were conducted in primary health care facilities. The IDIs were carried out in a neutral central location in Sodo district, in people's homes and in the offices of policy-makers and planners who were based in the capital city, Addis Ababa. At all times privacy was ensured. Apart from service planners, all participants received remuneration for transport costs and FGD participants also received refreshments. The FGDs followed recommended methodology (Krueger and Casey, 2009). For the FGDs, a note-taker was present in addition to the facilitator, in order to observe and document non-verbal communication.

Interview guide

The IDI and FGD topic guides were developed collaboratively across the PRIME research programme consortium and tailored to the different categories of respondent and country context. The topic guide drew on our review of the literature and focused on aspects of intervention provided by the health care system ('biomedical intervention'), especially adherence to medication, engagement in care (outreach), case management (continuity of care), as well non-health sector aspects, in particular rehabilitation, social inclusion and reintegration (countering stigma, discrimination and abuse). The topic guide explored aspects of delivery of integrated mental health care in relation to psychosis (the focus of this paper) and other disorders. Where needed, a standardised vignette for psychosis was used to orientate respondents (Alem *et al.*, 1999, Wig *et al.*, 1980).

Data analysis

IDIs and FGDs were audiotaped, transcribed in Amharic and then translated into English by the interviewers prior to coding. Any ambiguities or points of interest were discussed and noted within the transcripts. Analysis was carried out concurrently with data collection. Each research assistant kept field notes. After each set of data collection, CH discussed with the research assistants about emerging themes and unexpected findings, to inform iterative development of the topic guides and theoretical sampling. A framework analysis approach was utilised (Smith and Firth, 2011) which involved independent coding of text by SM and CH and verification meetings with the interviewers. Qualitative software was used for data management (ATLAS.ti. Version 5.0, 2003, NVivo qualitative data analysis software. Version 9, 2010).

Ethical considerations

The study was approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University, and the University of Cape Town human research ethics committee. After being informed fully about the study, respondents gave voluntary consent.

Findings

The findings are structured under the following themes, which reflected the most salient domains of long-term care for people with SMD: (1) 'Restoring the person's life', (2) Engagement with families, and (3) Delivering long-term, collaborative mental health care. Cutting across these themes was the salience of poverty. For full quotations grouped by theme refer to Supplementary file 1.

"Restoring the person's life"

Respondents spoke of the complexity of the process of rehabilitation, recovery and reintegration for people with SMDs. The required interventions were considered to be those targeting basic needs for food, shelter and livelihoods support of people with SMD, overcoming social exclusion and attending to spiritual recovery. Community respondents expressed willingness to respond to the needs of those with SMD akin to similar community mobilisation for people living with HIV/AIDS: provision of shelter and food. A local health service planner spoke positively of the community's willingness to help by providing food and economic support:

> … The process of restoring the person's life will be a time taking process as this is a person who has lost many things in the course of his illness. ... Our community is very cooperative. . ... We have ample experience with HIV where people provide each other with support.

IDI 6, Local health service planner

The need for tangible support to meet basic needs was reported across all categories of respondents but emphasised particularly by service users and family members. Poverty alleviation was considered to be critical to the success of any intervention to help people with SMD, in terms of accessing care, being able to take medication continuously, making a full recovery and protecting against relapse in the future.

> **…**A person may recover from his illness; but deprivation could cause him to go back to being "crazy". . ... What is expected of us is to help create jobs for these people.... Until something is done for these people they are in danger of relapsing.

FGD 6, Health volunteers

However, recovery was considered to be about more than meeting basic needs for survival. Many respondents spoke of the need to provide moral support and encouragement, as well as attending to the person's spiritual recovery.

> In helping that person to get back on track we need to provide him with a wide array of support through prayer; counselling; money and many other ways.

IDI 10, Religious leader

Some community leaders were uncomfortable with the idea of including people with SMD in positions of authority, even post-recovery. People with SMD spoke of how such stigmatising attitudes impeded their recovery.

> I have a strong interest to start working but no one understands and trusts me because I am mentally ill.

ID19, Person with SMD

However, the potential role of community members in promoting the social inclusion of those recovering from SMD was mentioned by the health volunteers and HEWs. In both instances, public contact with persons with SMDs was advocated in order to prevent discrimination.

> We can establish relationships with these people; spend time with them; take them out for some tea and coffee. If we spend some time with them, we can help them make small improvements. They generally tend to feel alienated and that they are outcasts.
>
> FGD 6, Health volunteers

HEWs expressed willingness to involve people with SMD in the local community. Religious leaders also perceived that they had a role in overcoming negative stereotypes of people with SMD.

> Currently, there is no message transmitted from the religious leaders. As a result, the community is careless towards the needs of these people. They think that the person is crazy and there is no hope afterwards. ...The person's full life journey may be considered as ruined.
>
> IV05 Religious leader

There was some evidence of social desirability affecting responses in the health extension worker and community health volunteer groups, as well as at the healthcare administration level, with respondents speaking positively about the community's capacity to mobilise and support vulnerable people. However, despite the enthusiastic response of these respondents, other respondents highlighted the lack of community activity to date for people with conspicuous mental illness and doubted the capacity of the community to be able to respond materially on an ongoing basis to the challenge of caring for those with long-term SMD. They explained that the successes associated with rehabilitation for those with HIV were only

possible because of additional external resources. People with long-term SMDs and their caregivers spoke from their own experience.

> The … problem is that it is a long-term illness. People will get tired of you if you are ill for [a] longer [period of time].…
>
> ID 16 Person with SMD

Engaging with families

Family members described their desperate efforts to seek effective help and ongoing care and support for their affected relatives. Many family members described crossing between two systems of healing, traditional healing and the health system, incurring substantial costs along the way. The emotional burden on family members and the need for support beyond the prescription of medication was also articulated by respondents.

> It's been a year since the younger one got sick. He sleeps all day; …. I have taken him to a holy water site [Ethiopian Orthodox Church]. Recently I have become tired and I have given up altogether.
>
> FGD 5, Family members

Religious institutions appeared to provide most of the limited support available for people with SMD who did not have family, although community groups sometimes helped with acute crises.

Equipping families to better meet the needs of their mentally ill relatives was emphasised, particularly by community level informants and less by the facility-based health workers.

Families needed to be informed about the rationale for long-term medication and the importance of engagement with health services. Beyond this, one religious healer also described how he counselled families to behave in a more therapeutic manner:

> R: Yes. I beg their parents not to chain them up. I plead to treat them in a caring manner with the help of God. I told her parents not to disappoint her because that might lead to relapse. There should not be arguing with her.
>
> IV08, Holy water attendant

> R: I think the family needs more treatment and encouragement than the patient. We explain to them that there is a cure for someone who is mentally ill. Illness is always there with human beings. We tell them not to lose hope. If they help the person receive psychological treatment, if the person takes his medication properly, if he receives good care, if the person keeps time in taking his medication, that person would be important member of the family and good citizen. Therefore, we tell them this.
>
> I: So you educate the family?
>
> R: Yes. We tell them to be patient.
>
> IV07 Religious healer

Delivering collaborative, long-term mental health care

The need for biomedical intervention, particularly long-term medication, for SMDs was endorsed by most participants although there were discordant views amongst some mental health service users. The proposal to integrate mental health care into primary care was

welcomed as important for improving access to affordable care. However, there was recognition of the limitations of medication and facility-based care, and the need for long-term residential mental health care for people with complex and refractory illness was mentioned. Religious healers and other community-based stakeholders, including people with SMD, gave greater emphasis to medication being just one component of care rather than sufficient in itself. Traditional and religious healers were considered by many respondents to have an important ongoing role alongside biomedical care, targeting the presumed root cause of the disorder (spirit possession) and allowing for potential cure.

> There are cases which can be cured by traditional and faith based healers … so for us spending time in hospital is a waste…. On the other hand there are people who can be cured by modern treatment…so it would be good if both were working together.
>
> ID23 Person with SMD

Many family members reported, however, that despite multiple trips to holy water sites and high levels of expenditure, they saw little benefit of the holy water. Health professionals and family members tended to focus more on medication. Health professionals in particular framed the potential role of traditional and religious healers in terms of improving engagement with facility-based care and adherence to medication:

A reliable medication supply, incentivising primary health care workers, systems to enable tracking of people who default from treatment and dedicated clinics for mental disorders, akin to those used in HIV and TB care, were advocated by health care provider respondents. These providers were familiar with the challenges of providing long-term care and advocated utilising strategies that had been successful for HIV and TB care to promote medication adherence, including attending the health facility to take medication ('Directly Observed Therapy') and a 'Guarantor' model where a person takes responsibility for guaranteeing that

the patient would receive the medication as prescribed. Respondents spoke of the benefits of using the new network of HEWs and the health volunteers as the mechanism for co-ordinating outreach from the health facility and long-term engagement in care.

Intervening with food or financial and psychosocial support was recommended for those persons whose adherence to medication and engagement in care might be jeopardised by extreme poverty, again drawing on the model of care employed for HIV treatment.

Discussion

In this paper we present findings from formative work to develop a service model of long-term mental health care for people with SMD integrated into primary care in a rural African setting. A broad range of stakeholders participated and emphasised the need for care that extended beyond the provision of medicine to also address basic needs for survival and to support social and spiritual restoration of people with SMD. The crucial role of the family and the need for accessible integrated and collaborative care were also important themes. Some religious healers and people with SMD gave less emphasis to biomedical care. An adapted version of the ICCC framework appeared highly appropriate for structuring the approach to long-term care for people with SMD.

Restoring the person's life

Participants prioritised interventions to meet the basic survival needs of people with SMD. This resonates with a previous qualitative study from rural Ethiopia in which people with SMD and their caregivers spoke of the difficulties adhering to psychotropic medication and

attending follow-up appointments due to food insufficiency and poverty (Teferra *et al.*, 2013). The bidirectional relationship between mental disorders and poverty is well-established (Lund *et al.*, 2011), and particularly salient in LMIC settings, where people with SMD and their families are often among the poorest in society (Lund *et al.*, 2011).

In this study, the community expressed willingness to provide support for basic needs of people with SMD, and so community mobilisation for instrumental support will form part of the planned intervention. However, the sustainability of this approach was questioned. Caregivers expressed doubts about the reliability and capacity of the community response. During scale up of access to antiretroviral therapy in persons living with HIV/AIDS, the need for externally-funded food supplementation and poverty alleviation strategies was recognised and included in many programmes (Au *et al.*, 2006, Hardon *et al.*, 2007). The potential need for such external support to ensure successful implementation of integrated mental health care will be investigated as part of the PRIME case study (De Silva *et al.*, 2015).

The need for rehabilitation, including opportunities for skill (re)acquisition, was recognised by respondents in the study. Raising awareness within families and the wider community about the importance of supporting people with SMD to resume previous activities and play their part within the community was seen as an essential first step. However, our findings indicated that the community level of the ICCC framework required expansion to include livelihoods initiatives and access to paying work. This was a particularly high priority for people with SMD.

The community-based health workers and volunteers were quick to emphasise their potential

role in reducing stigma by socialising with people with SMD and including them in community work, thus helping to restore their status. The potency of 'direct contact' interventions in reducing stigma has been shown in other settings (Thornicroft, 2006) and will be promoted in the PRIME intervention for SMD.

'Engagement with families'

In relation to recovery and reintegration of people with SMD, family members were regarded as an important resource. Several respondents conceptualised the unit of intervention to be the family and not the individual with SMD, recognising their vital role in bringing a person with SMD to care and providing them with ongoing support (Thara *et al.*, 2008). Ensuring that the family, as well as the person with SMD, is given adequate information about the nature of the condition and its treatment accords well with the ICCC framework, which broadens the notion of patient-centred care to involve other key actors.

The high level of emotional and financial burden experienced by family caregivers of people with SMD has been demonstrated previously in a rural Ethiopian setting(Shibre *et al.*, 2003). Providing locally accessible mental health care may by itself reduce the burden substantially (Shibre *et al.*, 2012). However, community-based self-help groups for service users and caregivers in Ghana were found to provide important benefits to caregivers in terms of both practical and emotional support (Cohen *et al.*, 2012) and may be a feasible and useful intervention for the Ethiopia setting. Attending to the mental health of family caregivers is likely to benefit care for people with SMD, again linking with the ICCC framework approach that recognises the interconnectedness of patient and family health.

Religious healers spoke of a potential role in advising the family on how to interact with their

family member with SMD; for example, to speak softly, not to argue with them, to treat them in a caring manner. In Western and some LMIC settings, familial 'high expressed emotion' towards a person with SMD, characterised by hostility, critical comments and emotional over-involvement, is associated with poorer clinical outcomes (Brown *et al.*, 1972, Leff *et al.*, 1987). Furthermore, structured family interventions tackling these patterns of interaction reduce the risk of relapse of psychotic disorders (Pfammatter *et al.*, 2006). Family intervention may, therefore, be fruitful area of collaboration between the public health system and traditional and religious healers in Ethiopia. Such a community level approach to improving patient outcomes is at the heart of the ICCC framework.

Delivering long-term, collaborative mental health care

Several lessons for the delivery of long-term care for SMD were drawn from existing service models for HIV/AIDS and TB and again accord well with the ICCC framework for interventions at health organisation and community levels. Health service and system innovations used for the care of people with HIV/AIDS and TB, such as task-sharing care in primary are, maintenance of a case register to track people defaulting from care, liaison with community health workers to provide community outreach and medication adherence support over extended periods of time, were all assumed to be applicable to the delivery of mental health care. Similarly for the community-level focus on awareness-raising to reduce stigma and community mobilisation to provide support.

The recommendations for adherence support drew largely on interventions used for TB, including the Directly Observed Therapy model. This approach has been applied successfully to the care of people with SMDs in India (Farooq *et al.*, 2011), although qualitative evaluation from another study revealed that families sometimes felt overburdened when

asked to support adherence preferring involvement of non-relatives (Mall S *et al.*, 2013). This approach aligns well with the ICCC framework emphasis on community level intervention running alongside patient level care.

Service users in particular favoured involvement of traditional and religious healers. Our previous strengths-based approach to mapping community resources in the PRIME implementation district underlined the strong presence of traditional and religious healers (Selamu *et al.*, 2015). However, this previous work also indicated that restrictive practices, such as chaining people with SMD, are widespread in such healing sites. The evidence base for collaborative care with traditional and religious healers is limited (Gureje *et al.*, 2015). Efforts will be directed at finding a workable model of collaboration which enhances the outcomes of people with SMD.

With care of people with SMD, an additional factor to be considered is the particular vulnerability of those people whose mental state impairs their decision-making capacity with regard to treatment. In our study, some people with SMD spoke of both the benefits and harms of being treated against their will, but the issue of non-consenting patients was notably absent from the discourse of other stakeholders. In ICCC framework terms, legislative changes to protect people with SMD who are not consenting to treatment would need to be addressed in order to provide an enabling policy and service environment for mental health care.

Informing a model of long-term mental health care for people with SMDs

The study findings led to development of a proposed model of care for people with SMD in rural Ethiopia adapted from the ICCC framework. See Figure 1. In keeping with the ICCC

framework, the ‘micro’ level interventions emphasise the patient/family-community-health facility triad in relation to poverty alleviation, adherence support, long-term access to care, rehabilitation, reintegration and traditional/religious healing. Similarly, for the ‘meso’ level, health care organisational changes are intimately linked to community participation, for example, in facilitating adherence, engagement and improved self-management and health promotion. The ‘macro’ level was not a focus of this study but a potential need for external resources to support poverty alleviation was clearly articulated by respondents.

Limitations

The study findings may not be generalisable to other settings, although are likely to be applicable to rural Ethiopian contexts.

Conclusions

In this formative study to develop a sustainable and feasible model of long-term care for people with SMD in rural Ethiopia, an adapted form of the ICCC framework appears to capture the multi-faceted and interconnected interventions needed for successful outcomes. The acceptability, feasibility and effectiveness will be evaluated as part of PRIME (De Silva *et al.*, 2015).

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Conflict of Interest

None.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Figure 1: An adapted ICCC framework (Epping-Jordan *et al.*, 2004) for planning long-term care of people with severe mental disorders in rural Ethiopia

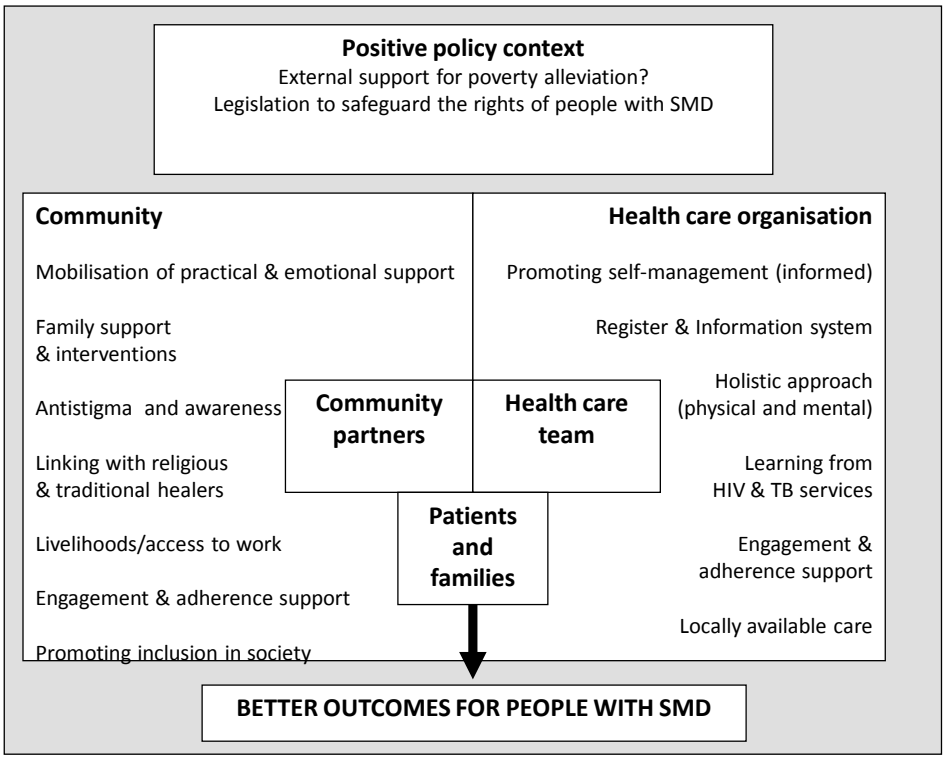

Table 1: Components of the Innovative Care for Chronic Conditions (ICC) Framework

Level	Explanation
Meso	At this level, the framework advocates for: • informed, motivated and prepared community partners • health care teams and patients to achieve improved patient outcomes • leveraging community resources for care
Micro	This level emphasises equipping health facilities to provide continuity of care including: • decision support for clinicians • clinical information systems • co-ordination of interventions, in collaboration with the community
Macro	This level considers the contribution of a 'positive policy environment', including: • integrated policies for chronic care • mechanisms for ensuring adequate human resources and medication supplies

Table 2: Sociodemographic characteristics of participants

Data collection modality	Participant type	Gender		Age (years)	Other characteristics
		Male	Female		
Focus Group Discussion (FGD) 1	Primary Healthcare (PHC) workers	4	3	26-39	Nursing diploma, degree, health officer Years of experience, 1-7
FGD 2	PHC workers	2	4	25-40	Nursing diploma, degree, health officers Years of experience, 3-20
FGD 3	Health Extension Workers	0	7	21-26	1 year HEW training Years of experience, 2-3
FGD 4	PHC worker supervisors	5	0	27-39	Nursing diploma, degree, health officers Years of experience, 2-7
FGD 5	Health volunteers	7	2	25-38	5th grade, up to diploma
FGD 6	Caregivers of persons with mental disorder	2	8	-	Family member with psychosis (n=1), epilepsy (n=4) and intellectual disability (n=2)
In-depth interviews	Traditional and religious healers	4	0	29-52	All literate, up to diploma
	Community leaders	4	0	53-70	4th to 8th grade
	Non-governmental organisation representatives	2	0	32, 33	Both degree level
	Service planners and co-ordinators	4	0	-	Degree, Masters, Post-graduate psychiatry qualification
	Service users	4	5	25-45	4 non-literate, 3 able to read and write, 1 8th grade, 1 diploma
	Caregivers	2	1	50-60	2 non-literate, 1 able to read and write

(Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. *Qual Saf Health Care* 2004;13:299-305.)

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Supplementary File 1: Quotations to support themes

Theme 1: Restoring the person's life

… The process of restoring the person's life will be a time taking process as this is a person who has lost many things in the course of his illness. This is one of the most challenging parts. Our community is very cooperative in this regard. . ... If the *kebele* [sub-district] is capable of supporting and restoring him it's a good thing, but if they can't, they refer that person to the district. We have ample experience with HIV where people provide each other with support.

IDI 6, Local health service planner

…A person may recover from his illness; but deprivation could cause him to go back to being "crazy". So we should begin from our own pockets in contributing to this end. ... What is expected of us is to help create jobs for these people; work in collaboration with aid organizations and the district administration. Until something is done for these people they are in danger of relapsing.

FGD 6, Health volunteers

What I personally think is when we look at this from a psychological, spiritual and humanity point of view, this is not something the person has brought on himself. ...In helping that person to get back on track we need to provide him with a wide array of support through prayer; counselling; money and many other ways. We need to be sympathetic towards this person.

IDI 10, Religious leader

I have a strong interest to start working but no one understands and trusts me because I am mentally ill. Regarding to social events my neighbours invite me for the feast but they don't ask me to support them … they always ask advice one another every day but no one seeks help from me …I am lonely …they don't take me as someone useful…but I can give some idea I am literate… I know many things.

ID19, Person with SMD

We can establish relationships with these people; spend time with them; take them out for some tea and coffee. If we spend some time with them, we can help them make small improvements. They generally tend to feel alienated and that they are outcasts.

FGD 6, Health volunteers

I: Mostly people with Mental illness are not allowed to be decision makers even after recovery. They may not be involved indecision making activities at Kebele, Woreda , Gott level.Most of the times may not be allowed to take part in social gatherings, or to express themselves. What do you think your role could be with respect to these things?

R.3: We should educate the community that mental illness is curable. We need to tell them that the person has the ability to get involved in the social activities and decision making.

I. What else?

R4: In the usual community gatherings we do, we can include mental health issues. We can instill the idea that the mentally ill could be involved in decision making. We can also involve them in the decision we make. If we do this the community will accept their role as able decision makers.

FGD Health extension workers

Currently, there is no message transmitted from the religious leaders. As a result, the community is careless towards the needs of these people. They think that the person is crazy and there is no hope afterwards. Even they may consider that the person's destiny is the grave. The persons full life journey may be considered as ruined. These are all negative impressions that our community has. There is no culture to support these people or take care of them. The community prefers teaching of a knowledgeable religious leader than what medical doctor could teach.

IV05 Religious leader

The other problem is that it is a long-term illness. People will get tired of you if you are ill for longer period of time. Your relatives could help you till you get well. But, people will get tired of you when you have an illness that stayed with you for years.

ID 16 Person with SMD

I have no confidence in the community's ability to give support. In my opinion, with God's help and with his family's support this person will support himself. He may recover; start working and support himself. But until that day comes the person may need the government's support. Aside from that I don't believe in what's being said about the community being able to give support. However much I like you, I will only be able to accommodate you for one or a maximum or two days. After that all I want to do is support myself.

FGD 5, Family members

Theme 2: Engaging with families

It's been a year since the younger one got sick. He sleeps all day; he doesn't do anything. I have taken him to a holy water site. Since recently I have become tired and I have given up altogether. He just stays at home with me; He takes the medications. They [her children with mentally illness] both stay home all day doing nothing.

FGD 5, Family members

R1: … We will counsel families so they should not be tired to care for their mentally ill family member.… R2: If there is a mentally ill family member who is on medication, that person would feel better through time. He/she would be led to a better life. But, if this person remains as a mentally ill without being treated, that person would be a burden for the family. Therefore, in the family, the person may need support and care. The family should encourage its mentally ill member to take medication. Such supports should be provided at the family level.

FGD 3, HEWs

R: It may be hard for us HDAs to identify these kinds of people. If that person has a problem it would be the family's responsibility to bring this problem to our attention. The existence of a problem has to be established first for us to be able to do anything about it. Our role is to sit with the family and discuss about the issue. Once we find the family it will be easier to reach the person. If we decide to simply contact the person without first talking to the family, the person may get defensive and tell us that there is nothing wrong with him. Contacting the family first will make the entire process smooth. So what we'll do first is contact the family, have a discussion with the person and then facilitate ways in which he can obtain the needed services from a healthcare providing institution. All of this will be facilitated with the

cooperation of the family. So I think it should be our role to engage in persuading and struggling [to convince people].

I: Do you all agree with this?

R: Yes

FGD Health Development Army

People without family might be vulnerable. These people may withdraw from care if their illness relapses. They may join street life and their life may be difficult…

IDI 13, Health service planner

What we [his parents] have found hard to deal with is his future prospects in life. All of my children have attained something in their lives. Those who have been studying have completed their studies; the rest have got married etc. As this one is my last child, I get concerned about what will happen to him when I and his mother pass away. I am worried about who will take care of him in the future.

FGD 3, Family members

R: Yes. I beg their parents not to chain them up. I plead to treat them in a caring manner with the help of God. I told her parents not to disappoint her because that might lead to relapse. There should not be argument with her. Whatever is lost they should let it go instead of bothering her as situations can be changed no matter what. I bind them not to blame her for anything by pledging the holy cross.

IV08, Holy water attendant

In addition to that we counsel them to treat them softly (politely and with respect) until they (the patient) gets treatment. I also advise the patients to relax and avoid stress.

IV02 Traditional healer

R: I think the family needs more treatment and encouragement than the patient. We explain to them that there is a cure for someone who is mentally ill. Illness is always there with human beings. We tell them not to lose hope. If they help the person receive psychological treatment, if the person takes his medication properly, if he receives good care, if the person keeps time in taking his medication, that person would be important member of the family and good citizen. Therefore, we tell them these.

I: So you educate the family?

R: yes. We tell them to be patient.

IV05 religious leader

Theme 3: Delivering collaborative, long-term care

There are cases which can be cured by traditional and faith based healers like mine so for us spending time in hospital is waste of time. On the other side there are people who can be cured by modern treatment…so it was good if both were working together and sort which one can be best treated by either of them.

ID23 Person with SMD

R3: … most of the people go to holy water sites in the first place. When we asked them where they would like to go, they say holy water is better. They go to the holy water priest

and drop out of modern care. … Therefore, the holy water priest should be educated. … If they are aware, they can also help people adhere to medication even after they go to holy water.

FGD 3, HEWs

… Once we identify which *kebele* [sub-district] this person is from we give the HEWs information . ... Every month each HEW exchanges progress reports, where they discuss about patients and even new HIV patients who came out. This is how we conduct the monitoring. It is not very challenging. If it is known where that person lives; if the village is identified, the HEW has the responsibility of going there regularly and following up. It's not only her responsibility but also of the health volunteers to report cases and to provide the needed support and follow up.

IDI 6, Local health service planner

If the person fails to properly follow the prescriptions we discuss the reasons. We ask is it because of a poor diet? If the problem is related to food, we develop a food support program.

I: Who organizes these kinds of things?

R: The community, *edirs* [social insurance groups for defraying costs of funerals]… The community is very open to this kind of things. If he doesn't have enough food, people prepare meals and take it to that person's home. If the person faces housing problem we rent a house for him. If it seems the person needs some counselling the community elders take care of that, so he doesn't stop taking the medication.

IDI01, Muslim leader

I: What kind of persons do you mostly refer to Amanuel?

R: Sometimes people complain about the medication. They say that the medication has some burning sensation. Then I encourage them by reassuring that they will recover and be healthy again. I tell them that they will achieve what their friends have achieved. If a person used to be a farmer, I give him reassurance that he can farm again. If a person used to be businessman, I give him hope and encouragement that he will achieve what his friends have realized. I mostly give them moral support and comfort. After discussing with their family, a close family member usually takes them to Amanuel hospital. They can adhere to the medication though they are attending holy water too. I ask them to come with their medication as they start the holy water treatment.

I: Does the policy of the holy water site allow attending to holy water and modern medication simultaneously?

R: Yes they can attend holy water. Sometimes I ask them to come with their medication. They mostly recover. However, if they feel anxious about something, their mind will be disturbed. Therefore, I strongly plead their family not to disappoint them. I ask them not to tell anything that might make them feel anxious.

I: So does that mean anxiety will contribute to relapse?

R: Yes. That is why I plea them not to.

IV08 Holy Water Attendant

Here, if a medical doctor comes to educate the community, the people think that it is his business. But, if the healthcare institute gives trainings for all religious fathers, it would be effective. There are Muslim religious leaders who have a very good knowledge of different issues in the community. In our church also, there are people who have good understanding. Working with these people will help to disseminate important information via their religious

forums. There are protestant leaders. There are also catholic leaders with a good base. These people could educate the community and I can say that they have the capacity to do so. They can explain to the community that there is a good quality service being provided.

IV 05 Religious leader

R: If we want to reduce the community's negative attitude towards people with mental illness awareness rising is the first and important step. Then this will also help people to bring those who are mentally ill to health facilities. In most cases people tend to take their mentally ill relatives to either holy water or traditional healers so this can also reduced by raising the mental health literacy of the community. You can use religious leaders and influential individuals in the community as a change agent.

I: you have said that we can use religious leaders as a change agents would you please explain it more?

R: As you know these people have significant influence on the community. In collaboration with health professionals they can teach and influence the community at the same time. The other strategy might be using women's, youths and other associations to raise the community awareness.

IV14 Policy-maker