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DISSERTATION APPROVAL

ADDIS ABABA UNIVERSITY
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Dissertation Title

Functioning in people with severe mental disorders in rural Ethiopia: development, adaptation and validation of measures

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ACRONYMS AND ABBREVIATIONS

A-LIFE	Psychosocial Functioning Schedule of the Adolescent Longitudinal Interval Follow -Up Evaluation-Baseline
AFFIRM	African Focus on Intervention Research for Mental Health
BFS	Butajira Functioning Scale
BPRS-E	Expanded version of the Brief Psychiatric Rating Scale
CAF	Community Adjustment Form
CBT	Cognitive behavioral therapy
CFA	Confirmatory factor analysis
CMD	Common mental disorder
CORE-OM	Clinical Outcomes in Routine Evaluation- Outcome Measure
CTT	Classical Test Theory
DIF	Differential item functioning
DMM	Double monotonicity model
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSS	Demographic surveillance site
ES	Effect size
FAST	Functioning Assessment Short Test
FGD	Focus group discussion
GAF	Global Assessment of Functioning Scale
GAS	Global Assessment Scale
HoNOS	Health of the Nation Outcome Scale
ICC	Intra-class correlation coefficients
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities, and

	Handicaps
IRT	Item response theory
KAS	Katz Adjustment Scale
LAMICs	Low and middle income countries
MHM	Single monotone homogeneity model
NGO	Non-governmental organization
NIH	National Institute of Health
NIMH	National Institute of Mental Health
PSP	Personal and Social Performance scale
QoL	Quality of Life scale
SAS	Social Adjustment Scale
SDS	Sheehan Disability Scales
SEM	Standard error of measurement
SF-36	Medical Outcomes Study Short –Form 36 Health Survey
SFS	Social Functioning Scale
SMD	Severe Mental Disorder
SNNPR	Southern Nations, Nationalities and Peoples’ Region
SOFAS	Social and Occupational Functioning Assessment Scale
SRM	Standardized response mean
SRQ	Self -Reporting Questionnaire
TaSCS	Task-Sharing for the Care of SMD in a low-income country
WHO	World Health Organization
WHODAS	World Health Organization Disability Assessment Schedule
WHOQOL-BREF	World Health Organization Quality of Life-BREF

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ABSTRACT

Background: Restoring impaired functioning is one of the most difficult challenges in treating people with severe mental disorder (SMD). Significant improvement in interpersonal relations, role performance and community living skills usually lag behind symptomatic improvement, but are valued more by people with SMD. As a result of this, the assessment of functioning is gaining emphasis as an outcome in research and clinical practice. Though numerous instruments to assess functioning are in existence, most have been developed in high resource countries and may not be generalizable to other cultures as the definition of functional recovery differs with sociocultural context. Existing functioning measures are limited by questions that are culture bound; they do not take in to account role differences between men and women in rural African societies and fail to present specific tasks that are important to local people. Therefore, there is a pressing need to develop and/or adapt and validate measures of functioning that address the limitations of existing instruments and are appropriate for the socio-cultural context in Ethiopia.

Objectives: The primary aim of this study wasto develop and validate a measure of functional impairment for people with SMD, which is socio-culturally appropriate for a rural, African low-income country setting.A secondary aim was to evaluate the psychometric properties of the cross-cultural World Health Organization Disability Assessment Schedule (WHODAS- 2.0) and to compare performance with the newly developed, contextually-informed measure.

Methods: A qualitative study (in-depth interviews and focus group discussions) was carried out to gain contextual understanding of day-to-day functioning in a rural Ethiopian setting and the functional impairments associated with SMD. Free listing and pile sorting exercises were conducted to identify key tasks that an adult person in the rural Ethiopian context is expected to accomplish, as well as to operationalize new scale items to measure functional impairment. Expert evaluation and cognitive interviewing were carried out for preliminary validation and initial reduction of items of the new scale, the Butajira Functioning Scale (the BFS). Pilot testing of the BFS was conducted with 200 people with SMD and their caregivers (n=200) in order to identify items that performed poorly and inform further item reduction. The psychometric properties (internal consistency, construct validity, convergent validity and sensitivity to change) of the finalized BFS were evaluated in an independent sample of people with SMD (n=150) and their caregivers (n=150) recruited in episode and a sub-sample of n=84 followed up for six weeks. Psychometric properties (internal consistency, convergent validity, construct validity and responsiveness to change) of the Amharic version of the World Health Organization Disability Assessment Scale (WHODAS-2.0) was carried out in the same sample to enable comparison with the BFS.

Results: The qualitative study participants emphasized that functional impairment in people with SMD arose not only because of the symptoms associated with the illness, but also due to poverty, social exclusion and lack of social support. In this rural Ethiopian setting, the ability to work productively, engage in family life, maintain self-care and fulfill social obligations were the most highly valued domains of functioning. Gender differences were most apparent in the domains of work and family life. Impaired functioning was reported to have a critical immediate impact on survival as well as more far-reaching impacts on the lifetime opportunities of people with SMD, their caregivers and the younger generation within the family.

The first draft of the BFS had 78 items in the women's scale and 84 items in the men's scale. Item reduction was carried out using expert evaluation, cognitive interviewing and pilot testing. The criteria considered for item reduction included understandability, relevance to the rural Ethiopian setting, whether or not the task is seasonal, insufficiently frequent, and specific to the locality, and psychometric properties of each item (e.g: item-item correlation, item-total correlation, test-retest reliability, factor loadings). The expert evaluation resulted in the BFS v2 with 69 items in the women's scale and 59 items in the men's scale. The cognitive interviewing brought the BFS v3, with 67 items in the women's scale and 50 items in the men's scale. The pilot study led to the finalized BFS comprising33 items, common to both men and women, and an additional eight items in the women's scale, with four domains: self-care, work, family and community participation.

The BFS had excellent internal consistency (Cronbach's α=0.99), acceptable convergent validity (r= 0.88 with WHODAS-2.0 and r= 0.32 with the Brief Psychiatric Rating Scale [BPRS-E]) and was sensitive to change following treatment (effect size =0.50). The caregiver version of the BFS had similar psychometric properties but higher mean values for each item and better responsiveness to change. Exploratory factor analysis of the BFS provided evidence of construct validity, with four underlying dimensions: self-care, work (shared items), work (women only items) and social functioning. Internal consistency of the overall WHODAS-2.0 and each domain was either very good or excellent. Convergent validity was good (r= 0.88 with the BFS and r= 0.52 with the BPRS-E). The WHODAS-2.0 was found to be sensitive to treatment changes (effect size= 0.50). As hypothesized, the six domains highly loaded onto the general disability factor and each item loaded significantly onto their respective domains. The factor loadings of each item in the one factor model of the 12 item WHODAS were also high. However, the goodness of fit indices for both the 12- and 36-item WHODAS were close to, but not within, the acceptable ranges.

Conclusions: The findings from the qualitative study indicate that, alongside medical treatment, there is a need to tackle social exclusion and poverty in order to improve functioning in people with SMD in this rural Ethiopian setting. An ecologically valid measure of functioning has been developed for people with SMD in a rural Ethiopian setting. The new scale (the BFS) is also likely to be applicable to similar rural African contexts. The BFS has acceptable psychometric properties, and is easy to administer, sensitive to changes following treatment and has content, construct and convergent validity. The BFS includes domains from existing measures, but has greater emphasis on social and occupational domains, which reflects priorities in the setting. The study showed that the WHODAS 2.0 has acceptable psychometric properties and can be used as a cross-cultural measure; however, the use of the scale in rural African settings requires careful and rigorous adaptation.

Recommendations: On the basis of the findings and the conclusions made, the study recommends the following.

- Mental health care providers need to involve family caregivers while providing treatment for people with SMD. This is because functional impairment in people with SMD has greater burden in family members and in turn, family members contribute to the functional impairment of people with SMD.
- There is a need for further investigation to identify the effective type of psycho-social intervention to enhance the functioning of people with SMD in addition to treating illness symptoms.

- Clinicians are suggested to use the BFS in their routine clinical practice as it may have utility in clinical settings to ensure comprehensive assessment of functional status and track recovery.
- Future research should explore whether or not a shorter version of the BFS is feasible; there is also need to test the feasibility and psychometric properties of the BFS in other rural African settings.
- In mental health research, there is likely to be value in using both the BFS and the adapted version of the WHODAS-2.0 in order to both measure locally relevant functioning indicators to be able to compare across settings.

1. INTRODUCTION

1.1. Background of the study

There is little consistency in how severe mental disorders (SMDs) are defined. The National Institute of Mental Health (NIMH) categorizes individuals as having an SMD if they meet three criteria[1]: a diagnosis of non-organic psychosis or personality disorder, duration (prolonged illness and long term treatment, operationalized as a two year or longer history of mental illness or treatment) and moderate or severe disability. More generally, SMDs are usually characterized as mental disorders which are enduring and associated with high symptom levels and disability. SMDs include both psychotic disorders (e.g. schizophrenia) and mood disorders (e.g. bipolar disorder and severe major depressive disorder). The symptoms, prevalence and consequences of each of these SMDs are described below.

Schizophrenia is a serious and disabling illness with usual onset in early adulthood and an estimated lifetime prevalence of one percent[2]. A systematic review of 1721 prevalence estimates from 188 studies conducted in 46 countries [3] found a point prevalence of 4.6 per 1000, period prevalence of 3.3 per 1000 and lifetime prevalence of 4.0 per 1000. According to this study, no statistically significant difference was observed in prevalence between males and females and between urban and rural areas; however, the prevalence of schizophrenia was lower in low- and middle-income countries compared to high-income countries and tended to be higher in migrant groups compared to native-born populations. The risk of schizophrenia has been shown to be higher in males, younger adults, single or previously married individuals, residents of urban areas, those with lower socio-economic status, those who have a family history of schizophrenia, those exposed to viruses, toxins or malnutrition and stressful life circumstances and those taking psychoactive drugs [4].

The clinical picture of schizophrenia includes a range of distinctive symptoms, including delusions, hallucinations, social withdrawal, behavioral dysfunction and several neurocognitive deficits, particularly in attention, memory and executive functioning [2, 5, 6]. Individuals with schizophrenia demonstrate impairment on cognitive tests which include working memory, processing speed, attention, executive functioning and general intelligence [7], as well as on psychosocial functioning, with particular difficulty maintaining relationships with family and friends and functioning in the work place [2, 6, 8]. Therefore, deficits in functioning are a defining feature of schizophrenia; they are detectable early in the course of the illness and they often persist after acute symptoms have resolved [9]. People with schizophrenia are at elevated risk of premature mortality compared with the general population [10]. High levels of both subjective and objective dimensions of burden are seen in family members of people with schizophrenia [11].

Bipolar disorder is a severe mental illness, with a lifetime prevalence of around one percent, which most often follows a chronic, relapsing and remitting course [12]. Bipolar disorder is characterized by episodes in which the person’s mood and activity levels are significantly disturbed. This disturbance may be in the form of an elevation of mood associated with increased energy and activity- mania; at other times, the person may experience a lowering of mood and decreased energy and activity –depression [13].Aggregate estimates of the prevalence of bipolar disorder indicate that approximately one percent of the general population meet lifetime criteria [14]. A review of population studies of bipolar disorder yielded an aggregate lifetime prevalence estimate of 1.2%, ranging from 0.1% in Nigeria to 3.3% in the United States [15]. Risk factors for bipolar disorder include genetic factors, medication (e.g. antidepressants, steroids) and medical conditions such as neurological diseases and thyroid disease, continuous lack of sleep, stress and triggering events (career, death of loved one and major life changes), co-occurring psychological and physical health conditions, drug or alcohol abuse, male gender, and younger [16].

Bipolar disorder is the sixth leading cause of disability worldwide [17]. Disability, poor outcome and cognitive dysfunction have long been associated with schizophrenia rather than with bipolar disorder, but there is accumulating evidence of cognitive and psychosocial impairment in bipolar disorder [18]. High rates of functional impairment among people with bipolar disorder, even among those in remission,have been documented in numerous studies [19]. A study of psychosocial functioning among bipolar youth [17] indicated that bipolar disorder is associated with significant psychosocial impairment with mild to moderate functional impairment across interpersonal and work domains. Bipolar disorder is associated with high cost for both the patient and caregivers, premature mortality and stigma [20].

Depression is one of the most important public health problems due to both its relatively high lifetime prevalence and the significant disability that it causes [13, 21]. Every year an estimated 5.8% of the adult population developsa depressive episode and the lifetime risk for a severe depression amounts to 12-16%. However, the life time prevalence rates of depression vary between populations, ranging from about 6% in China to over 20% in the Unites States [22]. Women have a 1.5 to 2 times higher risk ofdeveloping depression compared to men [23], but the ratio varies across income level of country [24]. In a typical depressive episode, the person experiences depressed mood, loss of interest and enjoyment, and reduced energy leading to diminished activity for at least two weeks. Many people with depression also suffer from anxiety symptoms and medically unexplained somatic symptoms [21]. Major risk factors for depression include social factors (low education, violence, poverty), chronic physical illnesses, female gender, being widowed, separated or divorced, being an urban dweller, unemployment and job loss, with a family history of depression, exposure to traumatic experiences as a child, stressful live events, having few interpersonal relationships, having certain personality traits (low self-esteem, overly dependent, pessimistic, self-critical), medications and drug and alcohol abuse [21, 22, 25].

Depression is associated with functional impairment, decreased quality of life, increased mortality [26] and a significant decrement in health status[25]. Evidence suggests that roughly 60% of depressed people reported substantial (severe or very severe) impairment, with many aspects of functioning are impaired by depressive symptomatology [27]. For instance, depression can result in household strain, physical limitations, occupational disruption, restricted activity days, an increased number of bed days, and poorer health status. Furthermore, depression affects work productivity by reducing cognitive processing, memory, attention and concentration and energy levels, as much if not more than, most other physical illnesses. Using data from World health Surveys, Moussavi, et al [25]found that depression produces the greatest disability compared with other chronic diseases considered in the study (angina, arthritis, asthma, and diabetes). Depression also brings societal burdens [28, 29], including disability in terms of lost wages, low productivity, and impaired interpersonal relationships. Depression accounted for 4.5% of the worldwide total burden of disease in 2007 and is also responsible for the greatest proportion of burden attributable to non- fatal health outcomes, accounting for almost 12% of total years lived with disability worldwide [30].

The ability to restore impaired functioning is one of the most difficult challenges in treating people with severe mental disorders [31]. Meaningful improvement in interpersonal relations, role performance and community living skills may substantially lag behind symptomatic improvement. With this understanding, the importance of functioning in the assessment of mental disorders was acknowledged with its inclusion in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980 [2, 6]. In the DSM-IV-TR [32], impaired social functioning is associated with, but separate from, the signs and symptoms of mental disorders. Functioning, therefore, should be an integral part of the assessment of the effectiveness of both pharmacological and psychotherapeutic treatments.

As it is clearly indicated in the World Health Organization Disability Assessment Schedule training manual [33], medical diagnosis alone fails to predict some aspects of outcomes, including work performance, social integration, level of care and length of hospitalization. Martinez-Aran and colleagues [34] commented that there is a gap between clinical and functional outcome in bipolar disorder. That is, while DSM IV-TR criteria for depression and mania require that symptoms be associated with marked psychosocial impairment, little is known about psychosocial functioning among people with bipolar disorder [17]. Lindenmayer [6] argued that symptom control has been the main focus of schizophrenia treatment to date. Impairments in patient functioning can lead to decreased medication adherence, increased risk of hospitalization, and diminished ability to either engage in relationships or to maintain employment. Isolated treatment of symptoms is not enough to reinstate good performance occupationally and in interpersonal relationships [35]. Alongside symptom remission, the goals of treatment must be to improve psychosocial functioning and quality of life. Some individuals suffering from a mental disorder may not regain their normal functioning even after treatment with medicines and rehabilitation [36].

Symptom measures, such as Self Reporting Questionnaire (SRQ) [37] and Brief Psychiatric Rating Scale (BPRS-E) [38, 39], somewhat reflect functional impairment but lack domain specific functional information [27]. Functional outcomes tend to be less responsive than symptom outcomes to treatment with medication. Functional improvements might lag behind symptom reduction. One limitation of many treatment trials is that they often focus on reduction of symptoms as the desirable outcome and do little to assess the effects of treatment on reduced disability [40, 41]. This is despite the finding that people with SMD may value functional recovery over and above clinical remission [42, 43]. Therefore, it is important that functioning is assessed independently of, and in addition to, the symptoms of mental disorders to improve long-term treatment outcomes for the patient. As Bolton and his colleagues have pointed out [28], assessing functional impairment in Africa is particularly important for two major reasons. First, impairment is a major justification for allocating scarce resources to mental health services. Second, it is not clearly known whether symptom criteria alone can predict functional impairment [28].

Although there are a number of different instruments available to assess functioning, there is currently no consensus as to which scale to use for clinical practice and research purpose [2, 35]. Most of the available measures have been developed in Western societies, and may not necessarily be generalizable to other cultures as the definition of functional recovery differs with contextual factors [35, 44]. Functioning scales developed in the West do not fulfill the suitability criteria for cross-cultural work[45]. Too many of the questions in the scales are culture-bound and difficult to adapt to other situations, especially to rural African settings [28], they do not take in to account the major differences between the roles of men and women which may be more marked in non-Western settings [45] and they fail to present specific tasks important to local people such as cooking and farming [28, 29]. No gold standard measure of functioning has been developed to date, and hence the development and evaluation of further scales to assess functioning is a pressing need [35].

The primary aim of this PhD research project was, therefore, to develop and validate a measure of functional impairment for people with SMD, which is appropriate for a rural African low-income country setting. In doing so, the study sought to develop a scale that was socio-culturally relevant, focused on the ability to complete tasks important to the wellbeing of the person and those around him/her and that addressed differences in the roles of men and women. A secondary aim was to evaluate the psychometric properties of the Amharic version of the World Health Organization Disability Assessment Schedule (WHODAS- 2.0) among people with SMD in a rural African low-income country setting.

1.2. Statement of the problem

The basic goal of the discipline of cross-cultural psychiatry is to describe the phenomenology of mental disorders within the sociocultural context and to develop indigenous assessment instruments which are valid for use in their local contexts [46, 47]. An important aspect of the measurement of functioning is the context dependence of the concept. Supporting this argument, Fossey and Harvey [48] pointed out that the concern of functioning is about the quality of a person's participation in personally and culturally meaningful occupations; and thus, an understanding of person-environment interaction within the particular sociocultural context is essential. In their view, service users' perspectives, values, and the real life contexts in which they live are insufficiently considered in existing functioning assessments. Thus, the innovative use of qualitative and quantitative research approaches is necessary to gain increased understanding of functioning concepts across cultures and improve the development of instruments to measure functional impairment.

Another important concern regarding functional assessment is that global functioning measures are less useful for identifying functional difficulties or improvements within specific domains of functioning, compared to scales which cover those specific domains [48]. Given the multiplicity of domains that must be measured to assess functioning in a comprehensive manner, a single score cannot effectively capture all of them. In support of this, Burns and Patrick [2] argue that there are many challenges that limit the measurement of functioning in people with severe mental disorders. Many of the domains that constitute most functioning measures are not relevant to people who are highly disabled by their illness or to certain cultures. For example, the domains of recreation, leisure time activities, work and occupation and extended social network relationships may not be relevant for the majority of people with severe disabilities. The domains of household activities, parental role, and relationships with external family may vary greatly between and within cultures. Thus, developing a single global instrument cannot be the best approach as tasks which define functioning are likely to vary greatly according to gender, cultural values and environment [45].

It is also argued that measures of functioning are not being routinely used in clinical practice in the assessment of mental disorders, including SMD [2, 6, 40,41]. This may be because clinicians are unable to see the clinical benefits, are more focused on monitoring changes in symptoms and syndromes [49], or due to the absence of brief scales and a shortage of time on the part of clinicians. In today's busy clinical practice, therefore, there is a need for shorter and simpler scales that can be routinely administered by other members of the treatment team than the mental health specialist [6].

There is limited research into the functioning of people with SMD in Africa in general and in Ethiopia in particular. For instance, in Africa only one research team has attempted to develop local functioning assessment instruments following an innovative approach [29, 45]. That work was carried out in Uganda and Rwanda and was only used to detect functional impairment in those with depression and other common mental disorders. Within Ethiopia, functional outcomes of people with SMD have only been evaluated using uncontextualised scales developed in Western cultures [50-52]. Even though population norms for rural Ethiopia have been established [50] and evidence of convergent and predictive validity obtained [52], concerns remain about the appropriateness of these scales, their sensitivity to functional impairment in both men and women, and their responsiveness to change. Despite this, there has never been any attempt to develop a local scale for measuring functional impairment in people with mental disorders or to evaluate the performance of an existing cross-cultural functioning measure. This PhD research project was, therefore, meant to address these important but neglected issues.

1.3. Rationale and significance of the study

Despite the great emphasis given to investigation of the risk factors for, and clinical impact of, different mental disorders, there has been less focus on assessment of the multiple dimensions of functioning and well-being in people with severe mental disorders, particularly in low and middle-income countries [41]. Moreover, although used increasingly in clinical trials, scales of functioning are not routinely used in clinical practice for the assessment of severe mental disorders [6].

There are a number of standard functioning instruments developed in high income, Western countries; however, none of them fulfill the criteria for cross-cultural work [45]. They contain too many items that are likely to be culturally biased and are difficult to adapt to other sociocultural contexts. In addition, these measures are not applicable, acceptable, and practical to administer routinely in mental health services, and little is known about the extent to which they are reliable, valid and sensitive to change [48]. Thus, there is a pressing need either to adapt and validate these standard instruments to local situations, or to develop an indigenous measure. This study aimed to address this important issue.

The findings and output of this study are expected to have theoretical as well as practical significance. It is hoped that this study would:

- add to the existing body of knowledge related to functional outcomes with respect to the disabling nature of severe mental disorders, particularly in interpersonal relationships, work, parental roles and contribution to community activities.
- contribute an original, locally relevant, valid and practical functioning measure that can be used in routine clinical practice as well as for measurement of functional outcomes in clinical trials and other epidemiological research studies.
- contributea well translated and validated Amharic version of a standard cross-cultural measure of disability that can be used for both clinical practice and measurement of functional impairment in clinical trials and other epidemiological studies.

Various groups of people or stakeholders stand to benefit from this study in different ways. The major ones are:

- clinicians and other health workers, at different levels, would get an easy to use, simple and brief instrument to assess functioning of people with severe mental disorders before treatment and to assess functional improvements during and after treatment.

- epidemiologists and other mental health researchers will be able to utilize the instrument, which is valid and reliable, to conduct further observational research or clinical trials on functioning, as research in this area is generally scarce in the Ethiopian context.
- people with different kinds of mental disorders in particular, and the community in general, would benefit from this study by getting better diagnosis and treatment, as the study is expected to improve mental health services by increasing attention towards functional assessment and the functional impact of intervention.

2. LITERATURE REVIEW

In this section, the available literature related to the issue of measurement of functioning in people with SMD across cultures is reviewed. The review is organized by sub-sections in line with the study objectives and research questions.

2.1. Conceptualization of functioning

Functioning in people with SMD has been conceptualised differently by different people, even among clinicians and mental health professionals. This is mainly because functioning is a complex concept that involves different domains and encompasses a wide range of behaviors [53]. For instance, according to Martinez-Aran et al. [18], functioning involves the capacity to work, study, live independently, and engage in recreation and romantic life. Similarly, Rosa et al. [19] argue that functioning is a complex concept and involves a number of different domains, which are identical to the ones identified by Martinez-Aran and Colleagues. The World Health Organization's (WHO) original classification of the functional consequences of diseases (ICIDH) distinguished the following aspects of functioning: physical and cognitive capabilities, ability to perform tasks and ability to maintain roles [48]. Another important reason for the variation in understandings of functioning is that relevant domains of functioning vary across cultures as people have different roles in those cultures. This is particularly the case for rural low-income country settings, compared to more Western-exposed urban settings.

Therefore, despite the wide-spread use of the term "functioning", there is limited consensus about its definition [2]. To better conceptualize the term functioning, various definitions will now be considered. To Aas [54], functional status can be defined as "the degree to which an individual is able to perform socially allocated roles free of mentally (or physically) related limitations." According to Fossey and Harvey [48] functioning concerns "the quality of a person's participation in personally and culturally meaningful occupations, for which an understanding of person-environment interaction is essential." Social functioning has been understood as the capacity of a person to function in different societal roles such as home-maker (or 'house wife'), worker, student, spouse, family member, or friend [35]. The concept also takes in to account an individuals' satisfaction with their ability to meet these roles, to take care of themselves and the extent of their leisure and recreational activities.

A WHO document that was prepared in order to guide rehabilitation in primary health care [36], broadly classified functioning into five categories:

1) Personal functional impairment (problems in looking after oneself, low level of meaningful activity, restlessness, general slowness)
2) Functional impairment in family role (deficiencies in participation in family life, marital role, parental role)
3) Social functioning impairment (little meaningful contact with people, loss of general interest and friction in social contacts)
4) Occupational functioning impairment (loss of interest in the job and reduction in work performance)
5) Emotional functional impairment (apathy, unable to enjoy anything, loss of emotional responsiveness and inappropriate emotions)

2.2. Measurement of functioning

It is possible to understand from the explanations given above that functioning is a broad construct that requires comprehensive assessment. The existing definitions of functioning, including the ones reviewed above, tend to be general, stating that functioning represents an interaction between the individual and the social environment. Such a high level of abstraction seems straightforward on the surface but is problematic because it does not provide much guidance as to what constitutes the relevant domains. As a result, a vast number of assessment instruments that relate to various domains of functioning and reflect different ways of framing functioning have been developed [48]. The field of functional assessment is overflowing with measures that are related to the assessment of daily functioning to varying degrees, but still lacks a measure of functioning that is comprehensive and psychometrically strong, and is based on a clear theoretical, conceptual understanding of the construct and its structure [53]. The WHODAS-2.0 is supposed to fulfill these criteria [55], although several limitations of the scale are indicated.

In a review of 301 studies, conducted by Burns and Patrick [2], a total of 87 different measures of functioning were identified. The scales varied greatly in terms of the number and types of domains of functioning covered. The number of domains ranged from three in the Global Assessment of Functioning (GAF) [54], up to 17 domains in the Community Adjustment Form

(CAF) [2]. According to this review, the types of domains measured also varied, including specific roles (work, parental, household, and family), social contact and interaction with others (including friends and neighbors), emotional relationships with partner and family, self-care (personal grooming and appearance), leisure activities and general interests, integration with society and participation in the community. At the end of the review, Burns and Patrick concluded that there is a striking lack of data available on the psychometric properties of many of the scales. Lindenmayer [6], on his part, argued that assessment of functioning is complex and has been a neglected area. A major limiting factor in the development of instruments appears to have been a failure or inability to develop a suitable model of functioning and its primary mediators and moderators [35].

Functioning measures available to date have the following limitations [35].

- Since most scales have been developed in Western societies, they may not be generalisable to other cultures as the definition of functional recovery differs with sociocultural context
- Many measures have been developed for a particular research project and are lengthy and impractical for use in clinical settings
- Patients, particularly those with severe mental disorders, may have only partial insight in to their illness, limiting the validity of self-report measures
- Ratings made by others may be limited by poor knowledge about the patients day-to-day life
- Rating scales developed for the general population or even for less severely ill patients may demonstrate ‘floor’ and /or ‘ceiling’ effects in the severely ill population (in the former, functioning of severely mentally ill people clusters at the bottom of a scale with little discriminatory power and in the latter functioning scores cluster at the top of a scale)

Regarding the current measurement of functioning, Rosa et al [19] also commented that mental health researchers traditionally measure one or two elements of functioning and fail to take into account all the other elements necessary for optimal functioning. They further noted that the majority of instruments available to date are very lengthy and have been focused on global or limited measures of functional recovery, rather than examining specific, discrete areas of psychosocial activity. Bolton, Neugebauer and Ndogoni [29] identified three basic problems with existing functioning measures when applied to sub-Saharan Africa:

1) Western cultural bias
2) Focus on components of tasks such as walking and lifting rather than on the ability to complete a whole task important to the well-being of the person and those around him/her
3) Lack of recognition of the role differences between men and women

2.3. Existing measures of functioning and their psychometric properties

In a systematic review of English language articles published between January 1990 and December 2006 [2], the three most frequently reported functioning scales in studies of people with schizophrenia were the Global Assessment of Functioning (GAF) scale, The Global Assessment Scale (GAS) and the Social Functioning Scale (SFS), while the three scales most commonly reported in randomized controlled trials were the Social and Occupational Functioning Assessment Scale (SOFAS), the Medical Outcomes Study Short–Form 36 Health Survey (SF-36) and the Personal and Social Performance (PSP) scale. Swartz et al [31], on the other hand, wrote that the most common measure of functioning employed in schizophrenia clinical trials is the Quality of Life (QoL) scale. A review of 170 publications that included outcome measurement in mental health by Jacobs [49] identified two measures as the most likely contenders for inclusion in a productivity index for mental health, namely the Health of the Nation Outcome Scale (HoNOS) and Clinical Outcomes in Routine Evaluation- Outcome Measure (CORE-OM).

Functioning measures that are currently available can be categorized broadly into two types: clinician-rated instruments and patient self-reported assessments, although most ratings are completed by clinicians [6, 49]. The major problems with relying on clinician rating for research studies include the cost, training, and the need to establish test-retest and inter-rater reliability; whereas the concerns with self-report from patients include the risk of social desirability, idiosyncratic completion, and the validity and feasibility in patients who are acutely unwell or lack insight into their condition [49]. Self-reported assessments provide an accurate representation of the outcome and provide rating contingent upon the inherent nature of the symptoms; while clinician rated scales are considered to be accurate due to rating by a trained professional and are generally valid [6]. The clinician-rated functioning instruments which are most commonly used in research and clinical practice [56] and were developed based on DSM-IV criteria are the Global assessment of Functioning (GAF), the Global Assessment Scale (GAS), the Social and Occupational Functioning Assessment Scale (SOFAS) and the Personal and Social Performance (PSP) scale. The most commonly used patient-report functioning instruments include the Social Functioning Scale (SFS) [56] and the Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM) [49]. There are also functioning scales that can be both clinician-rated and patient-rated; including the Community Adjustment Form (CAF) [2], the Medical Outcomes Study Short-Form 36 Health Survey (SF-36) [57] and the World Health Organization Disability Assessment Schedule (WHODAS-2.0)[55].

Irrespective of the type of the scale, clinician-rated or patient-rated, the decision about which functioning scale should be used needs to consider, according to Awad and Voruganti [56], such criteria as appropriateness to the population under study, adequacy of psychometric properties, consistency with the theoretical framework that the researcher uses to understand and define the construct, and sensitivity to relatively small changes over time. Other authors have suggested a number of other criteria against which functional outcome measures should be judged for their appropriateness [48, 49]. These include being relevant and appropriate, simple to use, having clear and objective meanings, reflecting the perspectives of all participants, capable of identifying positive treatment effects, psychometrically sound, inexpensive, understandable by a lay audience, amenable to quick and easy feedback, clinically useful and theoretically broad-based.

Below is a synthesis of the major characteristics (author, number of items and domains, scoring system, mode of administration, and strengths and weaknesses) and psychometric properties (reliability, validity and sensitivity to change) of the commonly used functioning instruments after conducting a comprehensive review of published articles, reports and scales [2, 6, 17, 19, 35, 49, 53, 54, 57-66].

Table 1: Characteristics of commonly used functioning scales for cross-country studies

Scale	Author	Items/Domains	Scoring system	Administration	Strengths	Weaknesses
Global Assessment of Functioning (GAF) scale	Hall, RC	Included as Axis V of the DSM IV-TR; measures global functioning with a single item in terms of three domains (psychological symptoms, social and occupational/educational functioning)	There are 100 scoring possibilities (1-100). The 100 point scales are divided into intervals or sections, each with 10 points and the 10 point intervals have anchor points or verbal descriptions describing symptoms and functioning	Observer/clinician	Quick and simple to use; short and easily accessible	Only assesses global functioning and not specific aspects of functioning; confounds symptoms and functioning
Global Assessment Scale (GAS)	Endicott, J et al	Developed based on GAF and includes the impact of psychological and general medical symptoms on functioning. Measures functioning in terms of three domains (impairment of daily functioning, reality testing and potential for suicide/violence) with a single item.	100 point scale like GAF, divided in to 10 intervals (from 1-10= hypothetically most impaired individual to 91-100= hypothetically healthiest individual). Scores are combined to have single rating of overall functioning.	Observer/clinician	Can be utilized in a wide range of patient populations; not only assesses symptom severity, but also effects of symptoms on life-skills functioning.	Subjectivity, lack of structure and requires combination of assessments.
Social Functioning Scale (SFS)	Birchwood, M et al	Measures functioning with 79 items in 7 domains (social engagement/withdrawal, inter-personal communication, pro-social activities, recreation, independence-competence, independence-performance, employment/occupation).	Raw scores for each subscale are converted to a standard score; overall functioning is based on the mean standard score.	Patient/Self	It requires little professional time, acceptable to patients , yields a great deal of information about an individual's abilities and activities.	Lengthy; may not be appropriate in people with severe mental illnesses; cannot be used across different cultural settings as it contains tasks that are culturally varied.

Scale	Author	Items/Domains	Scoring system	Administration	Strengths	Weaknesses
Social and Occupational Functioning Assessment Scale (SOFAS)	American Psychiatric Association	It is closely related to the GAF scale (single item scale); differs from the GAF in two ways 1. Symptom descriptors have been eliminated so that only social and occupational functioning are measured 2. Functioning due to overall illness is to be considered	More or less similar to the GAF	Observer/Clinician	Operationalizes functioning, incorporated the impact of psychological and general medical symptoms on patient functioning	Poor linguistic distinction of terms such as serious and major impairment
Social Adjustment Scale (SAS)	Paykel ,ES et al	It has 52 items in 8 domains (work, domestic relationship, parental role, relationship with external family, social and leisure activities, sexual activity, romantic involvement and personal wellbeing)	Each item rated on a 5-point scale, higher scores indicating greater impairment	Observer/Clinician	Comprehensive, assesses multiple domains of social functioning	Lengthy, does not entirely separate functioning and symptoms, the scoring of the measure is complicated
Medical Outcomes Study Short – Form 36 Health Survey (SF-36)	Ware, JE & Donald, SC	Consists of 36 items and 8 subscales measuring domains of physical functioning, bodily pain, social functioning, mental health, role limitation because of emotional problems, vitality, and general health perceptions	Raw subscale scores converted to 0-100, higher scores indicating better health and functional status	Observer/ Interviewer or Self	Comprehensive, considers different aspects offunctioning	Summary scores may not accurately reflect changes in health with time; assumes that mental and physical functioning are distinct aspects of health; includes symptoms, e.g. bodily pain.
Katz Adjustment Scale (KAS)	Katz, M & Lyerly, S	Has 205 items and 5 domains (psychiatric symptoms, social behavior, performance of social functioning related tasks, expectations of performance and leisure activities and expectations for these)	Items are summed to obtain total score and sub-scale scores	Observer/Clinician	Consists of multiple forms; Includes both self-report ratings and ratings from a close friend or relative; separates symptoms and functioning	Lengthy, friends and relatives may not know the patient very well

Scale	Author	Items/Domains	Scoring system	Administration	Strengths	Weaknesses
Personal and Social Performance (PSP) scale	Morosini, PL et al	Measures personal and social functioning in four domains with a single item (socially useful activities, personal and social relationships, self-care and disturbing and aggressive behaviors)	100-point, single item rating scale sub divided in to 10 equal intervals	Observer/Clinician	Clinically meaningful and has clear operational instructions on how to rate severity of disability, quick to use taking only a few minutes	It requires high level training
World Health Organization Disability Assessment Schedule (WHODAS-2.0)	World Health Organization	Consists of 36 items in six domains (Understanding and communicating, Getting around or mobility, Self-care, Getting along with others or interpersonal, Work and Participation in society)	Scores are computed for each domain by adding the item responses and transforming them into a range from 0 to 100, with higher scores indicating higher levels of disability. A global score is also calculated from all the items	Observer/ Interviewer or Self	Comprehensive, applicable to both psychological and physical disorders, applicable to multiple cultures	Items tend to assess basic functioning ability and may not be as informative for average to high functioning individuals
Health of the Nation Outcome Scale (HoNOS)	Royal College of Psychiatrists' Research Unit	Has 12 items and four subscales (Behavior, Function/impairment, Symptoms and Social)	Each item rated on a 5-point scale, a higher score indicating greater impairment	Observer/Clinician	Appropriate, well designed and thorough	It is general (not a specific functioning scale); difficulty in rating the social items; item 8 encompasses a large number of symptoms

Scale	Author	Items/Domains	Scoring system	Administration	Strengths	Weaknesses
Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM)	Psychological Therapies Research Centre, University of Leeds	The full CORE-OM comprises 34 items; it has 4 domains covering: Subjective well-being, Specific symptoms or problems, Functioning and Risk of harm to self or others	Each item rated in 5 levels from 0 (not at all) to 4 (all the time); the score in each item is added to give a total score and then divided by 34 to give an average ranging from 0 to 4; a higher score indicating more problems	Patient/Self	Inexpensive, user-friendly, sensitive to both low- and high-intensity psychological distress and pathological symptoms, has utility in different settings	Does not take into account cultural changes
Functioning Assessment Short Test (FAST)	The Bipolar Disorder Program, Barcelona, Spain	Has 24 items divided in among six specific areas of functioning (Autonomy, Occupational functioning, Cognitive functioning, Financial issues, Interpersonal relationships and Leisure time)	All of the items are rated using a 4-point scale; the global score is obtained when the scores of each item are added up. The higher the score, the more serious the difficulties are	Observer/Clinician	Simple, easy to apply and requires a very short time to be administered	Developed for people with bipolar only and may be difficult to use for other patients without adaptation; has not been tested for its cross-cultural application
Sheehan Disability Scale	David V. Sheehan	It is a composite of three self-rated items designed to measure impairment in three areas of the patient's life (work, social life and family life)	Items are rated on a ten point visual analog scale (there are verbal descriptions and numerical scores for each scale). The scale generates 4 scores (work disability score, social life disability score, family life disability score and a total score). To get a total score, which ranges from 0 to 30, the 3 individual scores are added up.	May be used as a self-report, administered by a clinician or rated by both independently.	The administration is flexible and simple. Scoring is quite straight forward and no manual is necessary; takes only 1-2 minutes to rate the scale.	It is not a comprehensive global measure; it measures only three areas of functioning and the aspects of functioning it measures are highly inter-correlated; the work item is not applicable for patients who are retired (non-working).

Table 2: Psychometric properties of commonly used functioning scales

Scale	Reliability	Validity	Sensitivity to change
Global Assessment of Functioning (GAF) scale	Overall reliability is good but is lower in the routine clinical setting; high correlation between self and expert ratings	Its concurrent validity and predictive validity are more problematic; poor discriminant validity with disease severity and physical limitations; GAF scores reflect the construct of global psychological, social, and occupational functioning that the scale was designed to measure	High severity of psychotic mental disorders associated with GAF scores; large measurement error when assessing intra-individual change in functioning. However, there is some empirical evidence for GAF sensitivity.
Global Assessment Scale (GAS)	Generally has good reliability, particularly high inter-rater reliability	Ratings correlate well with measures of overall severity of illness. Predicts re-admissions (former in-patients with scores below 40 had a higher probability of readmission than patients with higher scores)	Has a greater sensitivity to change over time than other ratings of overall severity or specific symptom dimensions
Social Functioning Scale (SFS)	High degree of internal consistency	Good construct validity; scores correlated with negative and positive symptoms	Scores significantly differentiate between people with and without schizophrenia, employed and unemployed and people with schizophrenia and their siblings
Social and Occupational Functioning Assessment Scale (SOFAS)	It has been shown to yield varying inter-rater reliability (from fair to very good)	Evidence regarding SOFAS validity is variable; has lower correlation with self-report measures but strongly related with measures of social adjustment and interpersonal problems	No data available [2]
Social Adjustment Scale (SAS)	Found to have 86% inter-rater agreement and a 0.80 correlation between interviewers' ratings. Moderate or high agreement between self-report and interviewer rating, self and informant and informant and interviewer ratings	Varied correlations between psychological symptoms and SAS scores are reported, indicating that its criterion validity is questionable; it may not accurately reflect the true magnitude of relations between symptoms and functioning as it confounds the two	No data available [2]

Scale	Reliability	Validity	Sensitivity to change
Medical Outcomes Study Short –Form 36 Health Survey (SF-36)	Has acceptable test-retest reliability, good internal consistency reliability (0.7 and above)	Can discriminate physical from mental conditions and distinguish between different types and levels of severity of clinical conditions; significant negative correlation between the SF-36 and the Brief Psychiatric Rating Scale (BPRS)	Scores showed improvement with treatment; discriminates between general population and schizophrenia patients but cannot differentiate between people with schizophrenia and other psychiatric disorders
Katz Adjustment Scale (KAS)	Internal consistency reliability coefficients were less than 0.70 (the minimally acceptable level) for most of the subscales as originally reported	Distinguishes the behavior of psychiatric patients at various level of adjustment in the community	Discriminates between various groups of individuals (Eg: hospitalized and day treatment patients)
Personal and Social Performance (PSP) scale	Overall good reliability	Highly correlated with the Positive and Negative Symptoms Scale (PANSS); able to discriminate between different categories of the Clinical Global Impression Scale (CGI-S)	A change on PSP scale scores correlate with changes in symptomatology on CGI-S and PANSS indicating some degree of relationship with psychotic symptoms
World Health Organization Disability Assessment Schedule (WHODAS-2.0)	Generally the subscales have good internal consistency, ranging from 0.61 t0 0.91; good test-retest and inter-rater reliability	Moderate to high correlations between domain scores of the WHODAS-2.0 and SF-36. However, there is no enough data on the validity of this scale	Improvement in scores are associated with alleviations of physical pain and psychological distress
Health of the Nation Outcome Scale (HoNOS)	Fair to moderate test-retest reliability and Inter-rater reliability; particularly lower reliability scores have been reported for items 1, 3, 7, and 10. Agreement is poor on items 4, 7, 8,9,11 and 12.	Perform well against other clinician rated instruments with the exception of against the BPRS and Beck Depression Inventory (BDI); has significant relation with other social functioning scales; shows poor performance against self-rated instruments	Correlations between total HoNOS scores and clinical judgments suggest that ratings corresponded with patients and clinicians views on change; however, limited in its ability to detect clinically meaningful change in circumstances where there are less dramatic changes
Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM)	Has been shown to have high test-retest reliability in a student sample; internal consistency has been reported excellent for the total score and its domains (>.75)	Convergent validation against a battery of existing measures and clinician ratings of risk is good; has strong discriminant validity	It has been shown to be sensitive to picking up change (change data from counseling in primary care, student counseling and psychotherapies all suggest that the CORE-OM is sensitive to change)
Functioning Assessment Short Test (FAST)	High internal consistency reliability (α= 0.909) and test retest reliability	High concurrent validity compared against the GAF scale ; good discriminant capacity compared between patient and controls	Found to be a sensitive instrument for the detection of different mood states
Sheehan Disability Scale	Fairly high inter-item correlations (0.70 to 0.79); high internal consistency (0.89)	Its criterion validity is substantiated by the significant relationship between symptomatology and impairment. The factor structure of the items demonstrates satisfactory construct validity.	It appears to reflect change over time with effective treatment; shown to discriminate between active drug and placebo and even between two active treatments

2.4. Cross-cultural validity of existing functioning measures

As Bolton and Tang [45] pointed out, there is a pressing need to employ a cross-cultural assessment approach that is suitable for use with different populations in low and middle-income countries. The approach needs to be within the resources usually available for this type of population.This requires the use of fully structured self or lay-interviewer administered instruments since highly trained clinical personnel familiar with the local culture are not available for many non-Western cultures. Suitability also refers to the need for adaptability across many types of cultures, demonstrable scientific validity and for generating data of practical significance both for researchers, clinicians and other health workers, non-governmental organizations (NGOs) and funding agencies who want to make use of the resulting data.

The process of translation and validation of instruments to measure mental health concepts in different cultures is referred to as cultural validation [67]. Cultural validation involves a series of steps in the translation process, field-testing and then research to demonstrate the reliability and validity of the adapted instrument. Flaherty and colleagues [68] have proposed five dimensions of equivalence that need to be assessed in order to establish cross-cultural validity of instruments. These are content equivalence (the content of each item of the instrument is relevant to the phenomena of each culture being studied); semantic equivalence (the meaning of each item is the same in each culture after translation into the language and idiom of each culture); technical equivalence (the method of assessment is comparable in each culture); criterion equivalence (the interpretation of the measurement of the variable remains the same when compared with the norm for each culture); conceptual equivalence (the instrument is measuring the same theoretical construct in each culture). Differential item functioning (DIF), Rasch analysis and confirmatory factor analysis are mechanisms to evaluate the cross-cultural construct validity of mental health measures which is important to facilitate the pooling of data in international studies [63, 69].

Reviewing the existing literature on self or lay interviewer-administered, standardised functional outcome measures, Bolton and Tang [45] found that the most widely used cross-cultural functioning instruments were the SF-36 and WHODAS-2.0. The SF-36 has been validated in the UK, United States and Australia [41]. The SF-36 has been translated and tested in more than 40 countries [70] and normed in 12 countries, including Ethiopia[52]. Regarding the WHODAS-2.0, multiple field trials have been conducted to examine the instrument's reliability, predictive validity and sensitivity to change [53]. In addition, WHODAS 2.0 has been translated into 15 different languages and appears to be applicable to multiple cultures[55]. Psychometric evaluation of the measure, however, is still in its infancy, and research comparing the performance of WHODAS to other measures of disability and functioning is needed. The Global Assessment Functioning (GAF) is also used extensively worldwide, has been translated into many languages and used in many outcome studies [54].

In conclusion, there are a large number of measures of functioning that have been developed in the West and adapted in different cultures, including in low and middle income countries (LAMICs). However, as Bolton and Tang [45] have argued, none of these standardised instruments fulfill the suitability criteria for cross-cultural work.

2.5. Functioning in people with severe mental disorders

Using World Mental Health Survey data from six LMICs andnine high-income countries, Ormel et al [40] found that the Sheehan Disability Scales (SDS) ratings for mental disorders were generally higher than for physical disorders. Consistently higher ratings were found for mental compared to physical disability in both high income and LMICs when individual SDS domains were considered rather than global ratings. The ten disorders that were considered in this study included anxiety disorders (panic disorder, generalised anxiety disorder, specific phobia, social phobia, post-traumatic stress disorder), mood disorders (major depressive disorder or dysthymia, bipolar disorder) and impulse-control disorders (intermittent explosive disorder, adult attention-deficit hyperactivity disorder, oppositional defiant disorder).The mental disorders with the highest mean SDS global disability ratings in both samples (high income and LMICs) were bipolar disorder and depression.This study, however, was limited by methodological concerns. Selection bias could have occurred as people with severe chronic physical diseases might be hospitalized or not able to participate in an interview to a greater extent than people with severe mental disorders, thus leading to under-estimation of the relative disabilities of physical compared with mental disorders. With respect to measurement, the study used self-report to assess physical conditions, which might also lead to an under-estimation of disability due to undiagnosed physical conditions. Furthermore, the physical conditions checklist used in the study did not include the infectious diseases that result in significant disability in LMICs.

There is ample evidence that schizophrenia is associated with severe and enduring psychosocial deficits [9] and thus, social dysfunction is considered to be a hallmark characteristic of schizophrenia that has important implications for the development, course and outcome of the illness. It is believed that decline in social functioning represents an area independent of negative and positive symptoms. It is the social deficits themselves that often worsen the course of the disease and may contribute to relapse [71]. A follow up study of three cohorts of 3,307 people with schizophrenia who had been discharged recently from psychiatric hospitals in Finland [72] found that impairment in social functioning was present in more than 80% of the patients. The study further indicated that people with schizophrenia seemed to experience increasing difficulties in taking responsibility for their own care, including medication as well as in managing money and emergencies. A concurrent increase in social withdrawal emerged; at follow up about 70% of the patients in each cohort were single.

A small (n=108) cross-sectional study of cognitive functioning across manic, hypomanic and depressed patients, indicated that 30 to 50% of people with bipolar disorder experienced significant social disability that might be related to persistent cognitive impairment [18]. A study of employment status in people with bipolar disorder [12] found that as many as 30 to 60% of people with bipolar disorder did not regain full social or occupational functioning after the onset of their illness. Functional recovery often lags behind recovery from symptoms and may still be incomplete when acute mood symptoms have subsided. The study showed a high rate of unemployment and a relatively low rate of competitive employment among people with bipolar disorder. Hence, the consequences of bipolar disorder can be severe, enduring and persistent. The study has methodological limitations, including possible selection bias (convenience sampling was used, with samples obtained through media announcements) and a cross sectional design. Another cross-sectional study of psychosocial functioning among young people with bipolar disorder [17] found mild to moderate functional impairment across interpersonal and work domains whereas recreational functioning was good, with little to no impairment. Subjects endorsed mild to moderate satisfaction with their current level of functioning. However, the study relied on patient and parent retrospective reports of functioning.

Data from the World Health Survey indicated that depression results in the greatest disability compared with other chronic physical diseases [25]. According to McKnight and Kashdan [27], there is evidence that roughly 60% of depressed people report substantial (severe or very severe) impairment. In addition, they argued that depression results in household strain, physical limitations, occupational disruption and restricted activity days, more bed days and poorer health status. Furthermore, McKnight and Kashdan wrote that depression affects worker productivity by reducing cognitive processing, memory, attention and concentration and energy levels as much if not more than most other physical illnesses.

In a study in Uganda where functioning was measured using a locally developed scale [28], significant associations were observed between symptoms of depression and difficulty with each task in the function assessment, for both men and women. The Pearson correlation between overall depression symptom severity scores and overall functional impairment scores was 0.53, implying that severity of depression symptoms was moderately but significantly associated with functioning. Nevertheless, since the study used a cross-sectional design it is difficult to demonstrate that depression caused the associated dysfunction; disability also makes people vulnerable to developing depression. A similar study by Bolton et al. in Rwanda [29] showed that functional impairment was substantially and significantly associated with symptoms of depression. Among men, depression symptoms were associated significantly with increased difficulty in performing all tasks except socializing and attending community meetings. For women, the association was significant for all tasks except transmitting culture to their children. Because of the cross -sectional nature of the study, however, a cause-effect relationship cannot be demonstrated.

In aprospective, population-based study of people with bipolar disorder in Butajira, a rural area of Ethiopia [50], level of functioning, as measured by SF-36, was below the normative general population level for the majority (88.4% at baseline and between 52.3% and 86% during subsequent years of follow up). A study of similar nature and in the same setting on outcome of major depression [51], as measured by WHODAS-2.0, showed that disability scores were significantly higher in the recovered group than in those with no depression. The study further indicated that individual disability domain scores were significantly greater for those with persistent depression than for those who had completely recovered, which implies that major depression is strongly associated with disability. In a population-based study of people with schizophrenia in the same area of rural Ethiopia [52], there was a strong association between positive and negative symptoms and poor functioning (measured by SF-36) at baseline. The magnitude of the difference between cases and the general population, even after follow up, was substantial indicating a high level of residual disability.

However, most of the studies reviewed above did not indicate the particular domains of functioning that were affected. They also used standardised Western instruments, which cannot reflect specific functional tasks that are relevant to the local context, and most of them employed cross-sectional outcome assessment.

2.6. Factors associated with the functioning of people with SMD

A large number of studies, mostly from high income countries, have shown associations between functional impairment in people with severe mental disorders and socio-demographic characteristics such as male sex, single marital status, urban residence, and lower socio-economic status [34, 50, 73]. In these studies, functional impairment among people with severe mental disorders was associated with illness characteristics and clinical variables, including younger age of onset, severity of negative and positive symptoms, long duration of untreated psychosis, co-morbid substance abuse, the side effects of medications, prior history of psychotic symptoms, low pre-morbid functioning, the number of prior episodes, prior admissions, persistent cognitive dysfunction and unable to access psychopharmacological and psychosocial treatment.

In a randomized controlled trail conducted to investigate the effects of antipsychotic medications on psychosocial functioning of people with chronic schizophrenia [31], non-urban residence and female gender were associated with greater improvement in psychosocial functioning. Many individuals with severe mental disorders such as schizophrenia and treatment-refractory mood disorders have prominent impairments in psychosocial functioning as they age [74]. This may be due to poor functioning in social relationships and independent living skills, growing medical co-morbidity and the loss of natural supports as age increases. Another study [35], on the contrary, showed that younger patients have more difficulty in achieving functional remission. This study also indicated that occupational status at admission has been shown to be predictive of functional outcome, as unemployed patients show significantly worse functional outcomes. Patients with longer overall illness also appear to have less favorable functional outcomes after adjusting for age. Similarly, a study of people with schizophrenia found that psychosocial functioning of those people with a long history of illness seemed to be worse compared to those with a shorter duration of illness [72]. Several variables were associated independently with current employment status [12]: performance on a brief neuropsychological test battery, total severity of symptoms, a history of psychiatric hospitalization and the level of maternal education.

Cognitive impairment observed in schizophrenia includes neuropsychological deficits in attention, working memory, verbal learning and problem solving. These deficits have been shown to be linked to impairment in functional status (social behavior, work performance, and activities of daily living) in cross-sectional studies [75]. For instance, in a small (n=108) cross-sectional study [18] psychosocial functioning, measured using the GAF, was related to measures of working memory and learning, short and long delay recall and recognition. Nevertheless, less is known about the relationship between cognitive and functional change over time. The results of a cross-sectional study on childhood sexual trauma and psychosocial functioning among people with schizophrenia [9] support the hypothesis that sexual trauma in childhood is predictive of poorer psychosocial functioning in adulthood. Specifically, participants who had a history of childhood sexual trauma had poorer role functioning, fewer of the psychological resources necessary for sustaining intimacy and higher levels of emotional instability and turmoil. However, most participants of the study were male, only a brief assessment of sexual trauma was used and confounding variables were not adjusted for in the analysis.

A cross-sectional study of substance use and psychosocial functioning in schizophrenia [76] found that compared with participants who were abstinent, those who used substances had significantly higher scores on the total Quality of Life Scale (QLS)and the interpersonal relations subscale of the QLS, indicating higher overall functioning and more frequent social contacts. Participants with a substance use disorder differed from those who used substances in having lower scores on the common objects and activities subscale, which measures the possession of common objects and engagement in certain community activities reflecting the extent of participation in routine social and instrumental activities). However, substance use disorder that involved cocaine use appears to be distinct and clearly associated with worse psycho-social functioning,especially in relation to work, school, or home making functions. The effect sizes were small and there was probable selection bias (the sample was recruited from patients voluntarily enrolled in the NIMH Clinical Anti-psychotic Trials of Intervention Effectiveness study). On the contrary, another study in people with schizophrenia found that use or abuse of illicit substances of any kind was correlated with less improvement in psychosocial functioning as measured by the Quality of Life scale [31].

A systematic review of studies on psychosocial outcome in people with bipolar disorder [73]by MacQueen and colleaguesfoundthat factors associated with functional outcome varied between studies and were difficult to confirm. The review indicated that high pre-morbid social or functional status appeared to be amongst the best predictors of psychosocial recovery. In contrast, according to MacQueenand colleagues review, some but not all studies found the presence of psychosis during illness predictive of worse psychosocial outcome. Other factors that have been associated with poor functional outcome include negative affective style in the family, longer duration of hospitalization preceding the follow-up period and younger age at onset. The above review further indicated that some studies found number of prior admissions or past episodes as predictors offunctional outcome. Co-morbidity also seemed to be an important factor in outcome; current or past substance abuse predicted poor outcome in some studies. Finally, the above review found that history of alcohol abuse appears to exacerbate cognitive dysfunction in bipolar disorder and to be associated with poor outcome; co-morbid anxiety disorders have also been shown to predict poorer treatment response in bipolar disorder.

A cross-sectional study of psychosocial functioning among bipolar youth [17] found that lower socio-economic status was associated with greater impairment in interpersonal functioning. Impairment in other domains of functioning did not differ by socio-economic status. Females with bipolar disorder reported more impairment in recreational functioning than males and were less satisfied with their current level of functioning. Similarly, another study [77] also confirmed that higher social status was associated with symptomatic and functional recovery and with more rapid onset of recovery. This was attributed to greater education and understanding of psychiatric illness as well as the availability of more extensive social and financial support systems. In aprospective study of bipolar disorder in Butajira, Ethiopia, male sex, rural residence and being married were associated with better functional outcome [50].

A study of functional outcome among people with bipolar disorder [34] reported that people with euthymic bipolar with high functioning do not differ from those with low functioning with respect to clinical variables. However, they differ in terms of medication (low functioning patients received higher number of medications) and cognitive functioning (low functioning patients performed worse on verbal memory and executive function measures). The study used cross-sectional design, with the possibility that people who were more unwell might tend to be tried on more / different medications, rather than vice versa.Artificial separation of the patients into two groups based on a cut-off score may also be considered as a limitation of the study. Another study of a similar nature among bipolar youth [17], however, reported that bipolar youth who had current psychosis had greater impairment in every domain examined (interpersonal, work, recreational and greater dissatisfaction with their level of functioning). Current depressive symptom severity was significantly associated with functional impairment in all domains (work, recreational, satisfaction, total) except interpersonal. Similarly, current manic symptom severity significantly predicted psychosocial functioning, as measured by Psychosocial Functioning Schedule of the Adolescent Longitudinal Interval Follow -Up Evaluation-Baseline(A-LIFE), in all domains. Participants in episode were significantly more impaired than those in partial remission or recovery in every functional domain examined.

A cross-sectional study on cognitive function across manic or hypomanic, depressed, and euthymic states in bipolar disorder[18] showed that psychosocial functioning was associated with neuropsychological measures rather than with clinical features. No relationship was found between psychosocial functioning and chronicity or duration of illness, total episodes, types of episodes, number of hospitalizations or suicide attempts. However, the sample size of the study was small and there appeared to be overlap between the different measures of cognitive functions. An interventional study of cognitive behavioral therapy (CBT) combined with medication for people with treatment resistant depression [78] resulted in significant improvement in both the depressive symptoms and the social functioning of the patients and maintained improvement after a one year follow up indicating that treatment is associated with functional improvement. Nevertheless, the study had no control group and significant loss to follow-up of subjects was observed.A systematic review of the relevant literature, from 1988 to 2005, revealed that short-term functional outcome improves after treatment of the first episode of psychosis, but long-term outcome remains relatively poor for a substantial proportion of patients and is associated with preadolescence onset, poor premorbid adjustment, and poor cognitive functioning [79].

As it is possible to understand from the reviews made above, studies on factors associated with functional outcome in people with SMD have inconsistent results. This is attributed mainly to methodological factors such as lack of the rigor of operational definitions of functional outcomes, failure to choose specific and ecologically valid instruments for measurement and sample sizes that were insufficient to generate meaningful results.

2.7. Development and validation of scales

The use of self-report scales and measures in research and practice has grown exponentially over the past generation in the health and behavioral sciences[80]. Similarly, the development and use of scales to measure functioning, in research and clinical practice, has grown tremendously in the past few decades. However, the majority of the instruments being used to assess functioning have focused on global measures of functional recovery rather than specific domains of human functioning [81]. A small number of other scales, such as the SAS, SF-36 and WHODAS-2.0, measure some elements of functioning but none are specific instruments developed to assess functional impairment as a result of a specific health condition and take a longer time to complete for the respondents. Hence, there is urgent need for the development of a simple functioning assessment instrument with good psychometric properties that is appropriate in a local context.

In developing a new measuring instrument, there are standard, logical and empirical steps that should be followed, which include the following [80, 82, 83] (Box 1).

Box 1: Steps for development of a new measure

1. Determine what you want to measure (the construct)
2. Conceptualization of the construct (using operational definition of the construct, literature review, review of previous scales and qualitative study)
3. Generate an item pool
4. Determine the response format
5. Have experts review the item pool and make necessary revisions
6. Cognitive interviewing and make necessary revisions
7. Pilot testing
8. Conduct qualitative and quantitative analysis and make necessary revisions
9. Design and conduct reliability and validity studies for the final form of the scale (establish the psychometric properties of the scale)
10. Develop guidelines for administration, scoring and interpretation of scores

Several criteria have been proposed for assessing the psychometric soundness of behavioral measures [84]. They should demonstrate qualities such as content validity, criterion validity, and internal consistency and they should be parsimonious, all of which contribute to providing evidence of construct validity (the relationship of the measure to the underlying attribute it is attempting to measure). One of the issues in the process of instrument development and validation is, which of the two approaches (the classical test theory or item response theory), should be used to establish the psychometric properties of the scale.

Classical test theory (CTT) is based on the following major assumptions [82, 83, 85].

- The observed score is the sum of the true score and the error score
- The expected value (population mean) of the observed score is the true score
- The error scores and the true scores obtained by a population of examinees on one test is uncorrelated
- The error scores on two different tests are uncorrelated
- The error scores on one test are uncorrelated with the true scores on another test

CTT relies on the observed scores (usually weighted sum of examinees' responses on the test items) that are assumed to provide a good representation of a "true" score [86]. As Alen and Yen [83] pointed out, the assumptions of CTT are concerned with the means and correlations of true and error scores. That is, true score theory assumes nothing about the frequency distribution of scores and does not have formal statistical tests of the suitability of the model for a set of data. In addition, CTT does not provide information about how examinees at different ability levels on the trait have performed on the item [82]. CTT also assumes that item response data are continuous variables [80]. In other words, in the classical categorization of levels of measurement, item data are treated as interval-scale variables. The major advantages of CTT are i) its relatively weak theoretical assumptions make it easy to apply in many testing situations [85] ii) its extensions (e.g., generalizability theory) [83] and iii) despite its focus on test-level information, item statistics (i.e., item difficulty and item discrimination) are also important part of the model [80].

Item response theory (IRT), on the other hand, is more grounded in theory and models the probabilistic distribution of individuals' response at the item level [85]. Here it is assumed that the most important aspects of test performance can be described by the individual's standing on a latent trait (a hypothetical and unobserved characteristic or trait) [82, 83,87]. The basic concepts of IRT rest upon the individual items of a test rather than upon some aggregate of the items responses such as a test score [88]. IRT proposes models that describe how the latent trait influences performance on each item [83]; it also treats items truly as categorical variables [80].Generally, IRT is governed by three basic assumptions [89]. These are

- unidimensionality (one latent trait influences the responses to all the items)
- local independence (for a given individual, the responses to the items are independent)
- monotonicity (the probability to have a positive response to a given item does not decrease with the latent variable)

It is possible to understand from the above description that CTT and IRT differ significantly in their modeling processes, and they make fundamentally different assumptions, both about the nature of the construct being measured as well as about how individuals respond to test items. CTT estimates of constructs are test-dependent, and every test or scale has different psychometric properties; the estimate of measurement error is sample-dependent, as the only way to estimate the standard error of measurement (SEM) is to use information from a group of respondents [89]. In IRT, a person's true score is entirely independent of items because the underlying dimension of interest is only assumed to influence responses to test or items. The result of all of the above properties is that CTT scale scores and their interpretation are always context-specific (they are item- and sample-specific). In IRT, the reverse is the case (item parameters are independent of sample characteristics, and theta estimates are independent of specific items).

Empirical investigations of the comparison of CTT and IRT showed that they both provide similar information in some aspects and different information in others, and that IRT provides additional information regarding item and person statistics compared to CTT. For instance, Fan [85] found that the two measurement frameworks produced very similar item and person statistics both in terms of the comparability of item and person statistics between the two frameworks and in terms of the degree of invariance of item statistics from the two competing measurement frameworks. Similarly, Sharkness & Deangelo [87] revealed that in terms of evaluating specific items within the social and academic involvement scales, IRT and CTT provide similar information.

Sebille et al [89], on the other hand showed that IRT can improve the classical approach to measurement with advantages that include appropriate management of possible floor and ceiling effects, comparison of respondents across different instruments and interval measurements on the latent trait scale. Sharkness & Deangelo [87] on their part indicated that CTT can only tell researchers so much about the functioning of items and scales because its statistics rely on correlations, which are inherently population bound. IRT, by contrast, provides item statistics that are population-independent, and because of this it can provide a wealth of information not available under a CTT rubric.

2.8. Theoretical and conceptual framework

The methodologies in the new cross-cultural psychiatry to develop measuring instruments emphasize the use of the emic approach, which includes among others, ethnographic interviews and the study of people that local care providers consider ill [47]. Integrating the etic and emic approaches is also suggested to have culturally sensitive psychiatric measures, which permits communication between health workers in different cultures, and comparing research findings across different cultures. Methodologies which emphasize the unique contribution of socio-cultural factors to the presentation of mental disorders are termed as emic approaches; in contrast, the etic approach uses instruments developed in other cultures by semantic translation of the item content [46].

Bolton and Tang [45] followed a three stage procedure to create a valid and reliable local or population-specific functioning instrument in Uganda and Rwanda.

1. Creation of the template
2. Free listing and data analysis to identify tasks for the template (the tasks to be inserted in to the template are determined by the results of a free listing exercise -emic approach)
3. Use it in a survey, and make validity and reliability testing

Therefore, the methodology that was used in this PhD study involved the integration of both qualitative and quantitative methods, which is an example of the new cross-cultural psychiatry.

The biopsychosocial model posits that biological, psychological (thoughts, emotions and behavior) and social factors all play a significant role in human functioning [90]. To say this differently, the biopsychosocial model states that ill health and disease are the result of an interaction between biological, psychological and social factors; it has emerged over the past two decades and has sought to expand upon disease paradigms [91].The biopsychosocial model provides a perspective on the health concept that is not always in line with the medical one. Since different environments may have a very different impact on the same individual, with a certain health condition, two persons with the same disease may have different levels of functioning and two persons with the same level of functioning not necessarily have the same condition of health. The interconnections between biological, structural, functional factors, abilities, social participation, various contexts and personal and psychological dimensions do not allow simple aetiologies, focusing only on the physiopathological, anatomical and neurological levels [92]. The biopsychosocial model is gaining acceptance within educational institutions and medical fields and is proving very successful in the areas in which it is applied although this change is not being reflected in the practical areas of medicine [91].

The biopsychosocial model is considered as the basis of the World Health Organization International Classification of Functioning, Disability and Health (ICF), which is now widely accepted as a framework for disability and rehabilitation [90]. ICF is based on a biopsychosocial model of functioning and disability, in which functioning and disability are multi-dimensional phenomena experienced at the level of the body, the person and society.

In 2001, the World Health Organization adopted the new International Classification of Functioning, Disability and Health (ICF) [92]. ICF implemented a circular interactive model in which functioning and disability of a person are considered as the product of the dynamic interaction between health conditions and contextual factors, including personal and environmental ones. There are two consequences stemming from this approach. First, the context and the life environment of each individual dramatically influence the level of his/her functioning in presence of a given disability and, given the same impairment, different contexts have very diverse effects on individual functioning and adaptation. Second, any person during his/her life can experience a changing state of health which, in a given environment, becomes disabling (influencing negatively on the person’s functioning abilities). For instance, the WHODAS-2.0, a disability assessment instrument developed according to the biopsychosocial model, assesses the limitations in activities and restrictions in participation experienced by an individual, independently from a medical diagnosis.

Thus, the biopsychosocial model was used, in this study, as a theoretical framework to understand functional impairment and disability and to develop a socio-culturally appropriate local functioning measure in people with severe mental disorders in a rural African context.

3. OBJECTIVES OF THE STUDY AND RESEARCH QUESTIONS

3.1. General and specific objectives of the study

This PhD dissertation had two general objectives:

- Develop a measure of functioning for people with severe mental disorders (that is suitable for the local context in rural Ethiopia, considers the ability of the person to perform tasks that are crucial for his/her wellbeing and recognizes differences in the roles of men and women) and then determine its psychometric properties
- Evaluate the psychometric properties of the Amharic translated version of the WHODAS-2.0 (a cross-cultural, standard measure of functional impairment and disability) among people with severe mental disorders in rural Ethiopia

The specific objectives of this PhD dissertation were the following:

- Explore the context and conceptualization of the functioning of people with severe mental disorders in a rural Ethiopian setting, with particular emphasis to the views of people with SMD and their caregivers, health professionals and religious healers
- Develop a measure of functional impairment for people with SMD, which is appropriate for the local context in rural Africa and that differentiates the roles of men and women
- Determine the psychometric properties of the new measure (test-retest reliability; internal consistency; content , construct, and convergent validity and responsiveness to change)
- Improve and optimize the Amharic translation of the WHO’s Disability Assessment Schedule, version 2 (WHODAS-2.0)
- Determine the psychometric properties of the Amharic translated version of WHODAS-2.0 (internal consistency; content, construct and convergent validity and responsiveness to change)
- Compare the relative validity and contextual appropriateness of the local and cross-cultural measures of functioning

3.2. Research questions

In order to achieve the above specific objectives, the following research questions were formulated:

- How is the functioning of people with SMD conceptualized in rural Ethiopia, from the point of view of people with SMD and their caregivers, health professionals and religious healers?
- What are the dimensions (domains) of functioning in the study context/setting?
- How do these domains relate to domains of functioning identified in other cultural settings? Are they different for men and women?
- What are the psychometric properties of the local functioning scale developed (test-retest reliability; internal consistency; content, construct, and convergent validity and responsiveness to change)?
- What are the psychometric properties of the Amharic translated version of the WHODAS-2.0 in the study setting (internal consistency; content, construct, and convergent validity and responsiveness to change)?
- Is the local scale or the cross-cultural measure of functioning more valid and contextually appropriate for the study setting?

4. RESEARCH METHODS AND MATERIALS

4.1. Setting and context of the study

This study was carried out in and around Butajira town. The area is located in the Gurage Zone, Southern Nations, Nationalities and Peoples' Region (SNNPR), around 135km south of Addis Ababa, Ethiopia. There has been a demographic surveillance site (DSS) in the area since 1987 [93] which provides the necessary infrastructure and support for conduct of community-based research studies. The Butajira area has both urban and rural dwellers. In terms of topography, it varies from a tropical climate of dry lowlands at around 1,500m to a temperate climate of cool mountainous areas of up to 3,500m above sea level [94]. In the rural areas of Butajira, farming is the main livelihood of the residents while in the town small scale business is common[95]. In the Butajira area, as maize is the main subsistence grain, Khat (an amphetamine-like psycho-stimulant) and chili pepper are the main cash crops [94]. Although historically fertile, the area has become vulnerable to food insecurity due rapid population growth. The majority of the people in the Butajira area are Muslims or Orthodox Christians, and most are engaged in activities related to their religious beliefs. Administratively, the area is divided into *Woredas* (districts), and the population in each district is further divided into *Kebeles* (sub-districts). A number of informal social structures, such as *Idir* (funeral insurance groups) and *Iqub* (local saving groups) are commonly found in the area.

Both traditional and modern methods of treatment are used by people in the Butajira area for their mental health problems. Holy water is the most common traditional treatment for people with SMD. Holy water is spring water that is regarded as holy, given by God or by one of the saints, for healing the sick. Healing comes from baptism or drinking the water or both. The ceremony is usually associated with prayer and reading of the holy books by priests. At the time when this study was conducted, biomedical mental health care services in the Butajira area were delivered in the Psychiatric Unit of Butajira general hospital, which was led by two psychiatric nurses. However, a programme to train primary care workers and expand access to mental health care is underway [96].

Butajira is also the location of the course and outcome of severe mental disorders cohort study; "SMD course and outcome study" [95]. The SMD course and outcome study is a population-based cohort of people with SMD that has been running for the last more than 15 years. This course and outcome study provided an example of specialist community-based mental health care in the rural Ethiopian setting. This project was phased out and a new NIH-funded African Focus on Intervention Research for Mental Health (AFFIRM) project took over. Within the AFFIRM program, a randomized controlled trial, entitled "Task-Sharing for the Care of SMD in a low-income country" (TaSCS), is underway. The main aim of the TaSCS trial is to determine the effectiveness and cost-effectiveness of task sharing care of people with SMD within primary health care, compared to a model of specialist mental health care in Ethiopia [97]. This PhD research project was carried out as part of preparatory work to develop/adapt and culturally validate outcome measures for the TaSCS trial.

4.2. Design

A mixed method qualitative and quantitative study was conducted to address the research questions formulated in this study. The designs that were employed for each phase of the study are indicated in the table below (Table 3).

Table 3: Study designs employed for each phase of the study

Study	Study Design
Study 1: Explore the context and conceptualization of the functioning of people with SMDin rural Ethiopia	Qualitative study (in-depth interviews and focus group discussions)
Study 2: Development of a contextual measure of functioning for people with SMD	Qualitative study, free listing and pile sorting exercise, expert evaluation and consensus meeting, cognitive interviewing, cross-sectional pilot study and test-retest reliability study
Study 3: Evaluate the psychometric properties (internal consistency, construct and convergent validity and responsiveness to change) of the finalized local functioning scale	Clinic-based cohort study
Study 4: Validation (technical and content validity, internal consistency, construct and convergent validity and responsiveness to change) of a cross-cultural, standard measure of functioning (the WHODAS- 2.0)	Qualitative study and clinic based cohort study

4.3. Study 1: Explore the context and conceptualization of functioning of people with SMDin rural Ethiopia

The primary aim of this study was to gain in-depth understanding about the functioning and disability of people with SMD in rural Ethiopia, in order to inform development of a contextual measure of functional status. The study sought to situate functioning in people with SMD within their general life experience and within the norms and expectations of the wider community. Moreover, the study was intended to identify key tasks that an adult person in the rural Ethiopian context is expected to accomplish with a view to operationalizing new scale items (likely to be sensitive to change and useful indicators of recovery) to measure functional impairment.

Sample

A qualitative study was carried out involving a range of informants expected to have first-hand experience of the functioning of people with SMD in a rural Ethiopian setting, including people with SMD and their caregivers/close family members, health care workers, project outreach workers (who have worked closely with people with SMD in the community for the last 10 years) and religious healers. Details of the socio-demographic characteristics of the participants of the interviews and FGDs are presented in Table 4 below. Ten in-depth interviews and five focus group discussions (FGD) were carried out. Six in-depth interviews were conducted with people with SMD who were selected purposively from the Butajira SMD cohort. An interview format was preferred for people with SMD as there were concerns that groups could be stressful and too confronting. Project outreach workers were asked to identify people with SMD who were currently well and able to express themselves. Two psychiatric nurses, who have been working in the Butajira general hospital Psychiatric Clinic for some years, were also interviewed.

As the majority of people with SMD are taken to Holy Water healing sites within the Orthodox Christian Church, we also interviewed two Orthodox Christian healers from Butajira town. Four FGDs, six to ten participants in each group, were carried out with caregivers of people with SMD in the Butajira cohort. The selected caregivers were all close family members (parents, sons/daughters, siblings, or husband/wife) who were living with the person with SMD; they were also balanced in terms of gender mix. One FGD was conducted with all of the Butajira SMD cohort study project outreach workers, who were five in number (two females and four males). FGD was used with caregivers and project outreach workers to elicit more information through their interaction and to encourage sharing of their experiences.

Table 4: Socio-demographic characteristics of study 1 participants

	Interview (People with severe mental illness)	Interview (Psychiatric nurses)	Interview (Religious healers)	FGD (Caregivers)	FGD (Project outreach workers)
Number of participants	6	2	2	37	5
Age categories (years)					
<25	1	0	0	3	0
25-34	0	0	1	9	3
35-44	2	1	1	11	2
45-59	3	1	0	9	0
60 and above	0	0	0	5	0
Gender					
Male	3	2	2	21	3
Female	3	0	0	16	2
Residence					
Rural	5	0	0	31	0
Urban	1	2	2	6	5
Marital Status					
Single	1	1	1	5	0
Married	3	1	1	24	5
Widowed	0	0	0	6	0
Separated	2	0	0	2	0
Education					
Can't read and write	2	0	0	11	0
Read and write only	2	0	2	11	0
Primary	1	0	0	10	0
Secondary	0	0	0	3	2
Post-secondary	1	2	0	2	3
Religion					
Muslim	3	0	0	17	1
Orthodox	3	2	2	18	4
Protestant	0	0	0	2	0
Occupation					
Farming	4	0	0	22	0
Trading	2	0	0	12	0
Employed	0	2	2	3	5

Data collection procedures

All in-depth interviews and FGDs were conducted in Amharic, the official language of Ethiopia. All FGDs and in-depth interviews were conducted by the principal investigator. While the principal investigator was moderating the FGDs, a note taker summarized the discussions and noted the non-verbal communication. The in-depth interviews with people with SMD and psychiatric nurses and the FGDs with caregivers were conducted at the Butajira general hospital

Psychiatric Clinic, whereas in-depth interviews with religious healers were held in their respective churches at the site of Holy water treatment. The FGD with project outreach workers was conducted at the Department of Psychiatry, Addis Ababa University guesthouse in Butajira town. Privacy was assured at all times. All participants, except the psychiatric nurses and project outreach workers, received modest remuneration for their time and transportation costs. All interviews and FGDs were tape-recorded, with the consent of the participants. In-depth interviews lasted between 22 to 70 minutes, whereas the FGDs lasted between 65 to 81 minutes.

Participants were asked about the experiences, symptoms and day-to-day activities of people with SMD focusing, in particular, on tasks that people with SMD are, and are not, able to do during illness onset, recovery and relapse (see Appendix E). Planned probes, which included questions related to disability in terms of understanding/concentration, interpersonal relationship, self-care, work, social participation and mobility, wereidentified from theWHO’s Disability Assessment Schedule (WHODAS 2.0) [59, 98]. Nevertheless, the original topic guide was modified and adjusted iteratively as the study progressed.

Data analysis

The in-depth interviews and FGDs were transcribed verbatim in Amharic by an experienced transcriber. The principal investigator translated all transcripts into English, and his primary supervisor read and gave feedback on all of the translations. Open Code 4.02 computer software [99] was used to facilitate data management. Data analysis was undertaken in parallel with data collection, with frequent discussion of the emerging themes and issues between the principal investigator and his primary supervisor. This informed the iterative development of the topic guide.

Thematic analysis [100], the most commonly used qualitative analytic approach, was used to identify the prominent issues from the data. Efforts were made to allow codes to emerge from the data. Themes and categories were compared between men and women and between the different respondent groups (people with SMD, caregivers and health care professionals). The principal investigator and his primary supervisor coded two transcripts independently, and coding schemes were compared and disagreements were discussed and consensus reached. The principal investigator coded all the remaining transcripts applying the already identified codes and drawing upon additional codes, where the data required, frequently discussing with his primary supervisor. Higher order codes were derived from the primary codes with thorough discussion between the principal investigator and his primary supervisor. Similarly, overarching themes were developed from the higher order codes. Illustrative quotes were selected for each theme.

4.4. Study 2: Development of a contextual measure of functioning for people with SMD

In order to establish the pool of potential items for the new scale, a qualitative study (described in study 1 above), free listing and pile sorting exercise, review of standard and commonly used measures of functioning and disability and expert consensus meetings were conducted. An overview of the procedures followed to develop the scale is given in Figure 1.

Free listing and pile sorting

For the purpose of free listing and pile sorting, six group discussions (six individuals in each group) were conducted. Three of the groups were composed of women and the other three were composed of men. Participants were selected purposively. Project outreach workers were advised to approach those individuals who had lived in the area for most of their life, who were able to express themselves well in Amharic and represented a range of ages (all aged 18 and above). Efforts were made to make participants representative in terms of education, residence, age and gender. Initially, a free-listing exercise was carried out, asking participants to respond to the following questions; each group only replying with respect to the gender of the participants.

- ‘What are the tasks that men/women must do regularly to care for themselves?’
- ‘What are the tasks that men/women must do regularly to care for their family?’
- ‘What are the tasks that men/women must do regularly to care for their community?’

Once an exhaustive list of tasks has been generated, the facilitator of the group discussions probed using items on the World Health Organization Disability Assessment Schedule (WHODAS-2.0) [101] and any relevant items collected from other scales that had not been mentioned spontaneously. The facilitator asked whether these additional items were relevant for the community and included those which were recognized to be important. A pile-sorting exercise was then carried out using the full list of tasks identified as contextually important in order to identify which items appear to be related to one another, indicating particular domains of functioning. Lastly, participants were asked to rank the tasks in order of importance within the community. Each of the tasks was documented in Amharic, using the exact wording agreed by the group, and accompanied by a brief description of each task.

Item writing

Each of the tasks in the resulting item pool was translated into scale items following principles of scale construction[80, 82]. Items were framed in a question form like “how much difficulty did you have in accomplishing (…………………..)?” The response categories were a Likert scale, with five options (none, little, moderate, a lot, cannot do task), which are similar to the response categories in the WHODAS-2.0. This formed the first draft of the scale, named the Butajira Functioning Scale draft 1 (BFS draft 1), with 78 items in the women’s scale and 84 items in the men’s scale. There were 47 items common to men and women, 31 for women only and 37 for men only.

Expert consensus

A panel of experts, including mental health researchers familiar with the study setting, psychologists and social workers, reviewed each item in the draft scale, and rated them independently in terms of their relevance and representativeness. The expert ratings were analyzed systematically. An expert consensus meeting was conducted over two afternoons and those items that were not relevant to the rural Ethiopian setting, or measuring tasks that are seasonal, insufficiently frequent or highly specific to the locality (e.g. lowland vs. highland areas) were deleted. Additional items suggested by the expert panel members were also added to the draft scale. This resulted in draft 2 of the scale (BFS draft 2); with 69 items in the women’s scale and 59 items in the men’s scale. There were 37 items common to men and women, 32 for women only and 22 for men only.

Cognitive interviewing

Cognitive interviewing is defined as an in-depth interview of respondents to a questionnaire which involves the researcher studying “the manner in which targeted audience understand, mentally process and respond to the materials we present, with a special emphasis on breakdowns in this process[102].” During cognitive interviewing, a researcher is expected to ask respondents questions about what they thought each question is asking, whether they could paraphrase each question in their own words and the rationale for their answers [86].

Concurrently, any difficulties with comprehension, together with need for clarifications and any words or expressions that were found to be unacceptable or offensive or sensitive are noted.

In this study, the full list of items derived from the expert consensus meeting was tested using cognitive interviewing in a small number of people with SMD (n=30) and their caregivers (n=30) in two rounds. People with SMD were recruited consecutively from the psychiatric out-patient clinic in Butajira general hospital. Poorly understood items that could not be rephrased, and items that were sensitive or unacceptable to respondents were excluded, at this stage, through an expert consensus meeting.This led to draft 3 of the scale (BFS draft 3), with 67 items in the women's scale and 50 items in the men's scale. There were 50 items common to men and women, 17 for women only and none for men only. The common items to men and women increased from 37 in Draft 2 to 50 in Draft 3 because the farming related tasks that were expected to be only applicable to men were found to be relevant for women also.

Pilot testing

S*ample*

The Butajira Functioning Scale draft 3 was then pilot-tested in people with SMD (n=200) and their caregivers (n=200) recruited from the Butajira general hospital psychiatric out-patient clinic in order to carry out further item reduction and item refinement. A sub-sample of 50 people with SMD and 50 caregivers were selected randomly to participate inevaluation of test-retest reliability. Although there are no definitive answers regarding sample size requirements in classical test theory (CTT) models [89, 103,104], there are some general guidelines that can be considered. Citing different sources, MacCallum & Widaman [104] indicate different recommendations for absolute sample size requirements to conduct CTT models, including exploratory factor analysis. These recommendations range from 100-250 depending on the number of items in the scale and representativeness of the sample to the population in which the measure is targeted for. In view of the recommendation of the literature and the difficulty to get large sample size in doing research with people with SMD, a sample size of 200 was taken to conduct this study.

The inclusion criteria for the pilot study were as follows: a clinical DSM-IV diagnosis of schizophrenia, bipolar disorder or major depressive disorder with psychotic features made by psychiatric nurses, aged 18 years or over, rural residence and able to attend for a follow-up appointment seven days after the initial assessment. The exclusion criteria were participating in the Butajira Course and Outcome of SMD study (to avoid interference in the ongoing study), and presence of a severe co-morbid physical health condition or substance use disorder (as these may limit the participants' ability to complete self-report measures).

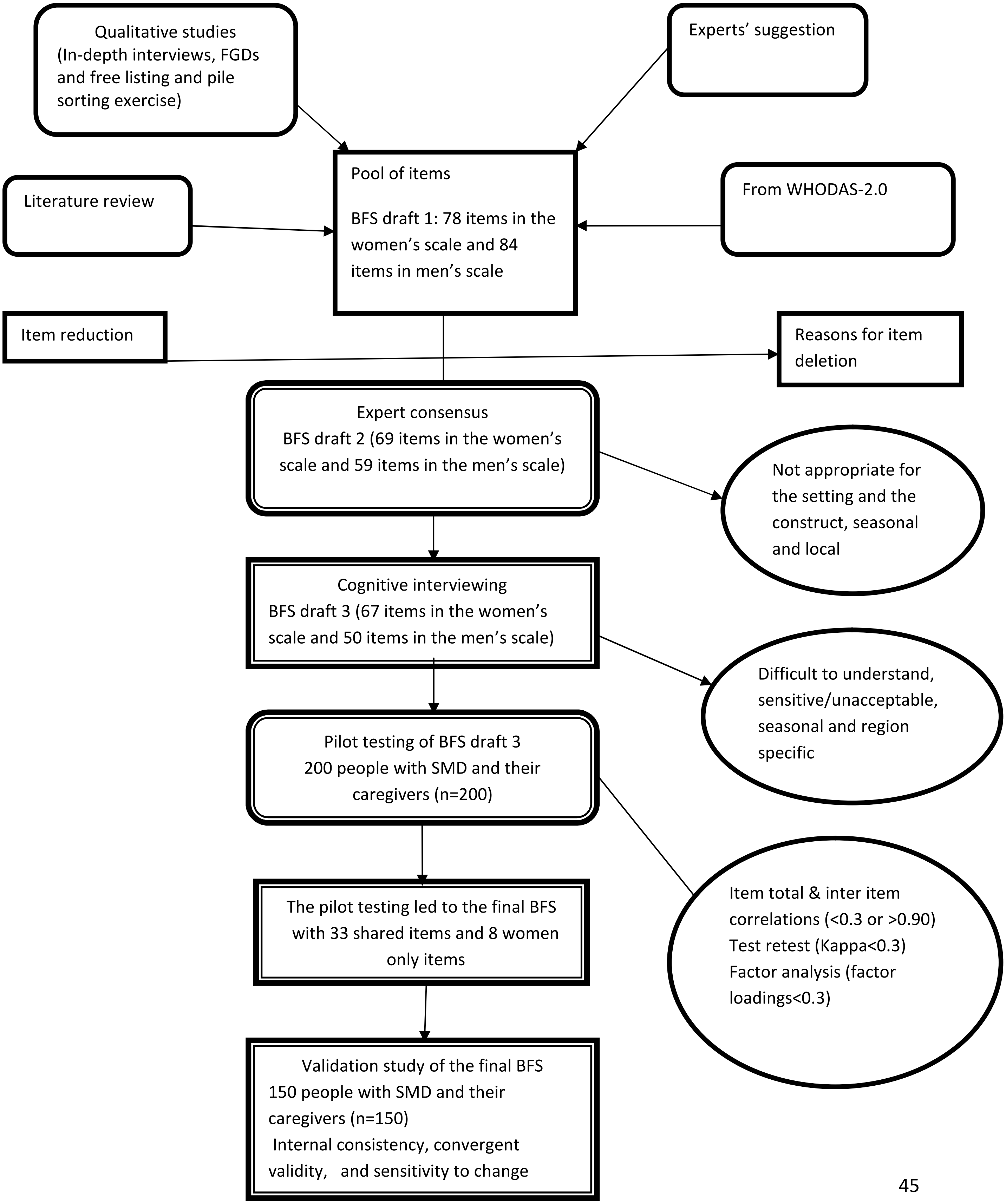
Data collection methods

Experienced data collectors conducted the interviews. Socio-demographic characteristics were measured using a structured questionnaire to collect data on gender, age, education, marital status and relative wealth of both people with SMD and their caregivers. The BFS draft 3 was then administered. Test-retest reliability was evaluated by re-administering the scale within seven days of the original administration.

Data analysis

Item reduction was carried out on the basis of a priori criteria. Descriptive statistics (frequency, percentage, mean and standard deviation) were used to examine the distribution of responses to each item. Items which had very low mean values compared to other items, and those which were endorsed or not endorsed by the vast majority of the respondents were considered for revision or deletion. Items with very low item-scale correlations (<0.3) and very low or very high item-item correlations (<0.3 or >0.90) [105] were either deleted or merged with other items. Test-retest reliability of each item was expressed in terms of intra-class correlation coefficients (ICC).Items which hadan ICC lower than 0.3 were either deleted or merged with other items. Exploratory factor analysis (with maximum likelihood extraction and varimax rotation)was used to identify potential number of dimensions, under the sub-scales which emerged from the qualitative studies, and items that load on each of these dimensions. Items which had factor loadings lower than 0.3 and items which had cross loadings (>0.40) were deleted, revised or merged with other items. This led to the final version of the scale (the BFS), comprising 33 shared items, 8 items specific to women and no items specific to men.

Figure 1: Flow diagram for the procedures followed to develop the BFS



4.5. Study 3:Evaluate the psychometric properties of the finalized local functioning scale

A facility-based cohort study was conducted to evaluate the psychometric properties of the finalized BFS.

Sample

New or acutely relapsed cases of 150 people with SMD and their caregivers (n=150) were recruited from the Butajira general hospital psychiatric out-patient clinic. In order to detect a correlation coefficient of 0.8 between two continuous measures (the BFS and the Amharic version of the WHODAS-2.0), with margin of error of 0.1, with alpha= 0.05 and power of 80%, a sample of (n=118) persons was required (calculated using G* Power software [[106]. The change in score on the two functioning measures (BFS and WHODAS-2.0) that is considered to be a meaningful indicator of improvement is unknown. Therefore, in order to calculate the required sample size, the effect size of the change in mean scores between the two time points is taken into account. In order to be able to detect a standardized effect size 0.6 (moderate to large), with 80% power and alpha= 0.05, to ensure that the standardized effect size is not as low as 0.3 (small), a sample size of 90 persons was required (calculated using G* Power software) [107].

The inclusion criteria included DSM-IV diagnosis of schizophrenia, bipolar disorder or psychotic depressionmade by psychiatric nurses, new onset or in acute relapse, age 18 or over and able to attend for a follow-up appointment six weeks after the initial assessment. The exclusion criteria were severe co-morbid physical health condition and substance use disorder (as these may limit the participants' ability to complete self-report measures).

Measures

The BFS was administered, together with the Amharic version of the WHODAS-2.0 and the expanded version of the Brief Psychiatric Rating Scale (BPRS-E).

*World Health Organization Disability Assessment Schedule (WHODAS- 2.0):*The WHODAS 2.0 was developed as a cross-cultural measure of the difficulty of daily activities and social participation experienced by a person in the past 30 days [108]. It is a generic instrument, not aimed at specific populations or specific health conditions [109]. The WHODAS 2.0 is available in different forms (12 and 36 item versions, self-administered or interviewer administered and responded by patient, caregiver and clinician) [55, 109-111]; and its validity and reliability have been tested in a number of studies [64, 109-113]. The WHODAS-2.0 has been adapted and validated in several languages and cultures, but limited to high-income and middle-income countries [109, 110,114].

*Brief Psychiatric Rating Scale (BPRS-E):*The BPRS-E is a 24-item observer-rated symptom scale covering four domains of symptoms of SMD (positive symptoms, negative symptoms, anxiety and depressive symptoms, and manic excitement or disorganization) and gives an overall indication of clinical symptom severity [38]. The BPRS-E has been used widely to detect clinical improvement in response to an intervention[115] and has been used previously in Ethiopia [116].

*Socio-demographic questionnaire:*A socio-demographic characteristics questionnaire was also used to collect data on the gender, age, education, marital status and relative wealth of both people with SMD and their caregivers. Moreover, the diagnosis of each patient was traced from the patient's cards.

Data analysis

Convergent validity was assessed by calculating Pearson's correlation coefficient (r) for the association between BFSscore and scores on the WHODAS- 2.0 and BPRS-E. Internal consistency was assessed by calculating Cronbach's alpha.

In order to evaluate the sensitivity to change of the BFS over time, both internal and external responsiveness were determined in line with recommended practice [117]. Internal responsiveness is the change in a measure over time and was evaluated by paired sample t-test, effect size (change in mean divided by standard deviation of the baseline score) and the standardized response mean (SRM), which is calculated by dividing the change in mean score by the standard deviation of the change scores (Δ mean / Δ SD). External responsiveness is the extent to which change in the index measure (the BFS) corresponds to change in an external, reference measure (the BPRS-E) [117]. Spearman rank order correlation of the change scores from the two measures was computed to determine external responsiveness to change.

Mokken scaling analysis was carried out for each sub-scale and the overall BFS. Mokken scaling is a non-parametric item response model which is used to measure the hierarchical properties of items in a scale [118]. It is used to assess if the items in a scale can be ordered by their degree of difficulty, and therefore, any person who endorsed a particular item will also endorse all the other items ranked lower in difficulty [119]. For a single monotone homogeneity model (MHM), three assumptions are required [120]: unidimensionality, local independence, and monotonicity. Double monotonicity models (DMMs), on the other hand, require an additional assumption that the order of item difficulties remain invariant over all values of the latent trait and thus, the item response function curves do not intersect [121]. This means that for any value of the latent trait, the probability of a positive response decreases with the difficulty of the item.

To assess single monotone homogeneity, Loevinger coefficients for each item (H_i) and for the scale (H) were estimated. Conventionally, scales with H between 0.3 and 0.4 are considered weakly scalable, values between 0.4 and 0.5 moderately scalable and values above 0.5 strongly scalable [122]. Violations of monotonicity and non-intersection between pairs of items were tested using overall criteria values [118] as an indication of the likelihood of assumption violations (≤40 satisfactory, 40 to 70 questionable violation and 80 and over strongly suggesting an assumption violation).

4.6. Study 4:Validation of the WHODAS- 2.0

Semantic, technicaland content validation of the WHODAS 2.0

In this study, the Amharic 36 item patient version of the WHODAS 2.0 was used as a starting point for further optimizing the translation, and examining technical and content validity. This version was used previously in the Butajira area [51, 123]..The translation of the original WHODAS 2.0 from English into Amharic was conducted following internationally established procedures [124]. As part of the free listing and pile sorting exercise, carried out to identify potential items for developing the BFS, the relative importance of different items of the WHODAS 2.0 to the Butajira setting was identified. For the details of how the free listing and pile sorting exercise was carried out, see study 2 above.

Further exploration of the content validity of the WHODAS was carried out by administering the scale to a sample of 20 people with SMD and their caregivers recruited from the Psychiatric Unit of Butajira general hospital. Cognitive interviewing was used to identify any difficulty with understanding of individual items and response categories, as well as acceptability and burden of the whole scale. Findings of the cognitive interviewing were then presented to an expert panel, composed of psychiatrists, psychologists, social workers and mental health researchers. The panel members suggested how each problematic item should be rephrased to be more easily understood by the respondents, while retaining semantic equivalence with the original scale.

Convergent and construct validation of the WHODAS 2.0

The facility-based cohort study, which was primarily carried out to validate the BFS, was also used to evaluate the sensitivity to change of the WHODAS-2.0. Internal consistency and convergent validity of the WHODAS-2.0 were assessed using the baseline sample.

Sample

As described under study 3 above, new or acutely relapsed cases of 150 people with SMD and their caregivers (n=150) were recruited from the Butajira general hospital out-patient psychiatric clinic. After six weeks follow up, both the WHODAS- 2.0 and BFS wereintended to be re-administered to a random sub-sample of 90 participants. For the details of the sample size calculation and the inclusion and exclusion criteria that were used to recruit the participants, see study 3 above. An additional 100 people with SMD and their caregivers (n=100) were recruited from the Butajira general hospital psychiatric clinic, with the same inclusion and exclusion criteria as the above, in order to give a total of n=250 sample which is considered to be adequate for conducting confirmatory factor analysis.

Measures

Data from structured questionnaires were collected by lay interviewer project outreach workers with more than 10 years of field work experience. Refresher training was given for one day to familiarize the data collectors with the new measures.

The Amharic translation of the 36-item version WHODAS 2.0 was administered. The WHODAS 2.0 is designed to assess the activity limitations and participation restrictions experienced by an individual due to any health condition [55]. The full version of the WHODAS 2.0 comprises 36 items in six domains [64]: understanding and communicating (6 items), getting around (5 items), self-care (4 items), getting along with others (5 items), activities at home, work and/or school (8 items) and participation in society (8 items). There are five response options for each item (none, mild, moderate, severe and extreme/cannot do). For each item, respondents are required to estimate the magnitude of their disability during the past 30 days. WHODAS 2.0 scores are computed for each domain by adding the item responses; a global score is also calculated from all the items [64]. A higher score indicates greater disability or worse functioning. The two best performing items from each domain were chosen for the 12 item version [112]. This short version of the WHODAS 2.0 covers all the six domains of the full 36 item version. There are self-administered, interviewer administered and proxy-administered versions, each of which are available in 36 item and 12 item formats [125]. In this study, the 36 item interviewer-administered version of the WHODAS 2.0 was used. WHODAS 2.0 has high internal consistency, moderate to good test-retest reliability [55] and good concurrent validity [64] in many clinical populations with chronic diseases.

The BFS was also administered for the same participants. As described in detail in the previous sections, the BFS is a local (emic) functioning scale developed for people with SMD in a rural African context as a primary objective of this PhD work. It was developed following standard procedures, including qualitative study [126], review of previous scales, free listing and pile sorting, expert consensus, cognitive interviewing and pilot testing, which all are described under study 1 and study 2. The finalized BFS has 33 shared items for men and women and 8 women only items in three domains: self-care (9 items), work (7 common items for men and women and 8 women only items) and social functioning (17 items). The BFS was found to be easy and fast to administer, with excellent internal consistency, construct and convergent validity and acceptable sensitivity to change over time.

The Expanded version of the Brief Psychiatric Rating Scale (BPRS-E) was used to detect severity of clinical symptoms[38]. For further descriptions of the characteristics of the BPRS-E, please see study 3 above.

A structured questionnaire was used to collect data on the gender, age, education, marital status and relative wealth of both people with SMD and their caregivers. Moreover, the diagnosis of each patient was extracted from the clinical notes.

Data analysis

Convergent validity (comparing the WHODAS 2.0 with severity of symptoms, as measured by BPRS-E total score) was assessed by calculating Pearson's correlation coefficient (*r*). The association between the sub-scales' and the overall scale's scores of the WHODAS 2.0 and the

BFS, other indicators of convergent validity, was evaluated by using Pearson's correlation coefficient. Internal consistency of each of the domain and overall WHODAS 2.0 items was assessed by calculating Cronbach's alpha.

As it was carried out for the BFS, in order to evaluate the sensitivity to change of the WHODAS 2.0, both internal and external responsiveness were determined [117]. Internal responsiveness was evaluated by paired sample t-test, effect size (ES I)and the standardized response mean (SRM or ES II). See study 4 for the descriptions about what ES I and SRM are. External responsiveness is the extent to which change in the index measure (WHODAS 2.0) corresponds to change in an external, reference measure (the BPRS-E) [117]. Spearman rank order correlation of the change scores from the two measures was computed to determine external responsiveness to change.

Confirmatory factor analysis was carried out to test whether the six domains of the 36 item WHODAS 2.0 and the one-dimensional nature of the 12 item WHODAS are applicable in the rural Ethiopian context. We conducted a second order CFA to test the structure of the 36 item WHODAS-2.0. The first order factors were the six domains, each containing four to eight items and the second order factor was the general disability factor as proposedby the authors(see Fig. 3).Goodness of fit was assessed with the following indices: χ^2 test, acceptable if χ^2/df is less than 3.0[127]; Confirmatory Fit Index (CFI), acceptable if its value ≥0.95[128]; Tucker-Lewis Index (TLI), acceptable if its value exceeds 0.90[128]; and root mean square error of approximation (RMSEA), good fit if the value is close to 0.06[129].

4.7. Data management and processing

FGDs and in-depth interviews were conducted in Amharic and audio-taped. The audio-taped FGDs and in-depth interviews were transcribed in Amharic and then translated into English for analysis. Independent translation was made for selected transcripts to improve reliability. With respect to the quantitative study, double data entry was carried out using EpiData version 3.1[130] by experienced data clerks and consistency checked. The data was analyzed using statistical soft wares (STATA version 13.0 and SPSS version 20.0). Computer, audio and transcribed files were handled anonymously and password protected.

4.8. Data quality assurance

Necessary measures were taken to ensure data quality throughout the study. The principal investigator facilitated all the FGDs and conducted all the in-depth interviews. Experienced data collectors, who have long years of service as field workers in the SMD course and outcome study project of the Department of Psychiatry, Addis Ababa University, conducted the structured interviews. In each phase of this PhD research project, training was given to the data collectors at least for a day to ensure that they properly understand the items of the instruments used and can build rapport and handle the participants properly, including people with SMD.

Skilled data clerks who have long experience of data entry in the mental health research projects of the Department of Psychiatry, Addis Ababa University did the data entry. In addition, one day training was given, in each phase of the project, to them to ensure that they understand the nature of the data and the instruments. Throughout the data collection and the data entry process, the principal investigator did close supervision of the data entry clerks and prompt assessment of the data. Efforts were also made to build trust among the data collectors and data clerks. To improve reliability and data quality, the principal researcher did check interviews or repeat interviews on randomly selected participants.

4.9. Ethical considerations

The study design was reviewed and approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University (approval date: April 10, 2013; and approval number: 051/2013). The following ethical issues were addressed throughout the study.

Potential risks

The risks associated with this research project were expected to be minimal. Even then, potential risks were minimized by ensuring that participants were aware of all possible risks and benefits prior to their decision to voluntary participation. The potential risks and the strategies used for minimizing them are discussed below.

Psychological distress in the interview/discussion process

Participants in FGDs, in-depth interviews and structured interviews might find discussing personal and community issues distressing. These risks were reduced by using skilled and experienced interviewers who could establish good rapport with the participants prior to and during the interviews. Discussing personal information might be particularly more distressing among people with mental illnesses and these risks were mitigated by establishing good rapport with the participants prior to and during the interviews as well as training the interviewers in handling difficult situations. Referral to specialist mental health care services was made when specific mental health needs were identified.

Confidentiality

Private information was collected from participants; however, only necessary personal information was collected and the data were de-identified where possible. Data were stored in locked cabinets and password protected computers which only the principal investigator could access. The principal investigator signed confidentiality forms, and identifying information was removed from all data prior to analysis and dissemination of research findings. An anonymous electronic copy of the data was kept with the principal investigator.

Least restriction or coercion to participate

It was ensured that all participants were fully informed of the study procedures. Informed consent was sought and recorded in writing. For non-literate participants, witnessed verbal consent was sought and recorded.

Burden on local communities

This research project might have some potential burden on the local communities where the study was conducted, including time required from health service staff and community participants. This was identified during the course of planning for the specific studies and was kept to a minimum.

Potential benefits

This research project was expected to have potential benefits to the various stakeholders. People with mental illnesses could benefit participating in mental health interventions. Researchers, clinicians and service users would benefit from the findings and products of the project (a contextually appropriate, easy to use and valid and reliable local functioning measure and a well translated and validated cross-cultural, standard instrument to measure the day-to-day functioning of people with SMD).

Reimbursement to participants

Persons attending FGDs and in-depth interviews at a central location in Butajira, and participants for the quantitative study (people with SMD and their family members/care givers) were reimbursed for travel and their time. Refreshment was provided for FGD and in-depth interview participants.

Informed consent

Informed consent was sought and recorded in writing prior to participation in the study. For non-literate participants, witnessed verbal consent was sought and recorded. More specifically, throughout the research project, the following procedures were followed as far as consent is concerned.

Qualitative study

We asked all the participants in advance whether they would like to participate, while giving them a brief information sheet. The information sheet explained the purpose of the study, the potential risks and benefits, and clearly stated that the person has no obligation to participate and can withdraw at any time. At the time of the interview /FGD, the consent form was given to the potential participant. At this point, the participant was able to choose whether or not to participate. Voluntarily signed informed consent was sought. It was clear from the information sheet that there were no repercussions for participants if they decline to participate. In case of participants with SMD, only those who were well at the time of the interview/FGD and were able to give voluntary informed consent were included.

Cross-sectional pilot study and prospective study

It was not possible to inform people with SMD and their caregivers about the study prior to the day of recruitment as many travel from far places to attend the Butajira general hospital psychiatric unit. People with SMD, and their accompanying caregivers, who were attending the Butajira general hospital psychiatric unit were approached, screened for eligibility and invited to participate in the study. In a private place, they were given an information sheet about the study which was also explained to them verbally. After being given an opportunity to ask questions about the study, voluntarily signed informed consent was sought.

For the cross-sectional pilot study, people with SMD who were stabilised, and were able to give informed and voluntary consent, were recruited. However, for the prospective study, people with SMD who were at first presentation or in acute relapse were recruited. For those persons who lacked capacity to consent, we attempted to establish rapport with the person so that they could have opportunity to form a trusting relationship and consider their decision. It is particularly important that those who lacked capacity to consent participated in this study. Therefore, when it was certain that a person is not refusing to participate, butlacks capacity to give consent due to mental illness, we sought permission from a guardian or family member. When interviews were conducted under such circumstances, these interviews were conducted only if the person being interviewed is not actively refusing. For a few of such participants we secured informed consent after their condition was improved during the follow-up assessment six weeks after the initial assessment.

Privacy and Confidentiality

The collection of personal data that are not important to the study was minimized. The forms were numbered with a separate list with names and contact details which were necessary for subsequent linking to the second set of questionnaires. We ensured that FGD participants were aware that confidentiality may not be guaranteed but we encouraged all participants to keep the information discussed in the focus group confidential. The records from the focus groups contained no personal identifier but included relevant socio-demographic information.

All data collected, including audio-recordings, are maintained in a locked cabinet or security protected computer with limited access. The data will be kept for 7 years with the principal investigator. Personal information was removed from the research records. After 7 years, the hard copies of the data will be destroyed while unidentified data will be maintained for future use. Only anonymous data were used for analyses. Audio recordings were transcribed and then destroyed to ensure that participants cannot be identified.

5. RESULTS

This section presents a summary of the major findings of the study. It is organized in line with the specific objectives of the study. The section begins with presenting the findings of the qualitative study, which explored the context and conceptualization of the functioning of people with SMD in rural Ethiopia. This is followed by the results of the free listing and pile sorting exercise and the pilot testing that were done for developing the local functioning scale (the BFS). Subsequently, findings pertaining to the psychometric properties of the finalized BFS were presented. Lastly, the findings of the study on the validity and psychometric properties of the Amharic translated version of WHODAS-2.0 are reported.

5.1. Context and conceptualization of the functioning of people with SMD in rural Ethiopia

Though some issues were emphasized to a greater or lesser extent than others, there were, generally lots of overlaps in the responses from the different groups of participants. Gender patterning of functioning and impairment was evident and there were differences of emphasis between the three categories of respondents (people with SMD, caregivers and professionals). Although mentioned by a few participants, differences in functional roles across the different religious groups and the importance of religious roles for social functioning were not emphasized. Participants rather focused on those functional tasks that were crucial for their survival. Overall, the data showed that functioning in people with severe mental disorders is conceptualized in terms of three broad and interrelated themes: (1) the broader context influencing functional impairment; (2) activities required to live and survive in rural Ethiopia; and (3) consequences of functional impairment.

The first theme is associated with the context of SMD and functioning, where participants described the different factors that contribute to the functional impairment and recovery of people with SMD. In the second theme, participants identified different kinds of functional limitations in people with SMD, which are relevant to their own and their family survival in the rural Ethiopian setting. These included able to care for self, working and being productive, able to fulfill family duties, engaging in social responsibilities, interacting with others in expected ways, able to travel long distances, and able to remember and concentrate. These clustered around the theme “living and surviving in rural Ethiopia: required functional tasks”. In the third theme, dreadful consequences of the functional impairment of people with severe mental disorders were emphasized in almost all the in-depth interviews and FGDs. These are clustered into the theme “consequences of functional impairment in people with SMD.”

Based on the findings, a conceptual model was developed (see figure 2 below) which illustrates how the three themes were related to one another. Another issue emerged from the data was differences between men and women patients, with respect to both the types of functional activities expected and patterns of impairment seen in people with SMD.

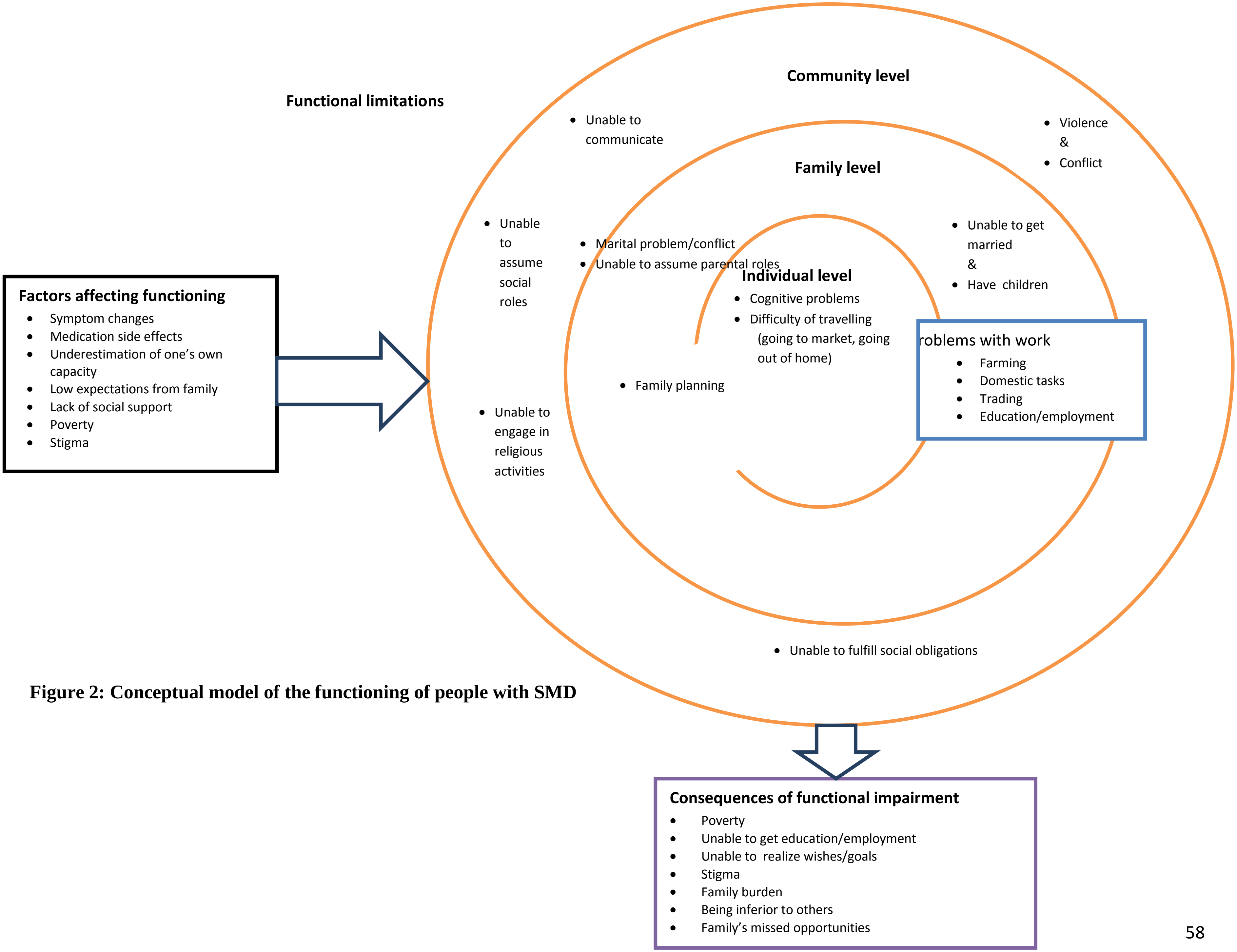


Figure 2: Conceptual model of the functioning of people with SMD

1. The broader context influencing functional impairment

In describing the context of SMD and functioning, participants identified factors that impeded or facilitated the day-to-day activities of people with SMD in the setting. Although symptoms were mentioned by all participants as a key factor affecting performance, in all cases the negative impact of a range of non-symptom-related factors was also emphasized: at the level of the person with SMD (underestimating one's own capacity and the impact of medication side effects), from family members or caregivers (a lack of support, reluctance to give the person with SMD autonomy or freedom, lowered expectations about the person's capabilities, fear which might lead to chaining up the patient unnecessarily) and the wider social and economic conditions (poverty, stigma and discrimination). This showed that there were several factors in the study context, apart from the symptoms of the illness, which influenced the functional status of people with SMD.

Patient related factors

The majority of participants, especially people with SMD and their caregivers, emphasized the importance of illness symptoms in impeding the ability of patients to accomplish their day to day tasks. People with SMD would be in a better position to accomplish their day -to -day tasks when the severity of symptoms had reduced or when symptoms had disappeared altogether. One of the project outreach workers described how illness symptoms affected day to day functioning of people with SMD as follows.

> *When we sit and talk together, I asked one patient the question "why don't you work?" I said to him "if you do farming, you can be a rich person". Then, he told me that 'when I do farming, I see something and it tells me to stop doing this and then I just sit down'. At another time, I happened to tell a patient that if you work hard, you can buy clothes, and you can also support others. When I said this to him, he told me that he is the government of the country. He said that he is governing the country and so "why do I need to work?"*
>
> *(Project outreach worker, female, 28, urban)*

One of the psychiatric nurses also spoke about the effect of illness symptoms on functioning as follows.

> *Symptoms, specially the severe symptoms make them [people with SMD] lose energy. For instance, if it is depression, their body loses energy. They lose their energy, get very tired, and "their body will be like cloth" [an Amharic idiom]. So, they will not be able to wash their clothes, prepare their food, move from one place to another, and go to the market and buy the thing they want to buy.*
>
> *(Psychiatric nurse, male, 45, urban)*

One of the important factors to impede the functioning of people with SMD was said to be underestimation of one's own capacity on the part of the people with SMD. Considering mental illness to be a non-curable, lifelong problem, and influenced by social pressures such as stigma and discrimination, respondents with SMD expressed the view that they would not be able to work and be successful in life. Under-estimation of one's own capacity in people with SMD was due to the loss of their self-efficacy and self-esteem as a consequence of the attitudes and beliefs described above.People with SMD also reported that side effects of psychotropic medications, such as loss of energy and fatigue, impeded their ability to engage in their daily activities.

Caregiver-related factors

All groups of respondents reported that family members or caregivers played a pivotal role in improving or worsening the functioning of people with SMD. Family members could improve the functioning of people with SMD that they are caring for through social support; and could further impair functioning by denying the autonomy of the person with SMD and having low expectations about the capacity of people with SMD to function. One of the psychiatric nurses described this as: *"….at home also family members prevent them [people with mental illnesses] from doing things when they try to engage themselves in some tasks."*

One of the religious healers described the importance of social support from the family to improve the functioning as well as the general health condition of people with SMD.

> *The caregivers shouldn't feel tired. They should try in different holy water places. There are people who stay for up to three years only in one holy water place. Those caregivers who have patience and don't feel tired usually bring about improvement and the patients become well. They become normal leaving all the problems we mentioned earlier.*
>
> *(Religious healer, male, 33, urban)*

Similar attitudes were said to prevail in the community at large. One of the religious healers commented as follows:

> *The community itself doesn't allow them [mentally ill people] to work. The community considers them as ill and rather than encouraging them to work, people from the community advise them to go to holy water places or to hospital. People from the community comment to them "you are ill and how can you work?"*
>
> *(Religious healer, male, 35, urban)*

Social exclusion and economic conditions

Social and economic conditions were reported by all groups of participants to be important factors affecting the functioning of people with SMD. Stigma associated with mental illness was considered to deprive people with SMD of social participation, interpersonal relationships, marital and family life, and even from employment.

> *They [people with mental illnesses] are considered as inferior in the community and if they want to get married, people in the community will rumor that they are mentally ill and parents will not allow giving their daughters/sons to this kind of persons. So, the community doesn't have a positive attitude towards people with mental disorders. The community considers people with mental disorders as inferior.*
>
> *(Project outreach worker, male, 36, urban)*

> *When there are community meetings in the Kebele, the Chair of the Kebele doesn't want me to be there. People say that he [the patient] doesn't act normal in meetings.*
>
> *(Man with SMD, 45, rural)*

Poverty was found to have both direct and indirect effects on the functional impairment of people with SMD. Unable to fulfill one's own and family member's needs, such as needs for food and clothing, could be an immediate factor in illness relapse and consequent disability. Participants reported that people with SMD were likely to be found at the lower economic level in the community, and that this would prevent them from getting married and participating in different activities of the community, such as "*Idir*" (funeral insurance groups), *kebele* (sub-district) meetings and religious celebrations. In this regard, a family member commented in the FGD that:

> *His [the person with SMD] major problem is related to money and poverty; otherwise he is fine. If he is able to get money, he can work and go well with his family members and his neighbors.*
>
> *(Caregiver, Male, 35, rural, brother of a patient)*

2. Living and surviving in rural Ethiopia: required functional tasks

Participants reported many activities or tasks that people with SMD struggled to accomplish. These tasks were considered to be vital for each and every member of the community to carry out and crucial for one's own and his/her family's survival. The most valued activities were related to caring for oneself, working and productivity, assuming family responsibilities, interacting with family members, neighbors and members of the community, engaging in community activities and societal responsibilities.

Self-care

One of the most serious functional limitations in people with SMD was reported to be problems with self-care. All groups of participants, especially caregivers and project outreach workers, reported that people with SMD had difficulties with taking care of themselves, for example, unable to wash themselves and their clothes independently. In line with this, a caregiver commented in the FGD:

> *He doesn't take care of himself unless we tell him to wash or change his clothes. He doesn't even ask us to wash his clothes or to give him water for washing his body. He doesn't wash his body or his clothes by his own initiative. You know...it is the children and I who wash his clothes and tell him to wash his body and keep his hygiene.*
>
> *(Caregiver, male, 40, rural, brother of a man with SMD)*

For caregivers, this particular functional impairment increased the burden of caring and was also a potent source of stigma. For people with SMD, self-care was clearly a valued activity that was required in order to be functional within a society. Project outreach workers also reported that they had observed people with SMD being unclean, wearing dirty clothes, and having long finger nails.

> *...That kind of thing is observed, even when they are taking medication; that is being unclean, unable to keep their hygiene, unable to cut their finger nails…Aaa...unable to change their clothes. We usually see these kinds of things on them [people with SMD).*
>
> *(Project outreach worker, female, 29, urban)*

Work

Participants gave a strong emphasis tomental illness impairing the ability to work. Some of the activities impaired by mental ill-health were limited to either men or women and others were expected to be undertaken by both men and women. The most important type of work for men in the study area was reported to be farming, which included seasonal tasks of varying difficulty: ploughing, digging, sowing, weeding, and harvesting. Men were also reported to be expected to carry out small-scale business or trading. Women were expected to do some, but not all, aspects of farming, including growing food in the immediate locality of the home, weeding, and supporting men with ploughing and harvesting. However, the most critical work activities carried out by women were reported to be various domestic tasks: for example, cooking food, cleaning the house, washing clothes, and fetching water. Women were also expected to engage in small-scale business or trading. All groups of participants reported that people with SMD had difficulty to accomplish these tasks, with differences during onset, recovery and relapse and also between men and women. In connection with farming as a common and vital aspect of work in the Butajira area, one of the religious healers, who knew the area for many years, had the following to say.

> *…farming, animal rearing, bee farming, planting and taking care of trees, farming maize, farming pepper etc. These are the major tasks in this community. But, when we see persons with mental illnesses, they don't do these tasks very well. Rather they move around with no purpose.*
>
> *(Religious healer, male, 33, urban)*

> *…also if there are things that should be accomplished in the season, they [people in the community] do. But those who are mentally ill (if their illness is severe), they can't*

> *accomplish these all. Even when they sometimes go out to work, even if they have the concept that they should work, they don't understand how to work, when to work and why they should work.*
>
> *(Psychiatric nurse, male, 45, urban)*

Respondents emphasized that it was not just a matter of going to work in the fields, but that the quality of the work and productivity had to be taken into consideration. People with SMD themselves acknowledged that they had difficulty to accomplish tasks that were crucial to their survival even when they were in the state of remission.

> *If I were healthy, I could have done small business. I do have a donkey at home, and I could have bought grain from Enseno and sold it at Butajira. I could have done trading with the donkey I have at home…so that I could have bought clothes for my children and we could have eaten enough.*
>
> *(Woman with SMD, 49, rural)*

However, it appeared that some people with SMD are able to work when they are well. For instance, a caregiver interviewed with a patient said "*she [the patient] doesn't bring other people into trouble; when she gets better she even wakes up early and prepares coffee and cleans the house.*"

Interpersonal relationships

Almost all respondents described that people with SMD have problems in their relationships with other people. They were reported to have poor communication with their family members, neighbors and with members of the community at large. Caregivers described a number of situations where the people they care for entered into conflict with others.

> *In my case, the problem that I consider as most difficult is she [the person with SMD] easily gets upset. She enters into conflict with the children and other people easily. She misinterprets what others are talking and feels angry.*
>
> *(Caregiver, male, 50, rural, father of a woman with SMD)*

> *He [the patient] talks alone; he has little communication and relationship with other people. He doesn't want to enjoy with other people; he wants to be alone. He stays at home for twenty four hours and doesn't do anything.*
>
> *(Caregiver, female, 30, rural, wife of a man with SMD)*

These could be considered as symptoms, but one's ability to get along with other people in the expected way was highly valued by the community. In addition, it was not easy to make a clear distinction between illness symptoms and functional tasks.

However, there were differences in terms of gender and whether the patient was in recovery or relapse. Participants described that patients had very poor communication, tended to instigate conflict with family members, neighbors and with the community, and were more violent against other people when they were in relapse or when their illness was just starting. Compared to women, men with SMD were described as more violent and with greater tendency towards getting involved in conflicts and more likely to have very poor communication. Regarding the participation of people with SMD in different community activities, a project outreach worker had the following to say.

> *Yes, our patients don't care/feel anything about weddings, even weddings of their family members. They don't consider the happiness of their family members as their own like any other person. The same is true for funerals or mourning. They don't feel the sadness of their family members. These are nothing for them.*
>
> *(Project outreach worker, male, 32, urban)*

People with SMD also acknowledged their limited participation in different community activities due to the illness. Some of them reported that the over-riding reason for their limited social participation was due to being stigmatized and discriminated against.

> *When there are community meetings in the Kebele, the Chair doesn't want me to be there. I don't act normal in meetings; it [the illness] drives me to beat people. So, I don't go to where there is community meeting. If I have, I send money through my wife or through my children.*
>
> *(Man with SMD, male, 46, rural)*

Some of the caregivers indicated that people with SMD that they cared for were able to work, manage the family and assume responsibilities in the family when they were in the state of recovery, but that they still might not be able to go out and engage in different community activities.

> *My brother [the person with SMD] is able to work and manage his money. But, he has limited social life. He is careless in terms of his relationship with other people. He even considers social activities and participation in community activities as useless. This is his major problem.*
>
> *(Caregiver, male, 55, rural, brother of a man with SMD)*

Family life

People with SMD were reported to have problems with regard to family life, particularly with getting married and having children. Respondents reported that negative attitudes from community members were an important reason impeding marriage of a person with mental illness. The other reported reason for reluctance to marry a person with mental illness was due to their poverty. People with SMD were seen to be on the lowest rung of the economic ladder, compared to the general population, due to their difficulties in working productively. The burden associated with caring for a mentally ill person was also considered to be a factor putting people off marrying a person with mental illness. Indeed, if a person with SMD was somehow able to get married, usually due to the support of family and relatives, the study respondents considered that divorce would be almost inevitable. In connection with this, a mother whose son was mentally ill for several years spoke the following.

> *He [the patient] was well and started working. By chance, after he got married, his wife left him and went to her parents saying that I don't want him, he is mentally ill, and I got married to him without being aware that he is mentally ill. Now, I know that he is mentally ill, and I don't want to live with him. Immediately after she left him and went to her parents, his illness relapsed and now he is spending the day at home chained up.*
>
> *(Caregiver, female, 60, rural, mother of a man with SMD)*

Almost all groups of respondents reported a difference between men and women with SMD in terms of the opportunity they had to get married and have children. Generally, men with SMD were able to make use of the traditional arranged marriage system in rural Ethiopian communities. That is, the relatives of the man with SMD could find a woman and ask her parents to marry the man. However, this kind of arrangement was not possible for women.

> *People don't expect that a women patient would be well in the future. Even after she gets better, she can't get married. But, the man will easily get married if he is better for six months, even for three months. The man can go to other places and get married.*
>
> *(Project outreach worker, female, 29, urban)*

3. Consequences of functional impairment

The inability of people with SMD to accomplish their daily activitieswas reported to have a number of devastating consequences, both for people with SMD and their family members. Of these the most serious ones included poverty, inability to get education and employment, difficulty realizing wishes and goals, stigma, a feeling of being inferior to others, family burden and missed opportunities for family members.

Poverty

Poverty was reported to be the most important consequence of functional impairment in people with SMD; and this was well articulated by a psychiatric nurse as *"there is poverty in everybody's house here, but they [people with SMD] are living below poverty; you see them sleeping in the street."*If someone was not able to work, relate well with other people and participate in different community activities, poverty was considered to be inevitable. The impact of functional impairment on economic status was reported to be especially severe when the person with SMD was the household head and breadwinner of the family.

> *The problem I have at home is that I can't buy clothes and change as I need. I can't buy clothes for my children; they can't eat whatever they need. There are times when they can't have dinner. There are times when they spend the night only drinking water. If I were able to work, all these things could have never happened.*
>
> *(Man with SMD, 48, rural)*

It was clearly observed in this study that poverty is both a cause and a consequence of functional impairment and disability. People with SMD, who are in the lower socio-economic status, are likely to have poor functioning, compared to those who are in the upper socio-economic status. Those who are better off had more access to resources, both material and social, that would help them to compensate for their loss of functioning. On the other hand, people who are not able to work are likely to be poor. Functional impairment was also reported to have an impact on the educational attainment and employment opportunities of people with SMD as well as their family members. Many people with SMD discontinued their education since they were not able to function well in school, due to stigma and because of the symptoms associated with the illness. As a result their employment choices were highly restricted, especially in urban areas.

Stigma and family burden

Other consequences of functional impairment were reported to be stigma and family burden. People with SMD were stigmatized not only because they had the illness or due to the symptoms associated with the illness, but also because they were not able to care for themselves, engage in productive activities, because they entered into conflict with other people, and because they did not participate in different community activities. Family members reported a heavy burden in caring for people with SMD, related to their social, economic and family life. Family members also discontinued their education due to the economic, social and time burden associated with caring for their mentally ill relative. In this connection, the father of a mentally ill woman described his burden as follows.

> *…she [the patient] brought two children when she was travelling around the different towns including Addis Ababa. Now, I don't know their fathers, they are living with me. I can't do anything. I can't help it. This is a very serious problem. She brought these two children, and they are God's creatures. So, I can't do anything, and I am caring and guarding them. I planned to give them to a project and I applied to an NGO, but they couldn't be happy and accept them. Now I am guarding them. This results in many problems. The illness [mental illness] brings this kind of danger.*
>
> *(Caregiver, male, 58, rural, father of a woman with SMD)*

The daughter of a mentally ill woman had the following to say about the burden that her mother's illness brought to the family.

> *I was a student but I dropped out from grade ten, after I promoted to grade eleven just to care for her [the person with SMD]. I decided to discontinue my education and take care of her. I don't have any other business than taking care of her.*
>
> *(Caregiver, female, 27, rural, daughter of a woman with SMD)*

Social status and failure to fulfill aspirations

Almost all groups of participants highlighted that people with SMD were considered to be inferior to other people of the same age in their community; and one of the psychiatric nurses described this as *"yes, if he [referring to any person with mental illness] was not mentally ill, his family members wouldn't hate him, and he wouldn't be considered as inferior in the community"*.This was true with respect to every area of life, such as in terms of their economic wellbeing, status in the community, educational attainment, and success in their marital and familial life. Their role, status, voice and position in the community was very low compared to people of the same age.

> *It is this illness which is making them [people with mental illnesses] lag behind other people and not to work hard and get money. Of course, if somebody is mentally ill, it is likely that he/she will be inferior or lag behind his/her friends.*
>
> *(Caregiver, male, 50, rural, father of a woman with SMD)*

Connected to this, respondents also spoke of the fact that people with SMD were not able to fulfill their wishes and goals. A caregiver described this in the FGD as "*generally, people with mental illnesses can't fulfill their wishes and they are inferior to anybody else; they are failures in their life.*"Respondents argued thatin order to realize wishes and goals, one needed to be able to function in terms of work, interpersonal relationships and participation in the activities of the community.

Apart from the burden that they reported as caregivers, family members complained that there were a number of opportunities that they missed in their life because they were carers of a mentally ill family member. Some family members said that they lost educational and employment opportunities; while others said that they spent much time and energy in caring their family member and had no time to work in the farm or to do business in the market.

> *When other mothers cook and feed their children, go to the market and bring all necessary things, our mother simply sits at home and waits for our support. She is not even able to wash her clothes. She wears unclean clothes. Why don't we feel sad when we see all these things? We can't attend our education properly. How can we give our attention and follow our education properly? When we start to go to school, and learn, tolerating all the problems at home, we feel sad and disappointment after coming back home and see her suffering with the illness.*
>
> *(Caregiver, female, 27, rural, daughter of a woman with SMD)*

5.2. Development of the BFS and pilot testing

Free listing and pile sorting

An equal number of males and females (18 in each gender) participated in the free listing and pile sorting exercise. The mean age of male and female participants was 31.0 and 26.4 years, respectively. In terms of religion, 17 were Christian and 19 were Muslim. All of the participants reported farming as their main occupation.

Participants identified different tasks that an adult person in the study setting is expected to accomplish (see Appendix 1) and then they pile sorted those specific activities into domains. Male participants grouped the specific activities/tasks they identified into the following domains: self-care, farming, family life, social participation, religious activities, trading and entertainment. Women grouped the tasks or activities they identified into similar domains, but with an additional domain of domestic tasks and no domain for entertainment. Both men and women respondents emphasized that tasks related to work, family, community participation and caring for oneself are particularly critical in the setting. When asked to rank order the domains and the specific tasks, participants across all groups placed farming activities at the top followed by domestic tasks, and then taking care of partners and children, participating in different community activities and finally caring for one self.

Pilot testing

Socio-demographic characteristics of participants

A total of 200 people with SMD and their caregivers (n=200) participated in the pilot study. The details of the socio-demographic characteristics of the participants are presented in Table 5.The average age of the participants was 30.5 and 36.8 in people with SMD and in caregivers, respectively. Most of the participants were either Gurage (54%) or Siltie (38.5%) in terms of ethnic group; and Muslim (74%) or Orthodox Christian (19%) in terms of religion. Over half of the participants, both in people with SMD and in caregivers, were either not able to read and write or had not received any formal education. The majority of the participants were farmers in terms of their occupation. While the majority of the caregivers were married, only less than half of the people with SMD were married. In terms of diagnosis, almost half of the people with SMD had schizophrenia (53%) and the remainder had either bipolar disorder (28%) or depressive disorder (19%) with psychotic features.

Table 5: Socio-demographic characteristics of the pilot study and validation study participants

Characteristics		Pilot study		Validation study	
		Service users (n=200) N (%)	Caregivers (n=200) N (%)	Service users (n=150) N (%)	Caregivers (n=150) N (%)
Sex	Male	124 (68.0)	118 (59.0)	81 (54.0)	121 (80.7)
	Female	76 (32.0)	82 (41.0)	69 (46.0)	28 (18.7)
Age	Mean (SD)*	30.5 (10.90)	36.77 (13.26)	30.42 (10.04)	35.09 (12.14)
Ethnicity	Gurage	109 (54.5)	108 (54.0)	60 (40.0)	58 (38.7)
	Silti	77 (38.5)	77 (38.5)	80 (53.3)	82 (54.6)
	Others	14 (7.0)	15 (7.5)	10 (6.7)	10 (6.7)
Religion	Orthodox Christian	38 (19.0)	40 (20.0)	27 (18.0)	25 (16.7)
	Muslim	147 (73.5)	148 (74.0)	118 (78.7)	120 (80.0)
	Protestant	15 (7.5)	12 (8.0)	5 (3.3)	5 (3.3)
Marital status	Single	92 (46.0)	46 (23.0)	53 (35.3)	34 (22.7)
	Married	93 (46.5)	140 (70.0)	81 (54.0)	112 (74.7)
	Divorced	2 (1.0)	1 (0.5)	4 (2.7)	0 (0.0)
	Separated	6 (3.0)	2 (1.0)	7 (4.7)	0 (0.0)
	Widowed	7 (3.5)	11 (5.5)	5 (3.3)	3 (2.0)
Education	Unable to read and write	58 (29.0)	54 (27.0)	57 (38.0)	34 (22.7)
	Read and write only	68 (34.0)	83 (41.5)	41 (27.3)	57 (38.0)
	Primary school	55 (27.5)	37 (18.5)	40 (26.7)	42 (28.0)
	Secondary school	12 (6.0)	17 (8.5)	10 (6.7)	10 (6.7)
	Post -secondary	6 (3.0)	9 (4.5)	2 (1.3)	6 (4.0)
Occupation	Farming	148 (74.0)	162 (81.0)	77 (51.3)	109 (72.7)
	Trading	8 (4.0)	6 (3.0)	12 (8.0)	13 (8.7)
	Government employee	3 (1.5)	6 (3.0)	1 (0.7)	8 (5.3)
	Student	9 (4.5)	9 (4.5)	9 (6.0)	6 (4.0)
	House wife	19 (9.5)	13 (6.5)	27 (18.0)	12 (8.0)
	No employment	11 (5.5)	2 (1.0)	22 (14.7)	1 (0.7)
	Others	2 (1.0)	2 (1.0)	2 (1.3)	1 (0.7)
Relative wealth	Less	107 (53.5)	92 (46.0)	67 (44.7)	42 (28.0)
	More	4 (2.0)	1 (0.5)	4 (2.7)	4 (2.7)
	Equal	89 (44.5)	107 (53.5)	79 (52.7)	104 (69.3)
Diagnosis	Schizophrenia	106 (53.0)	-	68 (45.3)	-
	Bipolar disorder	56 (28.0)	-	41 (27.3)	-
	Major depressive disorder	38 (19.0)	-	41 (27.3)	-

**Standard deviation*

Psychometric properties of the pre-finalized scale

There were no items that were endorsed or not endorsed by all the respondents (Appendix 2). Nevertheless, the responses (particularly the responses of service users) were skewed to the right; that is towards less severe disability. A few items were found to have exceptionally high or low mean values compared to the mean values of all other items in the sub-scale (Table 6).All items had acceptable levels of item-scale correlation (r>0.3). Most of the items had item-total correlations which ranged from 0.60 to 0.78. Around 15 items had item-scale correlations of 0.80

to 0.90. There were only two items which had <0.60 item-scale correlation. Item-scale correlations for most of the items were similar in both service users and caregivers.

No item had an inter-item correlation <0.30 and most of the items had item-item correlation >0.50. There were items with an item-item correlation >0.90: working in the field (ploughing, reaping), working in the field (weeding, digging, threshing, cleaning land for threshing),following up the wellbeing of the livestock, collecting grass and straw for livestock food, availing water for the livestock or taking them to water, and looking after livestock during the day. Items preparing food/cooking, preparing coffee, cleaning the house, cleaning cooking and serving utensils, able to keep cooking and serving utensils in order and fetching water, which are all household tasks supposed to be accomplished by women, were highly correlated with each other (r>0.90). Items related to taking care of children, which included bathing children (keeping children's hygiene), following up children's hygiene, advising and disciplining children, feeding children, supporting children in wearing clothes, changing children's clothes on time and able to keep children from danger had also inter-item correlation >0.90.

Most of the items had test-retest reliability >0.30 for both service users and caregivers. Only four items had ICC <0.30 in both the service users' and caregivers' data: able to eat food in a proper manner, brushing teeth, able to keep oneself from danger and working in the field (ploughing, reaping). Nevertheless, there were relatively more items with a test-retest reliability <0.30 in the caregiver data (Table 6).It appeared that items in the self-care domain had lower test-retest reliability than items in all other domains. Overall, higher test-retest reliability was found among service users than caregivers.

Table 6: Mean value, item-scale correlation and test-retest reliability of items in the pilot study

Item	Service users (N=200)			Caregivers (N=200)		
	Mean	Item-scale correlation	ICC*	Mean	Item-scale correlation	ICC
Self-care						
Able to eat food in a proper manner	0.59	0.65	0.24	0.73	0.55	0.17
Able to eat food on time	0.54	0.69	0.43	0.82	0.67	-0.06
Washing own body	0.58	0.75	0.44	0.88	0.83	0.07
Washing hands before and after eating	0.44	0.80	0.55	0.76	0.84	0.12
Washing own clothes	0.74	0.76	0.46	1.12	0.83	0.07
Cutting nails	0.58	0.81	0.53	0.97	0.89	0.25
Washing hair	0.57	0.84	0.53	1.05	0.92	0.22
Getting haircut (Getting hair dressed)	0.62	0.82	0.59	1.07	0.92	0.29
Brushing teeth	0.56	0.85	0.20	1.04	0.90	0.28
Able to change clothes when it gets dirty	0.59	0.74	0.43	1.09	0.84	0.17
Able to keep oneself from danger	0.52	0.67	0.22	0.84	0.74	0.13
Using the toilet properly	0.32	0.68	0.32	0.52	0.58	0.04
Work						
Working in the field (ploughing, reaping)	1.71	0.81	0.18	2.24	0.79	0.15
Working in the field (weeding, digging, threshing, cleaning land for threshing)	1.68	0.84	0.37	2.22	0.80	0.18
Kitchen gardening	1.32	0.88	0.35	1.80	0.89	0.42
Collecting grass and straw for livestock food	1.15	0.93	0.36	1.69	0.92	0.38
Following up the wellbeing of the livestock	1.02	0.90	0.51	1.51	0.92	0.37
Availing water for the livestock or taking them to water	0.95	0.89	0.53	1.42	0.90	0.41
Looking after livestock during the day	0.93	0.87	0.41	1.48	0.92	0.37
Tethering and untethering livestock	0.92	0.89	0.54	1.44	0.89	0.36
Cutting grass	1.23	0.89	0.48	1.65	0.91	0.39
Splitting firewood	1.56	0.79	0.41	1.93	0.81	0.36
Going to market	1.26	0.78	0.36	1.68	0.76	0.48
Travelling for one hour	1.03	0.71	0.46	1.25	0.60	0.41
Raising chickens	0.92	0.88	0.62	1.22	0.89	0.35
Preparing food/ Cooking	1.05	0.88	0.50	1.18	0.91	0.55
Preparing coffee	0.87	0.81	0.57	1.11	0.92	0.39
Cleaning house	0.88	0.85	0.62	1.18	0.91	0.33
Cleaning, cooking and serving utensils	0.87	0.86	0.32	1.17	0.90	0.37
Able to keep cooking and serving utensils in order	0.83	0.87	0.58	1.14	0.90	0.02
Fetching water	0.81	0.79	0.54	1.08	0.88	0.14
Going to mill house to get grain ground	1.29	0.77	0.32	1.53	0.86	0.64
Washing clothes of the household	1.21	0.88	0.52	1.39	0.88	0.62
Cleaning the animal area	1.27	0.88	0.60	1.29	0.91	0.49
Preparing local beverages for the household (Tela/Keribu/Kinato)	1.29	0.81	0.60	1.50	0.87	0.70
Doing handicraft (such as “kasha”, “mosob”, and “dantel”)	1.23	0.85	0.70	1.51	0.86	0.68
Social Functioning						
Following up children’s health	0.88	0.81	0.47	1.35	0.80	0.30
Entertaining or playing with children	0.80	0.81	0.49	1.22	0.81	0.22
Motivating and encouraging children in their education and other activities	0.83	0.84	0.40	1.32	0.85	0.35

Item	Service users (N= 200)			Caregivers (N=200)		
	Mean	Item-scale correlation	ICC*	Mean	Item-scale correlation	ICC
Communicating well (living in peace and agreement) with family	0.79	0.74	0.41	1.44	0.65	0.55
Discussing family issues with family members	0.92	0.78	0.40	1.58	0.78	0.42
Helping parents	0.99	0.82	0.43	1.65	0.84	0.43
Maintaining social contact with relatives	0.95	0.81	0.50	1.39	0.80	0.46
Following up children's hygiene	0.87	0.85	0.33	1.47	0.86	0.42
Advising and disciplining children	0.84	0.89	0.32	1.51	0.85	0.49
Feeding children	0.80	0.89	0.48	1.21	0.87	0.53
Supporting children in wearing clothes	0.85	0.92	0.35	1.19	0.89	0.60
Changing children's clothes on time	0.85	0.86	0.69	1.22	0.89	0.51
Washing children (keeping children's hygiene)	0.83	0.85	0.64	1.22	0.89	0.56
Able to keep children from danger	0.64	0.83	0.50	1.16	0.85	0.45
Communicating well (living in peace and harmony) with neighbors	0.70	0.79	0.53	1.08	0.72	0.53
Attending coffee ceremonies with neighbors	0.70	0.76	0.50	1.11	0.74	0.51
Doing different tasks in cooperation with neighbors	0.99	0.84	0.41	1.53	0.88	0.23
Going and attending when there is mourning in the neighborhood	1.02	0.85	0.41	1.52	0.81	0.29
Contributing to Keep security/peace in the neighborhood	1.01	0.89	0.42	1.56	0.90	0.37
Communicating well (living in peace and harmony) with the community	0.77	0.81	0.49	1.18	0.77	0.18
Talking (enjoying) with friends	0.72	0.80	0.66	1.20	0.79	0.33
Participating in "Idir"	1.06	0.88	0.54	1.62	0.87	0.34
Going to weddings, funerals, baptism, and other ceremonies	1.09	0.86	0.55	1.68	0.86	0.28
Visiting postnatal women, people who are sick, prisoners and elderly	1.02	0.87	0.41	1.66	0.90	0.42
Participating in and preparing Mahiber/Senbete/Lika/Dado	1.13	0.83	0.44	1.75	0.83	0.46
Attending Kebele and village meetings	1.21	0.84	0.57	1.80	0.87	0.44
Going to church/mosque	1.03	0.74	0.26	1.54	0.75	0.36
Praying (doing "selat")	1.12	0.69	0.22	1.51	0.75	0.40
Giving food or money for those who are in need	0.79	0.79	0.42	1.49	0.84	0.33
Participating in, supporting and coordinating religious celebrations	0.95	0.88	0.37	1.61	0.83	0.46

***Intra-class correlation coefficient*

Factor analysis

Exploratory factory analysis was carried out for each of the sub-scales (self-care, work and social functioning) which were identified through the free listing and pile sorting exercise(see Appendix 3).Factor analysis of the self-care sub-scaleidentifiedtwo factors (the eating factor and the hygiene factor), both in the service users' and caregivers' data. Two items relating to eating loaded separately to the other ten items (relating to hygiene).

For the work sub-scale, exploratory factor analysis was run separately for the shared items (items for both women and men) and the woman only items.Factor analysis of the shared work items for men and women identified a one factor solution in both the service users' and caregivers' data, which accounted for 72.8% and 73.8% of the variance among service users and caregivers, respectively. The women only work items, on the other hand,loaded onto two factors. Thirteen items loaded on a farming factor and the remaining 11 items loaded on the domestic tasks domain.

Exploratory factor analysis was conducted separately for the shared items for men and women and for the woman only items in the social functioning sub-scale.Factor analysis of both the men and women shared and the women only social functioning items showed the presence of two factors: (1) family and children and (2) community participation. In the shared social functioning items, nine of the items loaded onto the family and children factor and 17 of the items on the community participation factor. In the women only social functioning items, 14 items loaded onto the family and children factor, whereas 17 items loaded onto the community participation factor. Items that were presented to only women participants in the social functioning domain loaded clearly onto the family and children factor. Items at the family level and the community level had clear loadings, whereas items at the neighborhood level had cross loadings, especially in the caregivers' data.

5.3. The psychometric properties of the finalized BFS

One hundred and fifty people with SMD and their caregivers (n=150) participated in the validation study. The socio-demographic characteristics of these participants weresimilar to the pilot study participants (see Table 5).

Descriptive statistics and internal consistency

The frequency distributions of the scores in the overall scale and the sub-scales were approximately normally distributed in both the service users' and the caregivers' data. The mean scores of each sub-scale and the overall BFS among service users and caregivers were as follows: Self-care (7.97, 12.91), shared work items (12.67, 16.77), women only work items (18.43, 24.94), social functioning (25.42, 37.62), overall BFS (51.82, 75.47). Mean scores across all the sub-scales and the overall BFS were higher (indicating greater functional impairment) in the caregivers' data than in the service users' data. The minimum and maximum observed scores in the sub-scales and the overall scale were: Self-care (0, 36), shared work items (0, 28), women only work items (0, 60), overall BFS (0, 151). Internal consistency was above 0.90 (excellent) for all sub-scales and the overall scale. The overall BFS had internal consistency 0.99, and the subscales' internal consistency ranged from 0.94 to 0.98 (Table 7).

Table 7: Mean value, item –total correlation and alpha value of items in the validation study

Item	Service users (N=150)			Caregivers (N=150)		
	Mean	Item-scale correlation	Alpha	Mean	Item-scale correlation	Alpha
Self-care						
Able to ask for or prepare and eat food when needed	1.08	0.53	0.95	1.49	0.67	0.95
Washing own body	0.92	0.81	0.94	1.54	0.88	0.94
Washing hands before and after eating	0.70	0.84	0.93	1.25	0.82	0.94
Washing own clothes	1.10	0.83	0.93	1.80	0.81	0.94
Cutting nails	0.81	0.83	0.93	1.57	0.85	0.94
Able to change clothes when it gets dirty	0.97	0.85	0.93	1.61	0.89	0.94
Able to keep oneself from danger	0.89	0.71	0.94	1.27	0.72	0.95
Using the toilet properly	0.64	0.77	0.94	0.83	0.68	0.95
Washing hair	0.86	0.87	0.93	1.54	0.91	0.94
Work						
Working in the field	1.94	0.87	0.95	2.57	0.91	0.95
Kitchen gardening	1.88	0.90	0.95	2.59	0.92	0.94
Looking after and attending livestock during the day	1.78	0.89	0.95	2.39	0.92	0.94
Cutting grass	1.87	0.91	0.95	2.50	0.90	0.95
Splitting firewood	1.92	0.88	0.95	2.51	0.91	0.94
Going to market	1.73	0.81	0.96	2.34	0.85	0.95
Travelling for one hour	1.55	0.75	0.96	1.86	0.57	0.97
Raising chickens	1.46	0.80	0.96	2.01	0.86	0.99
Preparing food/ Cooking	1.51	0.89	0.95	2.22	0.95	0.98
Cleaning house	1.38	0.91	0.95	2.12	0.94	0.98
Going to mill house to get grain ground	1.80	0.84	0.73	2.29	0.97	0.98
Washing clothes of the household	1.52	0.89	0.89	2.25	0.94	0.98
Cleaning the animal area	1.57	0.90	0.90	2.26	0.93	0.98
Preparing local beverages for the household	1.48	0.82	0.82	2.28	0.94	0.98
Doing handicraft	1.81	0.74	0.74	2.35	0.93	0.98
Social functioning						
Following up children’s health	1.42	0.80	0.98	2.08	0.86	0.98
Motivating and encouraging children in their education and other activities	1.41	0.84	0.98	2.07	0.87	0.98
Communicating well (living in peace and agreement) with family	1.49	0.74	0.98	2.23	0.72	0.98
Discussing family issues with family members	1.60	0.85	0.98	2.45	0.89	0.98
Helping parents or close elderly relatives	1.56	0.88	0.98	2.28	0.90	0.98
Maintaining social contact with relatives	1.51	0.84	0.98	2.17	0.87	0.98
Following up children’s hygiene	1.44	0.91	0.97	2.21	0.91	0.98
Advising and disciplining children	1.47	0.91	0.97	2.28	0.92	0.98
Communicating well (living in peace and harmony) with neighbors	1.23	0.79	0.98	2.06	0.80	0.98
Doing different tasks in cooperation with neighbors	1.49	0.88	0.97	2.33	0.89	0.98
Going and attending when there is mourning in the neighborhood	1.54	0.87	0.97	2.32	0.89	0.98
Participating in “Idir”	1.61	0.79	0.98	2.18	0.86	0.98
Visiting postnatal women, people who are sick, prisoners and elderly	1.51	0.88	0.97	2.16	0.87	0.98
Participating in and preparing Mahiber/Senbete/Lika/Dado	1.65	0.78	0.98	2.20	0.85	0.98
Attending Kebele and village meetings	1.65	0.85	0.98	2.33	0.85	0.98
Going to church/mosque	1.50	0.73	0.98	2.13	0.83	0.98
Giving food or money for those who are in need	1.33	0.79	0.98	2.14	0.81	0.98

Convergent validity

The correlation between the sub-scale scores and the overall scale scores of the BFS and the WHODAS-2.0 and BPRS-E are presented in Table 8 and Table 9, respectively. As expected,a high correlation coefficient was found between the BFSand the WHODAS-2.0, indicating that the two scales are measuring the same construct. The highest correlation coefficients were found between specific domains measuring similar characteristics in the two measures, such as the BFS and WHODAS sub-scales of self-care, work and social participation. Inter-correlations between the overall scale and the different domains of the BFS and the WHODAS-2.0 ranged from 0.55 to 0.88 among service users and 0.36 to 0.89 among caregivers.

Positive correlations were found between the overall scale and all the domain scores of the BFS and BPRS-E scores, both at baseline and follow-up. However, correlation coefficients were found to be weak (0.13 to 0.28 among service users and 0.24 to 0.37 among caregivers) at baseline and moderate at follow-up (0.41 to 0.54 among service users and 0.41 to 0.53 among caregivers). As expected, as symptom scores increased, there was an increase in disability scores, indicating the convergent validity of the BFS.

Table 8: Pearson's correlation between WHODAS and the BFS (n=150): service users (caregivers)

	WHODAS							
BFS	Cognition	Mobility	Self-care	Getting along	HH* activities	Work	Participation	WHODAS
Self-care	0.64(0.69)	0.55(0.36)	0.77(0.81)	0.64(0.63)	0.59(0.63)	0.57(0.64)	0.59(0.63)	0.70(0.73)
Work (common)	0.76(0.80)	0.65(0.56)	0.67(0.60)	0.66(0.65)	0.76(0.84)	0.74(0.85)	0.72(0.73)	0.80(0.84)
Work (women only)	0.72(0.63)	0.67(0.50)	0.68(0.51)	0.63(0.54)	0.70(0.69)	0.68(0.68)	0.68(0.56)	0.77(0.68)
Social functioning	0.81(0.88)	0.64(0.45)	0.77(0.72)	0.76(0.81)	0.78(0.81)	0.75(0.82)	0.79(0.79)	0.86(0.89)
Overall scale	0.82(0.86)	0.70(0.51)	0.81(0.76)	0.76(0.77)	0.79(0.83)	0.77(0.83)	0.79(0.77)	0.88(0.89)

*Household

**Values in bracket are correlation coefficientsfrom the caregivers' data

Table 9: Pearson's correlation between BPRS-E and the BFS (n=150)

Scale	**Service users**		**Caregivers**	
	Baseline	**Follow-up**	**Baseline**	**Follow-up**
Self-care	0.27	0.49	0.24	0.49
Work (shared)	0.17	0.42	0.26	0.41
Work (women only)	0.13	0.41	0.20	0.41
Social functioning	0.28	0.54	0.37	0.53
Overall scale	0.25	0.53	0.32	0.52

Sensitivity to change

The scores in the overall BFS and in the sub-scales were reduced after treatment for six weeks for new or acutely relapsed cases. The changes were statistically significant, among both service users and caregivers, using the paired sample t-test. However, the effect sizes (ES) and standardized response means (SRM) were small as reported by the service users and moderate as reported by the caregivers (Table 10 and Table 11). Overall, the BFS is sensitive to small changes in clinical symptoms resulting from treatment. However, the inclusion of women only items in the work sub-scale, which are related to domestic tasks, did not improve the sensitivity to change of the BFS in general or the work sub-scale in particular.

Table 10: Internal sensitivity to change of the BFS (n=84): Service users

	Baseline		**Follow-up**		**Difference**		**ES****	**SRM*****
Scale	**Mean**	**SD***	**Mean**	**SD**	**Mean**	**SD**		
Self-care	10.17	10.42	8.11	9.79	2.06	10.68	0.20	0.19
Work (shared items)	14.17	9.42	12.19	10.15	1.98	10.44	0.21	0.19
Work (women only items)	21.85	16.97	18.26	17.30	3.58	15.93	0.21	0.22
Social functioning	28.88	23.19	24.08	22.82	4.80	23.97	0.21	0.20
Overall scale	60.89	46.64	50.45	45.98	10.44	46.07	0.22	0.23

**Standard deviation; **Effect size; ***Standardized response mean*

Table 11: Internal sensitivity to change of the BFS (n=84): Caregivers

	Baseline		**Follow-up**		**Difference**		**ES****	**SRM*****
Scale	**Mean**	**SD***	**Mean**	**SD**	**Mean**	**SD**		
Self-care	14.50	12.01	10.14	10.72	4.36	10.81	0.36	0.40
Work (shared items)	17.21	8.54	14.01	9.66	3.20	10.13	0.37	0.32
Work (women only items)	26.57	17.59	20.94	17.33	5.63	18.12	0.32	0.31
Social functioning	39.90	21.51	27.25	21.73	12.66	22.90	0.59	0.55
Overall scale	80.96	45.66	58.33	46.27	22.63	46.65	0.50	0.49

**Standard deviation; **Effect size; ***Standardized response mean*

In terms of external responsiveness, the BFS and BPRS-E scores co-varied (Table 12). That is, change in symptom severity scores are accompanied by change in scores of functional impairment.

Table 12: External sensitivity to change of the BFS in relation to BPRS-E as a reference measure (n=84)

Scale	Spearman's correlation coefficient	
	Service users	**Caregivers**
Self-care	0.21	0.24
Work (shared items)	0.30	0.36
Work (women only)	0.28	0.33
Social functioning	0.41	0.37
Overall scale	0.37	0.36

Factor analysis

Exploratory factor analysis of items shared between men and women in the finalized BFS identified factors corresponding to concepts of functioning obtained in the qualitative study, free listing and pile sorting and the pilot study: self-care (9 items), work (7 shared items for men and women and 8 women only items), and social functioning (17 items) (Table 13).

Table 13: Factor loadings of the men and women shared items in the validation study (n=150)

Item	Factor 1 (social functioning)	Factor 2 (self-care)	Factor 3 (work)
Able to ask for or prepare and eat food when needed		0.59	
Washing own body		0.79	
Washing hands before and after eating		0.78	
Washing own clothes		0.69	
Cutting nails		0.78	
Able to change clothes when it gets dirty	0.43	0.80	
Able to keep oneself from danger		0.63	
Using the toilet properly		0.63	
Washing hair	0.43	0.81	
Working in the field			0.82
Kitchen gardening			0.82
Looking after and attending livestock during the day			0.81
Cutting grass			0.80
Splitting firewood			0.83
Going to market	0.42		0.71
Travelling for one hour			0.48
Following up children's health	0.64	0.42	0.45
Motivating and encouraging children in their education and other activities	0.66		0.45
Communicating well (living in peace and agreement) with family	0.69		
Discussing family issues with family members	0.75		
Helping parents or close elderly relatives	0.77		
Maintaining social contact with relatives	0.73		
Following up children's hygiene	0.73		0.41
Advising and disciplining children	0.78		
Communicating well (living in peace and harmony) with neighbors	0.77		
Doing different tasks in cooperation with neighbors	0.74		0.42
Going and attending when there is mourning in the neighborhood	0.74		
Participating in *"Idir"*	0.71		
Visiting postnatal women, people who are sick, prisoners and elderly	0.72		
Participating in and preparing *"Mahiber/Senbete/Lika/Dado"*	0.66	0.43	
Attending *Kebele* and village meetings	0.65		0.40
Going to church/mosque	0.64		
Giving food or money for those who are in need	0.60		

Mokken Analysis

Loevinger H coefficients were estimated for the overall BFS, the sub-scales and for each item in the sub-scales. Robust evidence was found that the overall BFS and the sub-scales conformed to a strong Mokken scale. Loevinger H coefficients for the sub-scales and the overall BFS ranged from 0.67 (self-care and overall BFS) to 0.80 (work shared items) among service users and 0.69 (overall BFS) to 0.82 (work women only items) among caregivers. The Loevinger H coefficients for all items in all the sub-scales and the overall BFS exceeded 0.50 (see Table 14). There were no statistically significant violations of monotonicity across all the sub-scales and the overall BFS among both service users and caregivers, indicating no violations of the monotonicity assumption. There were, however, a number of statistically significant violations with respect to non-intersection (double monotonicity), with overall criteria values >80, which suggests an assumption violation. For the self-care sub-scale, there was only one item, “able to ask for or prepare and eat food when needed,” with statistically significant violations of non-intersection. In the work sub-scale, there was only one item, among both service users and caregivers, with statistically significant violations of double monotonicity, “travelling for one hour.” In the social functioning sub-scale and the overall BFS, there were several items with violations of non-intersection among both service users and caregivers.

Table 14: Loevinger H coefficients, and number of violations of monotonicity and non-intersection

Item	**Item scalability coefficient (Hi)**		**Monotonicity (#vi)***		**Non-intersection (#vi)**	
Self-care (H= 0.67)	**SU****	**CG*****	**SU**	**CG**	**SU**	**CG**
Able to ask for or prepare and eat food when needed	0.50	0.61	0	0	94	67
Washing own body	0.70	0.75	0	0	7	13
Washing hands before and after eating	0.73	0.74	0	0	16	7
Washing own clothes	0.73	0.74	0	0	22	9
Cutting nails	0.72	0.75	0	0	14	19
Able to change clothes when it gets dirty	0.73	0.78	0	0	15	26
Able to keep oneself from danger	0.62	0.65	0	0	14	24
Using the toilet properly	0.70	0.70	0	0	9	23
Washing hair	0.70	0.79	0	0	31	24
Work (shared items) (H= 0.80)						
Working in the field	0.82	0.84	0	0	18	32
Kitchen gardening	0.83	0.86	0	0	16	35
Looking after and attending livestock during the day	0.82	0.84	0	0	21	34
Cutting grass	0.83	0.83	0	0	18	33
Splitting firewood	0.82	0.84	0	0	20	31
Going to market	0.76	0.80	0	0	27	40
Travelling for one hour	0.72	0.60	0	0	66	177
Work (women only items) (H= 0.76)						
Working in the field	0.78	0.84	0	0	20	13
Kitchen gardening	0.80	0. 85	0	0	28	21
Looking after and attending livestock during the day	0.77	0.84	0	0	8	4
Cutting grass	0.79	0.83	0	0	21	17
Splitting firewood	0.77	0.82	0	0	9	9
Going to market	0.73	0.81	0	0	14	8
Travelling for one hour	0.72	0.61	0	0	4	110
Raising chickens	0.70	0.78	0	0	14	37
Preparing food/ Cooking	0.74	0.86	0	0	20	33
Cleaning house	0.77	0.86	0	0	24	11
Going to mill house to get grain ground	0.76	0.87	0	0	4	11
Washing clothes of the household	0.77	0.86	0	0	7	8
Cleaning the animal area	0.79	0.85	0	0	8	9
Preparing local beverages for the household	0.73	0.87	0	0	19	17
Doing handicraft	0.69	0.88	0	0	6	10

Item	Item scalability coefficient (Hi)		Monotonicity (#vi)		Non-intersection (#vi)	
Social functioning (H= 0.73)	**SU**	**CG**	**SU**	**CG**	**SU**	**CG**
Following up children's health	0.70	0.78	0	0	117	91
Motivating and encouraging children in their education and other activities	0.74	0.78	0	0	116	70
Communicating well (living in peace and agreement) with family	0.65	0.65	0	0	168	132
Discussing family issues with family members	0.74	0.81	0	0	109	51
Helping parents or close elderly relatives	0.77	0.80	0	0	93	72
Maintaining social contact with relatives	0.73	0.78	0	0	90	39
Following up children's hygiene	0.79	0.81	0	0	145	52
Advising and disciplining children	0.79	0.82	0	0	138	79
Communicating well (living in peace and harmony) with neighbors	0.71	0.72	0	0	66	85
Doing different tasks in cooperation with neighbors	0.77	0.80	0	0	107	39
Going and attending when there is mourning in the neighborhood	0.76	0.80	0	0	84	42
Participating in "Idir"	0.69	0.77	0	0	85	61
Visiting postnatal women, people who are sick, prisoners and elderly	0.77	0.78	0	0	88	44
Participating in and preparing Mahiber/Senbete/Lika/Dado	0.69	0.76	0	0	99	95
Attending Kebele and village meetings	0.74	0.76	0	0	81	64
Going to church/mosque	0.64	0.75	0	0	201	50
Giving food or money for those who are in need	0.70	0.73	0	0	95	50

** Number of violations; **Service users; ***Caregivers*

5.4. Validation of the WHODAS-2.0

Technical validity

The visual presentation of the list of health problems, definition of difficulty to accomplish a task and response categories (cards # 1 and # 2) were helpful prompts for respondents. It was difficult for almost all respondents to answer questions related to "for how many days were these difficulties present in the past 30 days?"

Translation and content validity

For details of the difficulties identified for each item and the resulting amendments, see Appendix 4. Iterative adjustments were made to the Amharic translations, including the addition of examples to items asking about broad and abstract experiences, and replacing less relevant and uncommon concepts to the setting with equivalent but local experiences. Misunderstanding of items was more apparent in people residing in rural areas who had no formal education.

However, there were questions that were difficult to understand even by those who were educated, urban and native Amharic speakers.

Items in the cognition domain were generally found to be abstract and difficult to understand.Many respondents requested the interviewer to repeat the question or to give more clarification.Some respondents only listened to the first component of a multi-clause question, ignoring or forgetting the other aspects (for example, focusing only on starting a conversation ignoring maintaining a conversation for the item "starting and maintaining a conversation").Mobility and self-care items were generally well understood by all the respondents and found to be easy to understand, familiar to the respondents and more concrete. In the mobility domain, the item "walking a long distance such as a kilometer [or equivalent]" was problematic as this distance is not considered to be a long distance in the study context. People in rural Ethiopia walk long distances almost every day for work or social activities, as there is limited access to transportation. Two of the items in the self-care domain ("eating" and "staying by yourself for a few days") were not considered to be relevant. For the item "staying by yourself for a few days," most respondents said that it never happened to them to stay alone by themselves.Most people lived with extended family and there was no tradition of independent living. Indeed, staying alone was considered to be dysfunctional, relatedto being depressed or wanting to be alone. We improved the relevance of this item by training interviewers to ask a hypothetical question; that is whether or not the person would be able to stay by themselves for a few days if they were left alone. The item asking about "eating" was modified to ask about difficulty with properly feeding oneself.

Many of the items in the "getting along with people" domain were initially problematic. For instance, the Amharic translation of the item "sexual activities" was found to be offensive and unacceptable, especially for people who were single, widowed and separated. Caregivers (proxy respondents) were embarrassed to be asked about the sexual activities of their family member and had little knowledge of the person's private life. For the item "sexual activities", we changed the Amharic translation to ask about romantic relationships. Nobody understood correctly the items "how much of a problem did you have because of barriers or hindrances in the world around you?" and "how much of a problem did you have living with dignity because of the attitudes and actions of others?" These items required simplification and addition of examples.

Items in the household activities domain were mostly straightforward to understand. However, respondents requested examples of household activities. It was also difficult for some respondents to distinguish among items “doing important household tasks well, getting all the household work done and getting household work done as quickly as needed.”A similar problem was observed when these questions referred to work or school. Some male respondents were of the view that it was not their responsibility to accomplish household activities.

Psychometric properties of WHODAS 2.0

A total of 150 people with SMD and 150 caregivers participated in the facility-based cohort study to determine the convergent validity and sensitivity to change of the WHODAS-2.0. A random sub-sample of 84 people was followed up out of the intended 90.An additional 100 people with SMD and their caregivers (n=100) were recruited for CFA analysis, giving a final sample size of 250. The socio-demographic characteristics of the participants are presented in Table 5.

Internal consistency

Internal consistency of all items of the scale and of the items in each domain, as indicated by Cronbach’s alpha coefficient, was either very good or excellent (ranging from 0.82 to 0.98). Cronbach’s alpha coefficients for the cognition (6 items), mobility (5 items), self-care (4 items), getting along with people (5items), life activities (8 items), participation (8 items) sub-scales and the overall WHODAS (36 items) were 0.96, 0.92, 0.88, 0.89, 0.98, 0.94 and 0.98 among service users and 0.96, 0.87, 0.82, 0.88, 0.99, 0.91, and 0.98 among caregivers, respectively.

Convergent validity

Both at baseline and follow-up, the scores of the overall scale and all the domains of the WHODAS 2.0 were found to have positive correlation with the BPRS-E scores (Table 15). Correlation coefficients ranged from 0.13 to 0.22 among service users and 0.20 to 0.34 among caregivers at baseline; whereas correlation coefficients ranged from 0.29 to 0.51 among service users and 0.40 to 0.53 among caregivers at follow-up. Correlation coefficients between the sub-scales and the overall WHODAS 2.0 and BPRS-E were weak at baseline and moderate at follow-up, and higher among caregivers than among service users. Overall, higher scores in BPRS-E were associated with higher scores in the overall WHODAS 2.0 and all the domain scores. All the sub-scales and the overall WHODAS 2.0 were strongly and positively correlated with the sub-scales and the overall BFS (see section 5.4 above).

Table 15: Pearson's correlation coefficients between BPRS-E and WHODAS 2.0 (N=150)

Scale	Service users		Caregivers	
	Baseline	Follow-up	Baseline	Follow-up
Cognition	0.18	0.50	0.34	0.50
Mobility	0.13	0.29	0.20	0.40
Self-care	0.22	0.51	0.32	0.53
Getting along	0.22	0.43	0.24	0.53
HH activities	0.16	0.43	0.27	0.42
Work/school	0.13	0.43	0.26	0.43
Participation	0.22	0.45	0.27	0.49
WHODAS	0.21	0.47	0.32	0.52

Sensitivity to change

The mean scores of the overall WHODAS and of all the domains were reduced after six weeks of treatment for new or acutely relapsed cases and found to be statistically significant among both service users and caregivers. However, the effect sizes and the standardized response means were small among service users (ranging from 0.17 to 0.35) and moderate among caregivers (ranging from 0.14 to 0.57). For both service users and caregivers, the lowest sensitivity to change was in the mobility sub-scale while the largest sensitivity to change was in the work/school sub-scale (Table 16 and Table 17).

Table 16: Internal sensitivity to change of the WHODAS (N=84): Service users

	Baseline		Follow-up		Difference		ES**	SRM***
Scale	Mean	SD*	Mean	SD	Mean	SD		
Cognition	18.26	8.13	15.40	7.67	2.86	8.77	0.35	0.33
Mobility	12.24	5.89	11.23	5.64	1.01	5.86	0.17	0.17
Self-care	9.27	5.09	8.08	4.57	1.19	4.75	0.23	0.25
Getting along	13.89	6.28	12.10	6.23	1.80	6.77	0.29	0.27
Household activities	12.74	5.70	11.10	5.59	1.64	5.84	0.29	0.28
Work/school	12.93	5.75	11.04	5.56	1.89	5.80	0.33	0.33
Participation	24.54	10.21	22.10	9.80	2.44	9.38	0.24	0.26
Overall WHODAS	103.87	42.14	91.04	41.45	12.83	40.51	0.30	0.32

**Standard deviation; **Effect size; ***Standardized response mean*

Table 17: Internal sensitivity to change of the WHODAS (N=84): Caregivers

	Baseline		Follow-up		Difference		ES**	SRM***
Scale	**Mean**	**SD***	**Mean**	**SD**	**Mean**	**SD**		
Cognition	20.36	7.36	17.02	7.82	3.33	8.42	0.45	0.40
Mobility	12.52	5.78	11.69	5.74	0.83	5.90	0.14	0.14
Self-care	10.85	4.93	8.71	4.83	2.13	4.67	0.43	0.47
Getting along	15.77	6.03	12.69	6.41	3.08	6.61	0.51	0.47
Household activities	14.68	4.77	12.18	5.57	2.50	5.77	0.52	0.43
Work/school	14.88	4.74	12.17	5.64	2.71	5.72	0.57	0.47
Participation	27.82	8.59	23.81	9.40	4.01	8.88	0.47	0.45
Overall WHODAS	116.88	37.29	98.27	41.30	18.61	39.25	0.50	0.47

**Standard deviation; **Effect size; ***Standardized response mean*

Spearman's correlation coefficients between the change scores of the WHODAS and BPRS-E showed that the scores on the two measures co-vary together. That is the change in symptom severity scores were accompanied by the change in disability scores. However, the correlation coefficients were either small or moderate, ranging from 0.13 to 0.32 among service users and 0.25 to 0.40 among caregivers (Table 18).

Table 18: External sensitivity to change of the WHODAS-2.0 in relation to BPRS-E as a reference measure (N=84)

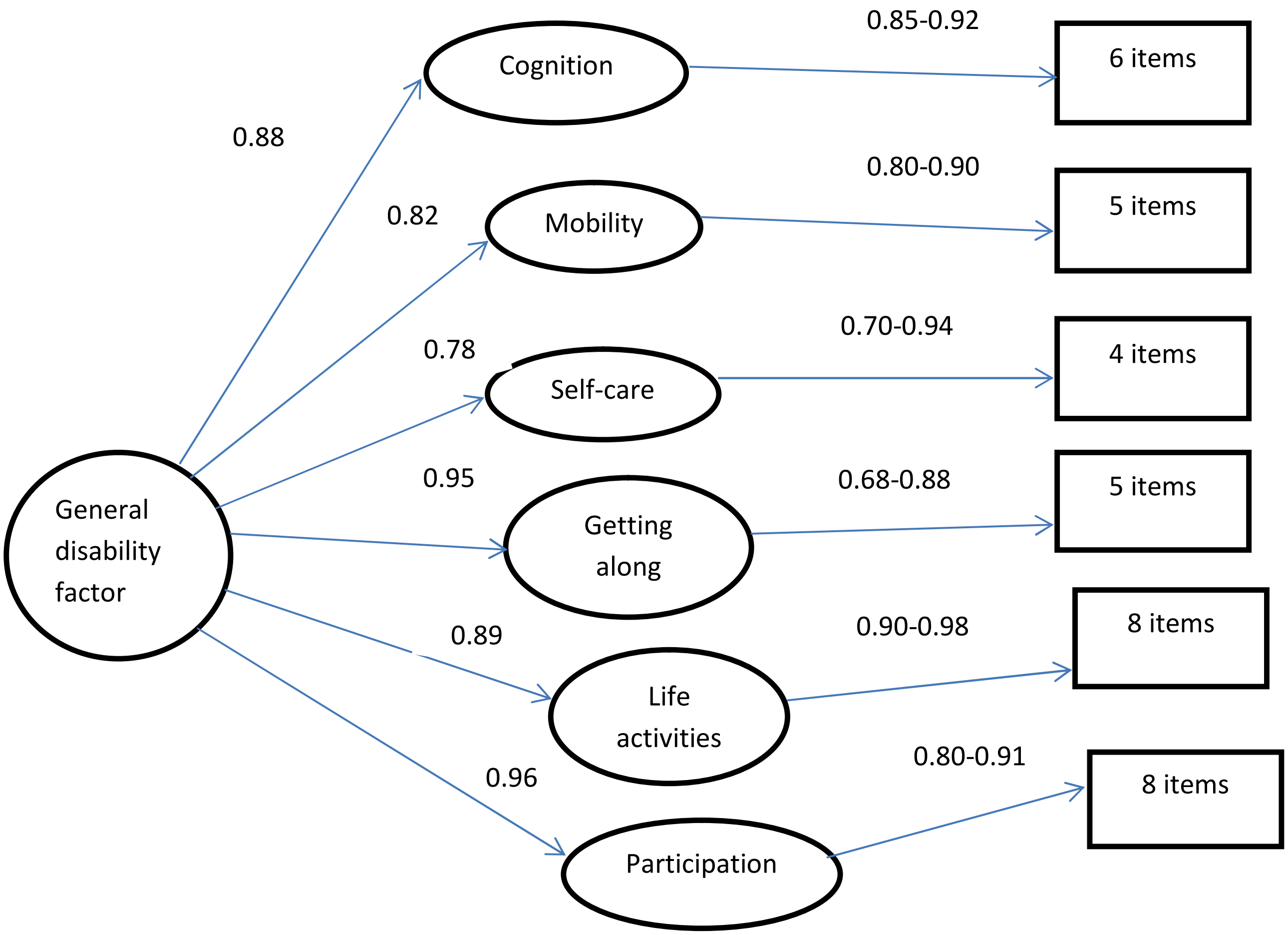
Scale	**Spearman's correlation coefficient**	
	Service users	**Caregivers**
Understanding	0.32	0.39
Mobility	0.13	0.33
Self-care	0.20	0.27
Getting along	0.27	0.25
Household activities	0.20	0.35
Work/school	0.24	0.34
Social participation	0.20	0.28
Overall WHODAS	0.26	0.40

Confirmatory factor analysis (CFA)

The second order factor, the general disability factor, had factor loadings ranging from 0.78 (self-care) to 0.96 (participation). Among the six first order factors, the items of Domain 5(life activities) had the largest factor loadings (0.90-0.98), whereas the items of Domain 4 (getting along with people) had the smallest factor loadings (0.68-0.88). Overall, the six domains highly loaded onto the general disability factor and each item loaded significantly onto their respective domains, with the smallest factor loading being 0.68. The goodness of fit indices were close to, but outside of, the acceptable ranges (*χ^2/df= 3.46; CFI= 0.89; TLI= 0.88 and RMSEA= 0.099).* Both factor loadings and goodness of fit indices were similar in the service users' and caregivers' data.

The item-factor loadings of the one factor model of the 12 item WHODAS were high, ranging from 0.71 to 0.89 among service users and 0.50 to 0.88 among caregivers. There were two items with factor loadings below 0.60 among caregivers,which were both in the mobility sub-scale. The goodness of fit indices were a little outside of the acceptable ranges, both among service users and caregivers (χ^2/df= 10.13; TLI= 0.79; CFI= 0.82 and RMSEA= 0.19 among service users and χ^2/df= 7.68; TLI= 0.80; CFI= 0.84; and RMSEA= 0.16 among caregivers

Figure 3: Second order confirmatory factor analysis of the WHODAS-2.0, 36 item version



6. DISCUSSION

The primary aim of this study was to develop and validate a contextually appropriate measure of functioning for people with SMD in rural Ethiopia. The study was also intended to optimize the Amharic translation of a cross-cultural, standardised measure of disability and determine its psychometric properties. The methodological approach involved a qualitative study, a free listing and pile sorting exercise, expert consensus, cognitive interviewing, a cross-sectional pilot study and evaluation of test-retest reliability, followed by a facility-based cohort study in an independent sample. In this section, the major findings of the study are interpreted in relation to the objectives and research questions of the study and also in relation to the wider literature. The focus of discussion will be the context and conceptualization of the functioning of people with SMD, development of the BFS, psychometric properties of the BFS, translation and technical and content validation of the WHODAS and psychometric properties of the WHODAS. More in-depth discussion is presented in the three manuscripts (one published, two under review) in Appendix O.

6.1. Qualitative study to explore the context and conceptualization of the functioning of people with SMD

In the qualitative study, the context and conceptualization of the functioning ofpeople with SMD were explored in a rural African setting. The study found that functional impairment in people with SMD is perceived to be the result of not only symptoms associated with the illness, but also a multitude of factors which can be grouped into patient-related factors, caregiver-related factors, social exclusion and economic conditions. Participants reported that there were a number of different kinds of tasks that people with SMD were not able to accomplish. These tasks are highly valued by family members, neighbors, and the community at large, and they are crucial for one’s own survival and the survival of family members. Furthermore, study participants reported that functional limitations in people with SMD bring about adverse consequences to both people with SMD and their family members, including poverty, stigma, burden, diminished education and employment opportunities, being unable to realize wishes and goals and a sense of being inferior to others.

There is generally limited literature in relation to in-depth exploration of the functioning of people with SMD in LAMICs. In qualitative studies from India, Nigeria and Ghana, respondents spoke about the impact of severe mental illness on work or occupational functioning, social functioning and daily activities [131, 132], marital prospects [133], sex life, ability to concentrate and energy for everyday life [134]. On the part of family members, severe mental illness was reported to bring about burden and a sense of moral or social failure [135]. Therefore, the present study is generally consistent with qualitative studies conducted in other LAMICs.

Previous quantitative studies conducted in rural Ethiopia investigated the associationbetween socio-demographic and clinical characteristics and functional impairment in people with schizophrenia and bipolar disorder. In a course and outcome study of people with bipolar disorder in rural Ethiopia [50], male sex, rural residence, being married and having a history of treatment with antipsychotic medication at baseline were significantly associated with better functional outcome. The study further showed that severity of depression and mania symptoms was associated with poor functional outcome. In the same setting, symptom scores of people with schizophrenia were inversely associated with improvements in physical and social functioning and role limitations [52]. Findings in the present study are consistent with these epidemiological studies and help to clarify and contextualize how socio-demographic and clinical characteristics may be associated with the functioning of people with SMD.

From high -income countries, there are a number of population-based and clinic-based studies that have investigated factors associated with functional impairment in people with SMD. The findings may be summarized as follows: socio-demographic (male sex, older age, lower level of education, urban residence, being unemployed, and lower socio-economic status) and illness characteristics (greater number of episodes, longer duration of illness, younger age at onset of the illness, greater number of hospitalizations, suicide attempts, family history of the illness, history of psychotic symptoms and comorbidity) [34, 73], cognitive impairment [75], trauma in childhood [9], substance use [76] and lower level of premorbid functional status [73] are all associated with poorer functional outcome in people with SMD. In this study,respondentsmade little mentionof predisposing vulnerabilities in explaining functional impairment (childhood trauma, pre-morbid functional status and cognitive impairment).

From the perspectives of people with SMD, caregivers, and health care providers in this study, clinical features of mental illnessdid not bring any positive functional benefit within society; for example, mental illness did not open up new occupational roles as healers, as has been found in some African cultures.On the contrary,a bleak picture of critical impairment of functions required for survival of people with SMD and the family was conveyed. This study identified a number of factors (including stigma, family burden, human rights abuses, mistreatment and violence by caregivers, caregivers' underestimation of the patient's ability to function, severe poverty, lack of autonomy, lack of social support and substance use), which are all threats to the ability of people with SMD to accomplish their day to day tasks. This indicates that functional impairment in people with SMD is the result of not only symptoms associated with the illness, but also other social, economic and family related causes.

The study participants indicated that people with SMD have functional limitations acrossvarious aspects of life: self-care, family life, work, interpersonal relationships and participation in community activities. Although the domains of functional limitations identified in this study accord more or less with those that are recognized cross-culturally and included within the WHODAS [136], there was greater elaboration and emphasis of the work and family/children aspects of functioning. The specific activities/tasks identified under each domain of functioning are less generalizable; they are relevant to the local situation in rural Ethiopia for the survival of both the person with SMD and family members; and are different for men and women. This is consistent with what Bolton and Tang [45] have commented saying that functional tasks vary greatly according to sex, culture and environment.

Epidemiological studies conducted in both high- income and LAMICs showed that people with SMD have functional limitations in different areas of life. Using World Mental Health Survey data, Ormel and Colleagues [40] found higher disability ratings for mental disorders, in both high- income and LAMICs, compared to physical disorders. There is ample evidence that schizophrenia is associated with severe and enduring psychosocial deficits [72]]. It is believed that decline in social functioning represents an area independent of positive and negative symptoms of schizophrenia [71]. A follow-up study of three cohorts of 3,307 persons with schizophrenia conducted in Finland [72] showed that impairment in social functioning was present in more than 80% of the patients at baseline.

Studies in low-income countries also confirmed that people with SMD have disabilities in different domains of life. Assessment of functioning of people with major depressive disorderin Uganda and Rwanda, using a locally developed instrument, [28, 29] showed that functional impairment is significantly associated with severity of symptoms. A follow-up study of people with bipolar disorder in rural Ethiopia [50] found that at baseline, the mean scores of all the domains of functioning of cases were significantly lower than the normative group. Domains of social functioning and role limitations due to mental health problems were significantly lower at follow-up in cases. A study of people with schizophrenia in the same setting [52] showed that the mean scores of all the domains of functioning of the cases were significantly lower compared to the mean scores of the general population, at both baseline and follow-up. A study of a similar nature and in the same setting on people with major depressive disorder [51] indicated that disability scores, as measured by WHODAS-2.0, in all of the six domains were significantly greater for those with persistent depression compared to those who were in complete recovery.

Epidemiological studies (both from high- income countries and LAMICs) showed that people with SMD have functional limitations far below the general population. However, these studies do not indicate the specific and valued functional activities that these people are unable to accomplish. The current study may contribute with regard to this issue by providing contextual detail from a typical low income country setting.

The other important finding of this study is with respect to the impact that impaired functioning may have on both people with SMD and their family members. All participants of this study stressed that functional impairment in people with SMD is associated with stigma, severe poverty, and family burden. In many studies, family caregivers of people with SMD are found to suffer from significant stresses and high levels of burden in terms of cost, time, stigma and missed opportunities [11, 135, 137]. Hence, our findings, in this regard, are consistent with the literature both from high- income countries and LAMICs.

The findings of this qualitative study indicate that treating illness symptoms alone may not be enough to improve the lives of people with SMD in this setting. A study of the effect of a community based rehabilitation program for people with psychotic disorders in a very-low-resource setting found evidence of effectiveness [138]. A recent meta-analysis of the effect of psychosocial interventions on social functioning in LAMICs found that psychosocial interventions are effective for people with depression [139]. Utilizing locally available resources from the community [140], such as social institutions, churches/mosques and micro-finance institutions and peer and group education may help people with SMD and their family members to maintain social functioning and tackle the poverty resulting from functional impairment. This study also shows that family caregivers not only have significant impact on the impairment and recovery of people with SMD, but are also affected by the care burden of their mentally ill family member. Therefore, involving caregivers in the treatment of people with SMD may be helpful. In addition, socio-culturally appropriate family level interventions, which may help to reduce care burden, need to be designed and provided. There is evidence from LAMICs that family interventions improve the functioning of people with SMD [141-143].

6.2. Development of the BFS

Through the free listing and pile sorting exercises, it was possible to identify the broad domains of functioning and the specific daily activities that an adult person is expected to accomplish in a typical rural African setting. Participants emphasized that these activities are crucial for the survival of both the person and the people around him/her. It appears that men and women are expected to accomplish a number of similar tasks, except domestic tasks, which are left only to women. Women are expected to be involved in almost all tasks that men are expected to accomplish, but men are not expected to be involved in domestic tasks. The domains of functioning identified in this study are similar to the domains found in various cross-cultural measures of functioning [57, 62], including the WHODAS [55], although some domains of functioning such as mobility and understanding were not prioritized in this study. However, the specific activities in each domain are less generalizable, and are relevant to the context where the study was conducted. They are directly or indirectly crucial for the survival of both the person and his/her family members. The finding that daily functional activities that are relevant to the local situation in rural Ethiopia (and similar agricultural communities across Africa) and show differentiation by gender is consistent with the ideas of Bolton and Tang [45], who said that functional tasks vary greatly according to sex, culture and environment.

In both the service users' and caregivers' data of the pilot study, endorsement of items showed a very good distribution of responses. There were no items endorsed by everyone or not endorsed by any participants. Overall, responses were skewed to the right, which is expected as the sample for the pilot study comprised people with SMD who had been taking medication for some time and whose condition had stabilised. Few items were found to have mean values higher or lower than all the other items within the relevant sub-scale. This is logical when we see these items taking the context into account. For example, farming related activities, such as ploughing and harvesting, are known to be the most difficult tasks in rural areas. Using the toilet properly was found to be the easiest of all items, which is to be expected in people with SMD who are stabilized, though this task may be more difficult in people who are more acutely unwell.

All items performed well in terms of item-total correlation. Only two items had an item-total correlation <0.60 and the lowest item-total correlation was 0.47. However, there were a number of items with an item-item correlation >0.90, though no items with an item-item correlation <0.30. Those items with an item-item correlation >0.90 were considered for merging, deletion, or modification. The majority of items performed well with regard to test-retest reliability but four items were found to have test-retest reliability <0.30 (computed with kappa) among both service users and caregivers and these items were considered for revision or deletion. Overall, items were found to have better test-retest reliability in the service users' data compared to in the caregivers' data.

Exploratory factor analysis of the piloting data was done in each of the sub-scales to identify the items which load onto the dimensions identified. In the self-care sub-scale, two items loaded onto the eating factor and ten of the items loaded onto the hygiene factor. We found that the items related to eating (able to eat food in a proper manner and able to eat food at the right time) were understood to relate to appetite and availability, which are not indicative of an individual's ability to care for him/herself. Hence, these two items were merged and rewritten as "able to ask for or prepare and eat food when needed." Nevertheless, it is logical and acceptable for items related to eating and related to hygiene loaded separately. In the work sub-scale, a one factor solution was found for the men and women shared items, but for the women only items a two factor solution (farming and domestic tasks) was found. It is striking for the farming and domestic related tasks loaded separately. In rural Ethiopia, all domestic tasks are expected to be accomplished by women. In addition, women are expected to support their husbands or their parents in all aspects of farming.

Factor analysis of the social functioning items, both the shared items and the women only items, resulted in two factors (family and children and community participation), although there were items which cross-loaded. This clearly reflects the reality in rural Ethiopia, where adult people are not only expected to take care of their family members (parents, children and siblings), but are also expected to participate in different kinds of community activities such as *"Idir"* [local self-help group], weddings, funerals, meetings and in other social gathering and developmental activities.

Overall, the factors we identified through exploratory factor analysis are consistent with the findings of our qualitative study [126] and the free listing and pile sorting exercise. Although there are some similarities (in terms of occupational functioning and community participation) with the domains in the WHODAS [55, 144, 145], family life and taking care of children, parents and older people are more clearly covered in the BFS, which reflect the greater emphasis given to these aspects of life in Ethiopia. Furthermore, the specific activities under each domain are different from tasks presented in different cross-cultural measures of functioning.

6.3. Psychometric properties of the BFS

The validation study showed that the newly developed functioning measure (the BFS) had excellent internal consistency. The BFS had a positive and strong correlation with WHODAS-2.0 indicating that the two instruments measure the same construct. The new measure was also demonstrated to have a positive correlation with symptom severity, both at baseline and follow-up. Previous studies showed that there is positive correlation between symptom severity and functional impairment [28, 50-52]. Nevertheless, the correlation between symptom severity and functional impairment was found to be higher at follow-up than at baseline. This may be due to low variability of scores at baseline. For the validation study, the sample comprised new presentations and cases in a state of relapse, reflected in the high symptom and functional impairment scores. Low or moderate correlation between symptom severity and functional impairment was therefore to be expected. In the qualitative study of this PhD research project [126] it has been found that functional impairment in people with SMD is the result of not only symptoms related to the illness but also a multitude of other factors related to the person with SMD, family and the socio-economic condition.

The new functioning measure has the ability to detect changes overtime. Statistically significant mean changes in functioning scores were found after six weeks of treatment of new cases and cases in relapse. When we see the changes in terms of effect size and SRM, they are small among service users and moderate among caregivers. The small effect size among service users may be due to under reporting of their functional impairment [146], lack of their capacity to evaluate themselves as a result of active symptoms [147] and medication side effects. The positive and statistically significant correlation between the change scores of symptom severity and functional impairment indicated that change in symptom severity is accompanied by change in functioning impairment. This gives evidence to the convergent validity of the new measure.

In the qualitative study and the free listing and pile sorting exercise, women were found to be expected to accomplish all aspects of domestic work in addition to supporting men in farming related activities. So, including domestic tasks in the scale and having separate versions for men and women is useful to have the full picture of functioning of women with SMD. Nevertheless, the validation study showed that the scale including the women specific items had the same properties as the scale only incorporating shared items, in terms of both convergent validity and responsiveness to change. The women-specific work items also had a moderate or strong correlation with the shared work items. Therefore, the scale comprised only of shared items has utility for studies where a shorter scale would be advantageous (for example, in large-scale epidemiological studies). However, for a more contextually valid evaluation of functioning in women with SMD, the scale version including the women-only items may be advantageous. This may be the more appropriate approach when one needs to know about all aspects of the functioning of women with SMD or to assess individual improvement in routine clinical practice.

In the Mokken scale analysis, the overall BFS and each of the individual sub-scales conformed to IRT principles, at least at the level of a single monotone homogeneity model (MHM). Item scalability coefficients (Hi) were all positive and exceeded the threshold of 0.3, implying that items meet MHM assumptions. The H coefficient exceeded 0.50 for each of the sub-scales and the overall BFS, and among both service users and caregivers, suggesting that the BFS and its sub-scales are capable of ordering individuals on their respective latent traits for functioning. Similarly, monotonicity diagnostics were satisfactory for all items in all of the sub-scales and the overall BFS.

Findings were more mixed in terms of meeting the more stringent criteria for a double monotone model (DMM), in which the rank ordering of item difficulties is invariant across all levels of the trait. For the sub-scales of self-care and work, there was only one item in each that violated the non-intersection assumption (“able to ask for or prepare and eat food when needed” in the self-care sub-scale and “travelling for one hour” in the work sub-scale). Nevertheless, there were a number of non-intersection violations in the social functioning sub-scale and in the overall BFS. Measurement properties with respect to DMM could be improved by omitting the items violating non-intersection, but to do so would reduce the content and ecological validity of the scale. It should be also noted that non-intersection is not among the fundamental IRT assumptions [120], and the majority of IRT models do not imply invariant item ordering [119].

6.4. Semantic, technical and content validation of the WHODAS-2.0

In this study, the Amharic translation of the 36 item WHODAS was improved for a rural Ethiopian context, while retaining semantic equivalence with respect to the original scale, and its psychometric properties were assessed in a sample of people with SMD and their caregivers. Items in the mobility and self-care domains were found to be the easiest to understand and items in the participation domain were the most difficult to understand by the participants in this rural, low income country setting. There was some evidence that the experiences assessed by the WHODAS items and the way in which the items were framed favor educated and urban respondents. Our improved version of the WHODAS had excellent internal consistency, and there was good evidence for convergent and construct validity and responsiveness to change in clinical state of people with severe mental disorder.

There are five items in the WHODAS which ask about “how many days were a difficulty present or were the person totally unable to do the task or cut back usual activities in the last 30 days.” This study indicated that the majority of the respondents were not able to remember the exact number of days that they were functionally impaired, unless they were unable to do the task or cut back usual activities for the whole month. Because of this we were not able to use the data from these items for any analysis. It was not possible to identify other published studies from a rural African context to compare findings with this study regarding the difficulty of the WHODAS items. In some studies from LAMICs, including rural China [144, 148], some items were found not to be applicable to the context, with similarities to our findings (e.g. with sensitivity of the item asking about “sexual activities” in both contexts). Overall, the findings of this study suggest that the WHODAS items require rigorous adaptation (forward and backward translation, cognitive interviewing, expert consensus and pilot testing) to ensure that they have content validity while retaining content equivalence in settings such as rural Ethiopia.

Using a cross-cultural, standardised measure of functional impairment and disability is an advantage for the purpose of comparing research findings across different cultural contexts. This study shows that WHODAS-2.0 could be used as an outcome measure in different cultural contexts with careful adaptation. However, our technical and content validation indicates that there are items in the WHODAS which are difficult to understand and are not relevant to rural African contexts. Male respondents were generally less interested to respond to items in the household activities domain believing that women are totally responsible for accomplishing all types of tasks at home. Overall, it will be useful to use the WHODAS for the purpose of comparability, especially in urban areas; however, this measure of functioning lacks contextual depth and has some items which are not relevant to the rural African setting. This study highlights the importance of also using a functioning measure that is developed based on locally relevant tasks as a more sensitive measure in rural low income country settings. Recent attempts to develop local, health condition specific functioning instruments [149] have demonstrated that it is possible to develop measures that are easy and quick to administer, and psychometrically sound, with items that are contextually relevant and acceptable.

6.5. Psychometric properties of the WHODAS-2.0

In this study the overall WHODAS had excellent internal consistency (0.98). The internal consistency of the sub-scales was either very good or excellent, ranging from 0.82 to 0.98. These internal consistency values are in line with the findings from many other previous studies conducted in samples of people with a range of different health conditions [55, 64, 150, 151], but higher than a few other studies [109].

The score of the overall WHODAS and the sub-scale scores had a positive correlation with symptom severity scores, both at baseline and follow-up. The correlation coefficients were higher at follow-up than at baseline, which may be explained by the distribution of scores. There was low variability of both the WHODAS and BPRS-E scores at baseline (scores were consistently high) as we included new or acutely relapsed cases. The finding that symptom severity and disability scores were positively correlated is consistent with previous studies [28, 51,52]. Moreover, the weak/moderate correlation between symptom severity and disability scores was expected based on the findings in the qualitative study. In the qualitative study [126], functional impairment in people with SMD was linked not only with illness symptoms, but also with other personal, family, social and economic factors. The scores of the overall WHODAS and the sub-scales were found to have a positive and strong correlation with the overall score and the sub-scale scores of the BFS, the locally developed and ecologically valid functioning measure for people with SMD. This is important evidence to support the convergent validity of the WHODAS-2.0 in the rural African context for this study population of people with SMD.

In the present study, the WHODAS-2.0 was able to detect small changes over time. Statistically significant mean changes in disability scores were found after six weeks treatment of new and acutely relapsed cases. However, the effect sizes and SRM were small among service users and moderate among caregivers. The change in the overall WHODAS scores in terms of effect size was 0.30 among service users and 0.50 among caregivers. The smaller effect sizes using the service user responses to the WHODAS may be due to under-reporting of functional impairment by people with psychosis [146], both at baseline and follow-up. Since the sample comprised new or acutely relapsed cases of schizophrenia, bipolar disorder and depression with psychotic features, the service users may have lacked the capacity to accurately evaluate their functional status [147]. Medication side effects may also contribute to the smaller effect sizes among service suers. For both the service user and caregiver WHODAS responses, the effect sizes were smaller than those observed in previous studies [55, 152]. Nonetheless, there was a positive and statistically significant correlation between the change scores of symptom severity and disability, indicating that change in symptom severity is accompanied by change in disability scores. Although the correlations are weak, this gives evidence to the convergent validity of the WHODAS in this rural African setting.

The WHODAS sub-scale with the smallest effect size was mobility (0.17 among service users and 0.14 among caregivers). Other sub-scales had effect sizes ranging from 0.23 to 0.35 among service users and 0.43 to 0.57 among caregivers. This finding was expected and consistent with previous studies [152]. The mobility sub-scale had the smallest mean value at baseline; it is also expected that mental health problems have more impact on occupational and social functioning rather than on mobility [27].

The high factor loadings and the goodness of fit indices indicated that the six domain structure and the global score of the 36 item WHODAS-2.0 and the global score of the 12 item WHODAS could be used in this rural African setting. Nevertheless, none of the indicators of goodness of fit were within the recommended ranges. CFA modification indices suggested that the goodness of fit indices may be improved if some items from some domains were allowed to correlate. Overall, accepting the original structure proposed by developers would improve comparability with past and ongoing studies on the WHODAS. Our findings regarding the factor structure of both the 36 -item and the 12- item WHODAS are more or less similar with previous studies, both from specific populations [119, 125, 150, 151] and from modified versions [144, 148, 153].

An important finding in this study was that the 36 -item and the 12 -item WHODAS had similar psychometric properties, including internal consistency, convergent validity, responsiveness to change and factor structure (both factor loadings and goodness of fit indices). However, in terms of technical and content validity, understandability and contextual relevance, the 12 item WHODAS was superior. In previous studies, the 12 item WHODAS has been demonstrated to be feasible and acceptable [110]; and is similar in terms of psychometric properties to the full version [119]. These findings all indicate that the single factor 12 item WHODAS, covering all domains of the 36 item version, is the preferred version in this rural low income country setting.

There are recent initiatives in LAMICs, including Ethiopia, to scale up evidence-based packages of mental health care [154] through task sharing and integrating the service into primary health care. This is recommended by the WHO in the Mental Health Gap Action Program (mhGAP) [21] and endorsed by the Federal Ministry of Health of Ethiopia [155]. It is necessary to evaluate the impact of scaling up mental health care on functional outcomes, in addition to clinical outcomes. For this purpose, there is a need for a contextually relevant, but internationally comparable, and validated measure. The findings of this study indicate that adapted versions of the WHODAS can meet this need for the mhGAP priority disoders, particularly for severe mental disorders.

7. STRENGTHS AND LIMITATIONS

The study was conducted in arural area of Butajira, which is a typical rural Ethiopian setting and, therefore, the findings of the study may be generalizable to other areas of rural Ethiopia in particular and to other rural African settings in general. The present study was embedded in a population based cohort study (the Butajira SMD cohort study), which has been running for the last 15 years. For the qualitative study and the cognitive interviewing study, service user and caregiver participants were recruited from the Butajira SMD cohort and this may enhance the representativeness of the sample used for these particular studies. Rigorous procedures (qualitative studies, free listing and pile sorting exercise, a review of the literature and existing scales, expert consensus, cognitive interviewing, a cross-sectional pilot study and independent validation study) were followed to develop and validate the new measure.

Three important contributions to the mental health field have arisen from this study: 1) the contextualization and conceptualization of the functioning of people with SMD in the rural Ethiopian setting, 2) development of a new measure of functioning for people with SMD which is contextually appropriate, easy and quick to administer and has potential for use in routine clinical practice, and 3) validation of a cross-cultural, standardised measure of functioning which has utility for comparing study findings cross-culturally. In addition, the study assessed the validity of the new measure and the WHODAS-2.0 in different aspects (content, construct, convergent and predictive validity). The study also assessed the responsiveness to change of both the local and the cross-cultural measures.

Although the study has several strengths, there were also several limitations. Functional expectations and ways of life are different in urban and rural areas, and hence, aspects of the findings of the qualitative study, such as those related to required functional tasks, may not be generalisable to urban areas. Ethiopia, as a country, has a diverse population with over 80 ethnic groups and this would potentially limit the generalizability of the findings to other rural parts of Ethiopia. Nevertheless, social systems and the main livelihoods, which are important determinants of understanding functioning and disability, are very similar for the majority of the Ethiopian population. Another possible limitation of the qualitative study was the failure to include other groups of participants, including health extension workers, community leaders, elders and traditional healers, who might have brought additional perspectives to the context and conceptualization of functioning in people with SMD. The other potential limitation of the qualitative study was the sampling strategy. People with SMD who were well and able to express themselves were purposively selected. Similarly, caregivers of people with SMD who were able to speak Amharic and could express their ideas well were included in the FGDs. This might have resulted in a sampling bias.

One possible limitation of the validation study (studies 3 and 4) is that the WHODAS and the BFS were administered one after another with no time gap in between. Therefore, the responses to the items of the first scale might have influenced the responses to the items in the next scale (an order effect). A number of studies have indicated that functional improvement after treatment, in people with SMD, lags behind symptomatic changes [6, 31]. Therefore, the six weeks follow-up period in the validation study may not have been sufficient to have evaluated the extent to which the new functioning measure could detect meaningful changes. Due to the nature of the study design and logistical constraints, the test-retest reliability of both the finalized BFS and the WHODAS-2.0 were not assessed. Another limitation of the present study may be the relatively small sample size that was used for Mokken scaling analysis and confirmatory factor analysis. Feasibility constraints limited the number of people with SMD that could be recruited.

The researcher faced three important challenges in the conduct of this study. The first challenge was that recruiting new or relapsed cases of schizophrenia, bipolar disorder and depression with psychotic features took longer than expected. The researcher needed to stay in the out-patient psychiatric clinic of Butajira hospital for five months in order to recruit the target sample of 150 people. The second challenge was participant drop out in the cohort study. All the 150 new or relapsed cases were appointed to come after six weeks for reassessment, but only 84 attended. Since participants were from rural areas contacting them by telephone or by other means was not possible. The other challenge the researcher faced throughout this study was balancing contextual relevance and cross-cultural comparison in developing the local functioning scale. In the one hand there was need to make items locally relevant, on the other there was a need to make the scale applicable to wider areas and to be comparable to other existing functioning measures.

8. CONCLUSIONS AND RECOMMENDATIONS

In the qualitative study, the conceptualization of the functioning of people with SMD was explored in a rural Ethiopian setting. The participants of the study identified many factors that contribute to the functional impairment of people with SMD apart from the symptoms associated with the illness. The day-to-day tasks that are valued by the family, neighbours and the community and are crucial for survival were reported to be impaired in people with SMD. Adverse impacts of functional impairment were considered to extend beyond the person with SMD to also affect the functional capacity of the family. Family caregivers have an important impact on the impairment and recovery of people with SMD; while also being affected by the care burden of their mentally ill family member.

In order to bring about functional improvement in people with SMD, it would be important to think about designing appropriate and evidence-based rehabilitation services relevant to the setting [156]. A further conclusion from the qualitative study is that tackling social exclusion and poverty is needed alongside medical treatment. Differences in the functional roles of men and women and the complexity and uniqueness of occupational and social activities in the study setting, support the argument that existing functioning scales are more suited to urban settings, and that there is a need to develop and validate socio-culturally and locally appropriate measures of functioning.

In studies 2 and 3, a measure of functioning for people with SMD (the BFS) was developed, with items relevant to the local context in rural low-income settings. The BFS is easy and fast to administer, has very good construct validity and excellent internal consistency and is sensitive to changes in clinical state over time. The final BFS comprised33 items that were common to both men and women, and an additional eight items for women only, covering the following domains: self-care, work, and family and community participation. The BFS included domains from existing measures, but has more emphasis on social and occupational domains, which reflects priorities in the setting. Nevertheless, future research is needed to adapt and determine the validity and reliability of the BFS in other parts of rural Ethiopia in particular and in other parts of rural Africa in general. It will be invaluable to study the sensitivity to change of the scale with a longer period of follow-up. Moreover, it is needed to test out a shorter version of the scale.

In the fourth study (study 4), the Amharic translation of the 36-item WHODAS was improved and the psychometric propertiesdetermined. Cognitive interviewing and expert consensus helped to identify difficult to understand, sensitive/unacceptable and unsuitable items and modification was made to have a betterAmharic version of the scale. Internal consistency, convergent validity, internal and external responsiveness to change and confirmatory factor analysis indicated that the WHODAS-2.0 has acceptable psychometric properties in rural African settings as was found in other parts of the world. In the study it has been shown that use of the WHODAS in rural African settings requires rigorous adaptation (forward and backward translation, cognitive interviewing and expert consensus). Overall, the WHODAS can be used as a cross-cultural measure in rural African settings, with careful adaptation. Test-retest reliability, sensitivity to change of the measure with longer duration of follow-up and item response theory analysis should be given priority in future research studies. In addition, the applicability and psychometric properties of the adapted version of the WHODAS should be investigated for other health conditions and in many other similar settings.

Based on the findings of the study and the conclusions made above, the following recommendations are forwarded.

- Family members or caregivers of people with SMD need to be aware that they have impact upon the functioning of their mentally ill family member. It may be beneficial to develop interventions for family members to better equip them to support functional recovery in their mentally ill family member. In addition, it is necessary to ensure that family members give the person with mental illness autonomy and respect their human rights and dignity. Psycho-educational programmes may be useful in helping to inform family members about what speed and level of functional recovery is realistic. This may help to tackle the tendency to underestimate the capacity of the person with mental illness; instead families would be encouraged to give the person a chance to carry out functional activities and to encourage the person to keep trying.
- As people with SMD and their caregievrs reported in this study, treating illness symptoms alone did not seem to be sufficient to improve the lives of people with SMD. Thus, mental health care providers can be trained to include treatment goals to reduce disability and address functional impairment, achieved through psychosocial

interventions. Moreover, it would be helpful to design and evaluate socio-culturally appropriate family level interventions targeted at improving the functioning of people with SMD.

- Clinicians and other mental health care providers need to be trained to consider functional status as part of their assessment of a person with SMD in their routine clinical practice, independent of the assessment of illness symptoms. The impact of greater consideration of functioning in clinical settings needs to be evaluated.
- It is recommended that clinicians and mental health care providers use the BFS in assessing the functioning of people with SMD as an input for diagnosis or in following up clinical and functional improvement during and after treatment. The BFS is an easy to use and quick functional assessment for people with SMD, with items relevant and meaningful to the rural Ethiopian setting and is sensitive to detect small changes after treatment.
- Mental health researchers are recommended to use both the BFS and the Amharic version of WHODAS-2.0 as functional outcome measures for conducting observational studies or clinical trials as they complement one other. The BFS is useful to measure functional tasks that are contextually relevant in the rural Ethiopian setting and are crucial for the survival of the person with mental illness and his/her family members. The Amharic version of WHODAS-2.0, on the other hand, is important to compare research findings cross-culturally.
- Future research should focus on adapting and validating both the BFS and the WHODAS-2.0 in other similar settings in Ethiopia in particular and in Africa in general. The test-retest reliability and responsiveness to change (with longer follow- up periods) of both the BFS and the WHODAS-2.0 should be given priority. Analysis of items, using item response theory, of both the BFS and the WHODAS-2.0 using large sample deserves the attention of researchers. Moreover, further research needs to be conducted to develop a shorter version of the BFS.

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APPENDICES

Appendix A: Domains and specific activities identified in the free listing and pile sorting exercise

Domain	Specific activity	
	Men	Women
Self-care (health)	Feeding self on time	Able to feed self
	Having balanced diet	Able to eat food on time and with no reminder
	Eating food that is comfortable to oneself	Wash self
	Protecting self from danger	Wash clothes
	Wash self	Changing clothes on time and with no reminder
	Wash clothes	Protecting self from danger
	Cutting nails	Using family planning
		Cleaning the house and the surrounding
	Getting haircut	Entertaining self
	Brushing teeth	
	Building latrine	
	Using mosquito net	
	Building a separate house for cattle	
	Changing clothes on time and with no reminder	
Farming (tasks related to farming)	Ploughing	Kitchen gardening
	Sowing	Preparing “Inset”
	Weeding	Sowing when it is done in line
	Digging	Digging
	Using weedicides and insecticides	Weeding
	Reaping	Making the land flat when “teff” is sown
	Threshing	Looking after cattle
	Planting “Inset”or false banana tree	Cutting grass
	Kitchen gardening	Rearing animals
	Harvesting pepper (gathering and sorting)	Making cattle’s food ready
	Planting and caring trees	Cleaning the land for the purpose of threshing
	Rearing cattle	Helping in harvesting
	Raising chicken	Working as daily laborer
	Bee farming	
	Splitting wood	
	Looking after cattle	
	Tethering and untethering cattle	
	Cutting grass	
	Building fence	
	Working as daily laborer	
Domestic tasks		Cooking/preparing food
		Preparing coffee
		Cleaning the house
		Fetching water
		Tidying house utensils
		Going to mill house to get grain ground
		Cleaning house utensils
		Washing clothes
		Tethering and untethering cattle
		Cleaning the animal area
		Preparing local beverages
		Doing handicrafts
		Splitting firewood

Domain	Specific activity	
	Men	**Women**
Family life (marriage and children)	Building house	Getting married
	Getting married	Having children
	Having children	Feeding and dressing children
	Feeding and dressing children	Washing children
	Following up children’s health and hygiene	Following up children’s health
	Buying clothes for children	Washing children’s clothes
	Advising and disciplining children	Changing children’s clothes on time
	Motivating and encouraging children	Sending children to school
	Sending children to school	Covering children’s educational expenses
	Covering the educational expenses of children	Making educational materials ready for children
	Making educational materials ready for children	Following up the educational performance of children
	Giving love for and entertaining children	Arranging time for children to study
	Discussing with family members about family issues, plans and goals	Protecting children from danger
	Making necessary things at home ready	Giving love for and entertaining children
	Helping and supporting parents	Discussing issues with children
	Helping children to be independent	Caring for husband
	Covering expenses during holidays	
	Arranging parties and inviting relatives	
	Splitting firewood	
Social life (social participation)	Attending coffee ceremonies with neighbors	Attending coffee ceremonies with neighbors
	Communicating well with family members, neighbors and the community	Communicating well with family members, neighbors and the community
	Doing different tasks in cooperation with neighbors	Contributing (money and grain) to “Idir”
	Keeping security (peace) in the neighborhood	Participating in “Idir” activities
	Going to weddings, funerals, birth day celebrations and other celebrations	Doing different tasks in cooperation with neighbors
	Contributing (money and grain) to “Idir” or a funeral insurance group	Supporting neighbors in different tasks when there is mourning or any other ceremony
	Doing different tasks in “Idir”	Going and attending when there is mourning in the neighborhood
	Attending “Idir” meetings	Giving gift to neighbors when there is mourning, wedding, birth day celebration or any other ceremony
	Working as executive committee member in “Idir”	Inviting neighbors during holidays
	Visiting post-natal women, people who are sick, prisoners, elders and relatives	Going to weddings, funerals, and birth day celebrations
	Participating in development activities	Visiting post-natal women, people who are sick, elderly and relatives
	Making contribution to development activities	Mediating those who are in conflict
	Participating in “Mahiber”/”Senbetie”/”Lika”/”Dado” (they all are local religious organizations)	Attending sub-district and village meetings
	Participating in Kebele (sub-distrct) and village meetings	Participating in elections
	Working as executive committee member (playing leadership role) in the community	
	Helping the elderly	
	Helping (supporting) orphans	
	Cooperate and contribute to building church/mosque	
	Participating in and having saving group	

Domain	Specific activity	
	Men	**Women**
Religious activities (Religious participation)	Going to church/mosque Praying Fasting Contributing (money or material) to building church/mosque Attending religious teaching Implementing religious rules Performing religious marriage Giving Participating in and preparing "Senbetie"/"Mahiber"/"Lika"/"Dado" Coordinating, participating and supporting religious celebrations Giving food to the poor ("Sedeka")	Going to church/mosque Praying Fasting Participating in and preparing "Senbetie"/"Mahiber"/"Lika"/"Dado" Celebrating religious holidays
Trading (Doing business)	Trading grain, pepper, cattle and other different kinds of commodities Going to market Saving Traveling long distance	Trading grain, sugar, gas, salt, soap, and other different kinds of commodities Saving
Entertainment	Visiting one's farm land Preparing for and celebrating holidays Chewing khat in group Taking alcoholic drinks Going to the town Talking (enjoying) with friends Listening radio Watching television Reading	

Appendix B: Descriptive statistics for the BFS piloting data

	Service users					**Caregivers**				
Items	**None N(%)**	**Little N(%)**	**Moderate N(%)**	**A lot N(%)**	**Can't do task N(%)**	**None N(%)**	**Little N(%)**	**Moderate N(%)**	**A lot N(%**	**Can't do task N(%)**
Self-care										
Able to eat food in a proper manner	137(68.5)	21`(10.5)	31(15.5)	10(5.0)	1(0.5)	130(65.0)	17(8.5)	33(16.5)	17(8.5)	3(1.5)
Able to eat food on time	141(70.5)	21(10.5)	28(14.0)	10(5.0)	0(0.0)	118(59.0)	26(13.0)	33(16.5)	20(10.0)	3(1.5)
Washing own body	135(67.5)	26(13.0)	29(14.5)	9(4.5)	1(0.5)	118((59.0)	24(12.0)	29(14.5)	23(11.5)	6(3.0)
Washing hands before and after eating	147(73.5)	26(13.0)	20(10.00	7(3.50	0(0.0)	124(62.0)	26(13.0)	28(14.0)	18(9.0)	4(2.0)
Washing own clothes	124(62.0)	22(11.0)	39(19.5)	13(6.5)	2(1.0)	102(51.0)	20(10.0)	41(20.5)	27(13.5)	10(5.0)
Cutting nails	135(67.8)	25(12.6)	27(13.6)	11(5.5)	1(0.5)	113(56.5)	21(10.5)	33(16.5)	26(13.0)	7(3.5)
Washing hair	136(68.0)	24(12.0)	32(16.0)	7(3.5)	1(0.5)	105(52.5)	25(12.5)	34(17.0)	28(14.0)	8(4.0)
Getting hair cut	131(65.5)	26(13.0)	33(16.5)	9(4.5)	1(0.5)	106(53)	20(10.0)	35(17.5)	32(16.0)	7(3.5)
Brushing teeth	134(67.0)	28(14.0)	31(15.5)	6(3.0)	1(0.5)	108(54.0)	23(11.5)	30(15.0)	31(15.5)	8(4.0)
Able to change clothes when it gets dirty	131(65.8)	29(14.6)	29(14.6)	9(4.5)	1(0.5)	100(50.3)	32(16.1)	33(16.6)	19(9.5)	15(7.5)
Able to keep oneself from danger	144(72.4)	21(10.6)	23(11.6)	9(4.5)	2(1.0)	120(60.3)	27(13.6)	26(13.1)	17(8.5)	9(4.5)
Using the toilet properly	158(79.8)	22(11.1)	15(7.6)	3(1.5)	0(0.0)	142(71.0)	26(13.0)	18(9.0)	14(7.0)	0(0.0)
Work (shared items)										
Working in the field (Ploughing, reaping)	67(37.5)	22(11.0)	42(21.0)	40(20.0)	29(14.5)	38(19.0)	17(8.5)	52(26.0)	46(23.0)	47(23.5)
Working in the field (weeding, digging, threshing)	67(37.5)	21(10.5)	47(23.5)	40(20.0)	25(12.5)	39(19.5)	18(9.0)	48(24.0)	51(25.5)	44(22.0)
Kitchen gardening	81(40.5)	26(13.0)	51(25.5)	32(16.0)	10(5.0)	50(25.0)	32(16.0)	51(25.5)	42(21)	25(12.5)
Collecting grass and straw for livestock food	92(46.2)	28(14.1)	44(22.1)	27(13.6)	8(4.0)	57(28.5)	28(14.0)	55(27.5)	40(20.0)	20(10.0)
Following up the wellbeing of the livestock	107(53.5)	22(11.0)	40(20.0)	23(11.5)	8(4.0)	72(36.0)	28(14.0)	45(22.5)	37(18.5)	18(9.0)
Availing water for the livestock	113(56.5)	24(12.0)	32(16.0)	23(11.5)	8(4.0)	78(39.0)	32(16.0)	38(19.0)	33(16.5)	19(9.5)
Looking after livestock during the day	114(57.0)	23(11.5)	34(17.0)	21(10.5)	8(4.0)	71(35.5)	31(15.5)	47(23.5)	33(16.5)	18(9.0)
Tethering and untethering livestock	112(56.3)	24(12.1)	34(17.1)	24(12.1)	5(2.5)	75(37.7)	29(14.6)	45(22.6)	35(17.6)	15(7.5)
Cutting grass	92(46.2)	19(9.5)	47(23.6)	31(15.6)	10(5.0)	60(30.0)	30(15.0)	50(25.0)	41(20.5)	19(9.5)
Splitting firewood	73(36.7)	15(7.5)	54(27.1)	39(19.6)	18(9.0)	49(24.5)	19(9.5)	58(29.0)	46(23.0)	28(14.0)
Going to market	94(47.5)	20(10.1)	36(18.2)	36(18.2)	12(6.1)	68(34.2)	15(7.5)	54(27.1)	39(19.6)	23(11.6)

Traveling for one hour	105(52.8)	22(11.1)	38(19.1)	31(15.6)	3(1.5)	88(44.7)	23(11.7)	50(25.4)	27(13.7)	9(4.6)
Work (Women only items)										
Raising chickens	43(57.3)	9(12.0)	11(14.7)	10(13.3)	2(2.7)	32(44.4)	11(15.3)	16(22.2)	7(9.7)	6(8.3)
Preparing food/cooking	40(53.3)	8(10.7)	11(14.7)	15(20.0)	1(1.3)	34(47.2)	7(9.7)	20(27.8)	6(8.3)	5(6.9)
Preparing coffee	43(57.3)	10(13.3)	11(14.7)	11(14.7)	0(0.0)	36(50.0)	8(11.1)	16(22.2)	8(11.1)	4(5.6)
Cleaning house	43(57.3)	10(13.3)	11(14.7)	10(13.3)	1(1.3)	34(47.2)	9(12.5)	15(20.8)	10(13.9)	4(5.6)
Cleaning cooking and service utensils	44(59.5)	5(6.8)	18(24.3)	6(8.1)	1(1.4)	34(47.2)	9(12.5)	16(22.2)	9(12.5)	4(5.6)
Able to keep cooking and service utensils in order	44(58.7)	9(12.0)	14(18.7)	7(9.3)	1(1.3)	34(47.2)	9(12.5)	18(25)	7(9.7)	4(4.6)
Fetching water	45(60.0)	10(13.3)	11(14.7)	7(9.3)	2(2.7)	39(54.2)	6(8.3)	13(18.1)	10(13.9)	4(5.6)
Going to mill house to get grain ground	33(44.0)	11(14.7)	12(16.0)	14(18.7)	5(6.7)	26(36.1)	9(12.5)	16(22.2)	15(20.8)	6(8.3)
Washing clothes of the household	36(48.6)	5(6.8)	16(21.6)	15(20.3)	2(2.7)	32(44.4)	6(8.3)	13(18.1)	16(22.2)	5(6.9)
Cleaning the animal area	34(45.3)	7(9.3)	16(21.3)	16(21.3)	2(2.7)	31(43.1)	9(12.5)	17(23.6)	10(13.9)	5(6.9)
Preparing local beverages for the household	33(44.0)	9(12.0)	15(20.0)	14(18.7)	4(5.3)	26(36.1)	8(11.1)	19(26.4)	14(19.4)	5(6.9)
Doing handicraft	35(46.7)	8(10.7)	15(20.0)	14(18.7)	3(4.0)	26(36.1)	8(11.1)	19(26.4)	13(18.1)	6(8.3)
Social functioning (shared items)										
Following up children's health	112(56.0)	28(14.0)	38(19.0)	16(8.0)	6(3.0)	77(38.5)	35(17.5)	44(22.0)	30(15.0)	14(7.0)
Entertaining or playing with children	126(63)	19(9.5)	29(14.5)	21(10.5)	5(2.5)	83(41.7)	41(20.6)	34(17.1)	32(16.1)	9(4.5)
Motivating and encouraging children	120(60.0)	22(11.0)	33(16.5)	21(10.5)	4(2.0)	78(39.0)	37(18.5)	39(19.5)	35(17.5)	11(5.5)
Communicating well with family	123(61.8)	23(11.6)	27(13.6)	23(11.6)	3(1.5)	74(37.0)	26(13.0)	48(24.0)	43(21.5)	9(4.5)
Discussing family issues with family members	112(56.3)	25(12.6)	33(16.6)	24(12.1)	5(2.5)	68(34.0)	25(12.5)	48(24.0)	41(20.5)	18(9.0)
Helping parents	114(57.6)	16(8.1)	34(17.2)	24(12.1)	10(5.1)	64(32.0)	23(11.5)	51(25.5)	43(21.5)	19(9.5)
Maintaining social contact with relatives	113(56.3)	21(10.5)	33(16.5)	29(14.5)	4(2.0)	81(40.5)	20(10.0)	50(25.0)	38(19.0)	11(5.5)
Following up children's hygiene	116(58.0)	21(10.5)	40(20.0)	19(9.5)	4(2.0)	76(38.0)	21(10.5)	50(25.0)	40(20.0)	13(6.5)
Advising and disciplining children	118(60.2)	18(9.2)	37(18.9)	19(9.7)	4(2.0)	72(36.2)	22(11.1)	49(24.6)	43(21.6)	13(6.5)
Social functioning (women only items)										
Feeding children	45(60.0)	8(10.7)	16(21.3)	4(5.3)	2(2.7)	32(44.4)	11(15.3)	18(25.0)	7(9.7)	4(5.6)
Supporting children in wearing clothes	44(58.7)	8(10.7)	15(20.0)	6(8.0)	2(2.7)	32(44.4)	11(15.3)	18(25.0)	7(9.7)	4(5.6)
Changing children's clothes on time	42(56.0)	10(13.3)	17(22.7)	4(5.3)	2(2.7)	32(44.4)	10(13.9)	18(25.0)	8(11.1)	4(5.6)
Keeping children's hygiene	47(57.3)	12(16.0)	12(16.0)	6(8.0)	2(2.7)	31(43.1)	11(15.3)	19(24.6)	7(9.7)	4(5.6)
Able to keep children from danger	47(62.7)	16(21.3)	5(6.7)	6(8.0)	1(1.3)	34(47.2)	8(11.1)	18(25.0)	8(11.1)	4(5.6)
Social functioning (shared items)										
Communicating well with neighbors	133(66.5)	22(11.0)	21(10.5)	20(10.0)	4(2.0)	97(49.5)	26(13.3)	40(20.4)	27(13.8)	6(3.1)
Attending coffee ceremonies with	130(65.3)	23(11.6)	25(12.6)	17(8.5)	4(2.0)	96(48.5)	28(14.1)	41(20.7)	24(12.1)	9(4.5)

neighbors										
Doing different tasks in cooperation with neighbors	106(53.0)	25(12.5)	40(20.0)	23(11.5)	6(3.0)	78(39.2)	17(8.5)	43(21.6)	44(22.1)	17(8.5)
Giving practical support to neighbors	99(49.5)	22(11.0)	45(22.5)	24(12.0)	10(5.0)	72(36.0)	20(10.0)	42(21.0)	49(24.5)	17(8.5)
Going and attending when there is mourning	105(52.8)	26(13.1)	35(17.6)	26(13.1)	7(3.5)	76(38.2)	19(9.5)	45(22.6)	44(22.1)	15(7.5)
Contributing to keep peace/security	108(54.3)	22(11.1)	38(19.1)	24(12.1)	7(3.5)	80(40.0)	15(7.5)	39(19.5)	45(22.5)	21(10.5)
Communicating well with community	125(62.5)	22(11.0)	28(14.0)	22(11.0)	3(1.5)	95(47.5)	25(12.5)	38(19.0)	33(16.5)	9(4.5)
Talking (enjoying) with friends	124(62.0)	15(7.5)	35(17.5)	23(11.5)	3(1.5)	93(46.5)	24(12.0)	44(22.0)	28(14.0)	11(5.5)
Participating in "Idir"	105(52.8)	21(10.6)	34(17.1)	35(17.6)	4(2.0)	72(36.5)	18(9.1)	44(22.3)	41(20.8)	22(11.2)
Going to weddings, funerals, baptism, and other ceremonies	100(50.0)	24(12.0)	40(20.0)	30(15.0)	6(3.0)	69(34.5)	19(9.5)	41(20.5)	50(25.0)	21(10.5)
Visiting postnatal women, people who are sick, prisoners	107(53.5)	21(10.5)	41(20.5)	22(11.0)	9(4.5)	70(35.0)	16(8.0)	49(24.5)	43(21.5)	22(11.0)
Participating in and preparing Mahiber/Senbete/Lika/Dado	95(47.5)	23(11.5)	48(24.0)	29(14.5)	5(2.5)	61(30.7)	21(10.6)	47(23.6)	49(24.6)	21(10.6)
Attending kebele and village meetings	86(43.0)	32(16.0)	45(22.5)	27(13.5)	10(5.0)	53(26.5)	27(13.5)	50(25.0)	48(24.0)	22(11.0)
Going to church/mosque	103(51.8)	26(13.1)	39(19.6)	25(12.6)	6(3.0)	75(37.5)	22(11.0)	45(22.5)	36(18.0)	22(11.0)
Praying (doing "selat")	97(48.5)	24(12.0)	44(22.0)	29(14.5)	6(3.0)	72(36.2)	27(13.6)	48(24.1)	32(16.1)	20(10.1)
Giving food or money for those who are in need	123(61.5)	23(11.5)	31(15.5)	18(9.0)	5(2.5)	81(40.5)	22(11.0)	36(18.0)	41(20.5)	20(10.0)
Participating in, supporting and coordinating religious celebrations	110(55.0)	26(13.0)	34(17.0)	24(12.0)	6(3.0)	71(35.5)	22(11.0)	42(21.0)	45(22.5)	20(10.0)

Appendix C: Exploratory factor analysis of the piloting data

Factor loadings of the self-care items

Item	Service users		Caregivers	
	Factor 1	**Factor 2**	**Factor 1**	**Factor 2**
Able to eat food in a proper manner	0.25	0.93	0.21	0.93
Able to eat food on time	0.33	0.84	0.38	0.81
Washing own body	0.68	0.35	0.78	0.33
Washing hands before and after eating	0.73	0.38	0.73	0.41
Washing own clothes	0.67	0.39	0.84	0.24
Cutting nails	0.75	0.35	0.91	0.24
Washing hair	0.88	0.29	0.94	0.24
Getting haircut (Getting hair dressed)	0.83	0.33	0.92	0.28
Brushing teeth	0.85	0.32	0.89	0.30
Able to change clothes when it gets dirty	0.71	0.24	0.81	0.25
Able to keep oneself from danger	0.57	0.32	0.62	0.41
Using the toilet properly	0.58	0.34	0.49	0.31

Factor loadings of men and women shared work items

Item	Service users	Caregivers
	Factor 1	**Factor 1**
Working in the field (ploughing, reaping)	0.77	0.75
Working in the field (weeding, digging, threshing, cleaning land for threshing)	0.79	0.76
Kitchen gardening	0.86	0.88
Collecting grass and straw for livestock food	0.94	0.93
Following up the wellbeing of the livestock	0.95	0.96
Availing water for the livestock or taking them to water	0.94	0.95
Looking after livestock during the day	0.92	0.97
Tethering and untethering livestock	0.93	0.94
Cutting grass	0.87	0.93
Splitting firewood	0.75	0.80
Going to market	0.76	0.75
Travelling for one hour	0.73	0.61

Factor loadings of women only work items

Item	Service users		Caregivers	
	Factor 1	**Factor 2**	**Factor 1**	**Factor 2**
Working in the field (ploughing, reaping)	0.29	0.89	0.35	0.73
Working in the field (weeding, digging, threshing, cleaning land for threshing)	0.27	0.90	0.38	0.72
Kitchen gardening	0.40	0.86	0.49	0.73
Collecting grass and straw for livestock food	0.51	0.80	0.37	0.86
Following up the wellbeing of the livestock	0.63	0.67	0.53	0.74
Availing water for the livestock or taking them to water	0.63	0.68	0.61	0.66
Looking after livestock during the day	0.63	0.63	0.55	0.76
Tethering and untethering livestock	0.66	0.65	0.67	0.62
Cutting grass	0.44	0.77	0.51	0.77
Splitting firewood	0.42	0.73	0.47	0.64
Going to market	0.55	0.59	0.50	0.64
Travelling for one hour	0.56	0.42	0.48	0.44
Raising chickens	0.76	0.51	0.64	0.64
Preparing food/ Cooking	0.71	0.53	0.82	0.44
Preparing coffee	0.84	0.30	0.88	0.40
Cleaning house	0.86	0.36	0.86	0.41
Cleaning cooking and serving utensils	0.82	0.44	0.92	0.33
Able to keep cooking and serving utensils in order	0.85	0.42	0.91	0.34
Fetching water	0.82	0.29	0.83	0.39
Going to mill house to get grain ground	0.55	0.49	0.70	0.50
Washing clothes of the household	0.64	0.59	0.80	0.42
Cleaning the animal area	0.62	0.63	0.75	0.53
Preparing local beverages for the household (Tela/Keribu/Kinato)	0.59	0.51	0.67	0.53
Doing handicraft (such as “kasha”, “mosob”, and “dantel”)	0.63	0.56	0.63	0.56

Factor loadings of men and women shared social functioning items

Item	Service users		Caregivers	
	Factor 1	**Factor 2**	**Factor 1**	**Factor 2**
Following up children's health	0.35	0.84	0.59	0.56
Entertaining or playing with children	0.31	0.89	0.50	0.66
Motivating and encouraging children in their education and other activities	0.39	0.84	0.53	0.68
Communicating well (living in peace and agreement) with family	0.41	0.64	0.17	0.81
Discussing family issues with family members	0.44	0.67	0.31	0.86
Helping parents	0.45	0.74	0.44	0.80
Maintaining social contact with relatives	0.51	0.63	0.43	0.73
Following up children's hygiene	0.42	0.83	0.49	0.77
Advising and disciplining children	0.49	0.80	0.49	0.76
Communicating well (living in peace and harmony) with neighbors	0.70	0.41	0.47	0.54
Attending coffee ceremonies with neighbors	0.68	0.40	0.52	0.51
Doing different tasks in cooperation with neighbors	0.71	0.48	0.66	0.59
Giving practical support to neighbors when there is mourning or any other ceremony	0.75	0.38	0.69	0.57
Going and attending when there is mourning in the neighborhood	0.76	0.44	0.68	0.47
Contributing to Keep security/peace in the neighborhood	0.74	0.52	0.66	0.63
Communicating well (living in peace and harmony) with the community	0.72	0.41	0.59	0.47
Talking (enjoying) with friends	0.74	0.38	0.65	0.45
Participating in "Idir"	0.75	0.51	0.73	0.50
Going to weddings, funerals, baptism, and other ceremonies	0.77	0.46	0.78	0.44
Visiting postnatal women, people who are sick, prisoners and elderly	0.77	0.45	0.83	0.44
Participating in and preparing Mahiber/Senbete/Lika/Dado	0.73	0.44	0.82	0.36
Attending Kebele and village meetings	0.72	0.47	0.84	0.40
Going to church/mosque	0.61	0.42	0.80	0.23
Praying (doing "selat")	0.59	0.38	0.77	0.26
Giving food or money for those who are in need	0.62	0.51	0.74	0.43
Participating in, supporting and coordinating religious celebrations	0.69	0.55	0.79	0.36

Factor loadings of women only social functioning items

Item	Service users		Caregivers	
	Factor 1	**Factor 2**	**Factor 1**	**Factor 2**
Following up children's health	0.87	0.40	0.69	0.49
Entertaining or playing with children	0.84	0.37	0.71	0.48
Motivating and encouraging children in their education and other activities	0.83	0.43	0.62	0.56
Communicating well (living in peace and agreement) with family	0.84	0.37	0.61	0.20
Discussing family issues with family members	0.87	0.40	0.68	0.36
Helping parents	0.80	0.41	0.71	0.44
Maintaining social contact with relatives	0.84	0.40	0.51	0.57
Following up children's hygiene	0.84	0.40	0.79	0.44
Advising and disciplining children	0.86	0.45	0.75	0.47
Feeding children	0.67	0.60	0.87	0.36
Supporting children in wearing clothes	0.65	0.67	0.93	0.34
Changing children's clothes on time	0.65	0.58	0.92	0.35
Washing children (keeping children's hygiene)	0.63	0.59	0.88	0.38
Able to keep children from danger	0.57	0.61	0.74	0.46
Communicating well (living in peace and harmony) with neighbors	0.49	0.62	0.56	0.51
Attending coffee ceremonies with neighbors	0.46	0.57	0.54	0.51
Doing different tasks in cooperation with neighbors	0.57	0.70	0.56	0.67
Giving practical support to neighbors when there is mourning or any other ceremony	0.44	0.78	0.46	0.73
Going and attending when there is mourning in the neighborhood	0.45	0.78	0.40	0.70
Contributing to Keep security/peace in the neighborhood	0.60	0.70	0.58	0.72
Communicating well (living in peace and harmony) with the community	0.62	0.60	0.49	0.60
Talking (enjoying) with friends	0.49	0.75	0.46	0.70
Participating in "Idir"	0.47	0.78	0.48	0.70
Going to weddings, funerals, baptism, and other ceremonies	0.37	0.83	0.37	0.79
Visiting postnatal women, people who are sick, prisoners and elderly	0.51	0.76	0.41	0.83
Participating in and preparing Mahiber/Senbete/Lika/Dado	0.53	0.65	0.37	0.79
Attending Kebele and village meetings	0.48	0.72	0.43	0.83
Going to church/mosque	0.45	0.56	0.25	0.84
Praying (doing "selat")	0.39	0.62	0.38	0.77
Giving food or money for those who are in need	0.50	0.63	0.49	0.67
Participating in, supporting and coordinating religious celebrations	0.56	0.64	0.46	0.75

Appendix D: Difficulties identified for each WHODAS item and the resulting amendments

Original item in English	Difficulty identified	Amendment/intervention	Adapted item in Amharic
Response categories	- There was a tendency to respond to each item dichotomously as "able to do the task" or "unable to do the task" - Difficulty to recall all of the response categories as the interview progresses	- Training of the interviewers to probe the respondents to catch all of the response categories and remind them while asking each item - We prepare flash cards and trained interviewers to use these as aids for respondents to easily understand and recall the response categories	
Meaning of health problems and difficulty to do a task	- Difficulty understanding the descriptions about what "health problems" and "difficulty to do a task" mean - Forgetting these descriptions as the interview progresses	- Improving the translation in an expert consensus meeting - We prepare flash cards and trained interviewers as to how they could use these as aids for respondents to easily understand what does health problems and difficulty to do a task mean	

Cognition			
Concentratingondoingsomethingfortenminutes?	- Tendency to focus on ability to do something, not on concentration - Focusing on the concentration, forgetting concentrating on doing a task - Unable to know the Amharic translation of "concentrating."	- Changing the Amharic translation of "concentrating" into an easier equivalent word - Connecting concentrating and doing something clearly in the Amharic version - Training interviewers to give emphasis on the connection between concentrating and doing something	**በሚሰሩትስራላይለጥቂትጊዜ (ለ10 ደቂቃ) ያህ**
Rememberingtodoimportantthings?	- There was a tendency to understand the question simply as remembering things, not to do things - Understanding the question as capacity to recall or no of problem of forgetting	- Connecting remembering and doing things clearly in the Amharic version - Training interviewers to give emphasis on the connection between remembering and doing things	**ማድረግየሚፈልጓቸውንነገሮችአስታውሰውለ**

Analyzingandfinding solutions to problems in day-to-daylife?	- Tendency to understand the question as solving problems related to the illness - Relating the question with work or thinking - This question was generally found to be complex, abstract and very difficult to understand	- Improving the translation, without changing the intention of the question, to simplify the item a little bit - Taking experts' suggestion regarding how the clarity of the item can be improved - Generally one of the problematic items even after interventions	**በእለትተእለትሕይወትዎውስጥየሚገጥምዎ**
Learninganew task,for example, learninghowtogettoanewplace?	- A few respondents said that they did not experience a new task to learn in the last 30 days	- Interviewers were trained to encourage respondents to recall a task they have learned in the last thirty days - Some examples of possible new tasks that could be learned in the area were given	**አዲስነገርወይምስራለመማርምንያህልይቸግር**
Generallyunderstandingwhatpeople say?	- There was no issue on this item		**በአጠቃላይሰዎችየሚሉትንለመረዳትምንያህ**
Startingand maintaining a conversation?	- This item was well understood by	- The translation was improved highlighting both starting and	**ከሰዎችጋርንግግርለመጀመርናእስከመጨረሻ**

	the respondents - The Amharic translation had a sense of maintaining a conversation once it is started - Starting a conversation was not highlighted in the translation	maintaining a conversation - Interviewers were trained to remind respondents to focus both on starting and maintaining a conversation	
Mobility			
Standing for long periods such as 30 minutes?	- There was no issue on this item		ረዘምላለጊዜቆሞመቆየትምንያህልይቸግርዎት
Standing up from sitting down?	- There was no issue on this item		ከተቀመጡበትለመነሳትምንያህልይቸግርዎት
Moving around inside your home?	- There was no issue on this item		እቤትዎውስጥመዘዋወርምንያህልይቸግርዎት
Getting out of your home?	- There was no issue on this item		ከቤትዎለመውጣትምንያህልይቸግርዎትነበር
Walking a long distance such as a kilometre [or equivalent]?	- Walking for a kilometer or for 15 minutes was not considered as a long walk in the	- We did not make amendment for this item as it would change its original sense - Became one of the problematic items in the	የተወሰነርቀትመንገድለመጓዝምንያህልይቸግ

	setting as people are to travel long for work or social activites	final adapted version	
Self-care			
Washingyourwhole body?	- There was no issue on this item		**ሰውነትዎንመታጠብ**ምንያህልይቸግርዎትነበ
Gettingdressed?	- There was no issue on this item		**ልብስዎትንለመልበስ**ምንያህልይቸግርዎትነበ
Eating?	- Some respondents understood this item as appetite, few others relate it with availability and quality of the food they eat	- We changed the sense of the Amharic translation to make it clear that the item is asking about difficulty to properly feeding oneself	**ምግብለመመገብ**ምንያህልይቸግርዎትነበር
Stayingby yourself forafew days?	- This didn't happen for most of the respondents - Seems inappropriate for a culture where extended family is	- This item was very difficult to amend as the experience is not existing in the setting - We trained the interviewers to ask respondents a hypothetical kind of question - Whether or not they	ያለሰውብቻዎትንለተወሰኑቀናትመቆየትሲኖ

	common - Some consider this as a problem by itself - They relate it with being depressed or wanting to be alone - Family members don’t allow them to stay by themselves even for a day	would be able to stay by themselves for a few days if they were left alone	
Getting along with people			
Dealing with peopleyou do not know?	There was no issue on this item		**ከዚህበፊትከማያውቋቸውሰዎችጋርለመጀመ**
Maintaininga friendship?	There was no issue on this item		ከአንድሰውጋርበጓደኝነትለብዙጊዜመቆየትም
Gettingalongwithpeoplewhoareclose toyou?	- It was difficult for a few respondents to know who these people are (people who are close to someone)	- We include in the item some examples of people who are close to someone (family members, relatives, close friends)	**ከቤተሰቦችዎ፤ከዘመዶችዎእናከቅርብጓደኞች**
Making newfriends?	- A few respondents said that they were not acquainted	- It was very difficult to make amendment on this item as the experience was not relevant to a few of the respondents; so	**አዲስጓደኝነትመጀመርምንያህልይቸግርዎት**

	with a new person in the last 30 days - In rural areas and small towns, there may not be opportunity to access new friends within 30 days	was one of the problematic item	
Sexualactivities?	- This question was a little bit sensitive, and for some respondents offensive and unacceptable - It is also not applicable to some respondents (single, widowed, separated) - It was even embarrassing for caregivers for being asked about the sexual activities of their family member	- As per the suggestion of the expert committee, we changed the Amharic translation to be a bit broad having the sense of making romantic relationship with opposite sex - This was more inclusive and less sensitive and offensive	**ከተቃራኒፆታጋርየፍቅርግንኙነትማድረግምን**

Life activities (house hold activities)			
Takingcareofyour<u>householdresponsibilities</u>?	- Household responsibilities were found to be very general and respondents needed a few examples - A few men respondents understood the item as doing domestic tasks such as cooking and washing clothes and said that they are to be accomplished by women	- We trained interviewers to give a few common examples of household responsibilities in the setting for those who needed - We modified the translation to make the item more inclusive beyond domestic tasks	<u>**የቤትናየግቢውስጥስራዎችንናሌሎችኃላፊነቶ**</u>
Doingyourmostimportant household tasks <u>wel</u>l?	- The same issue as the item “taking care of household responsibilities - Difficulty to make distinction among doing household tasks well, getting all the	- We trained interviewers to give a few common examples of household responsibilities in the setting for those who needed - We improved the translation and tried to make the three items clearly distinct	**በጣምአስፈላጊየሚሏቸውንየቤትናየግቢውስ**

	household work done and getting the work done as quickly as needed		
Gettingallthehouseholdworkdone thatyouneededtodo?	- The same issue as the item “taking care of household responsibilities - Difficulty to make distinction among doing household tasks well, getting all the household work done and getting the work done as quickly as needed	- We trained interviewers to give a few common examples of household responsibilities in the setting for those who needed - We improved the translation and tried to make the three items clearly distinct	መስራትያለብዎትንየቤትናየግቢውስጥስራዎ
Gettingyourhouseholdworkdoneasquickly asneeded?	- The same issue as the item “taking care of household responsibilities - Difficulty to make distinction among doing	- We trained interviewers to give a few common examples of household responsibilities in the setting for those who needed - We improved the translation and tried to make the three items	የቤትናየግቢውስጥስራዎችንበሚፈልጉትፍጥ

	household tasks well, getting all the household work done and getting the work done as quickly as needed	clearly distinct	
Life activities (work or school activities)			
Yourday-to-daywork/school?	- There was no any issue on this item		**የእለትተዕለትስራዎትንወይምትምህርትዎት**
Doingyourmostimportantwork/schooltasks well?	- The same issue as items on household activities - That is there was difficulty to make distinction among doing your work or school tasks well, getting all the work done that you need to do and getting your work done as quickly as needed	- We improved the translation and tried to make the three items clearly distinct	**በጣምአስፈላጊየሚሉትንስራወይምትምህርት**

Gettingalltheworkdonethatyouneedtodo?	- The same issue as items on household activities - That is there was difficulty to make distinction among doing your work or school tasks well, getting all the work done that you need to do and getting your work done as quickly as needed	- We improved the translation and tried to make the three items clearly distinct	**መስራትያለብዎትንስራወይምትምህርትሁሉ**
Gettingyourworkdoneasquicklyasneeded?	- The same issue as items on household activities - That is there was difficulty to make distinction among doing your work or school tasks well, getting all the work done that you need	- We improved the translation and tried to make the three items clearly distinct	**ስራዎትንወይምትምህርትዎትንበሚፈልጉት**

	to do and getting your work done as quickly as needed		
Participation			
Howmuchofaproblemdidyouhave<u>joiningin community activities</u>(for example,festivities,religiousorotheractivities)inthesamewayasanyoneelsecan?	- There was no issue on this item		<u>**በማሕበራዊእንቅስቃሴውስጥ**</u> (ለምሳሌ፡አመት ልክእንደሌላውሰውመሳተፍምንያህልይቸግር
Howmuchofaproblemdidyou havebecauseof<u>barriersorhindrances</u>intheworldaroundyou?	- Almost all respondents did not understand this question correctly. - This item was difficult to understand even by respondents who were educated and urban - It is too long, complex and abstract	- We tried to improve the translation and make some adaptation by including examples of barriers and hindrances to improve its clarity and relevance - But, it was one of the problematic items in the final adapted version of the scale	እንደአድሎናመገለልእናሌሎችምበአካባቢዎባ
Howmuchofaproblemdidyouhave<u>living with dignity</u>becauseofthe attitudesand actionsofothers?	- Almost all respondents could not understand this question correctly	- We tried to find a better translation for the concept of “living with dignity” in the expert consensus meeting - We tried to make some	ሰዎችለእርስዎባላቸውመጥፎአመለካከትናተ

	- Even better educated and respondents from urban areas didn’t understand what the question is about - It was very difficult for respondents to understand the meaning of “living with dignity” - The item is too long, complex and abstract	adaptation without changing the initial intent of the item - Still, it was one of the problematic items in the final version of the scale	
Howmuchtimedidyouspendonyourhealthconditionoritsconsequences?	- There was no issue on this item		ለሕመምዎመፍትሄለማግኘት፤ጠያቂለማነጋ
Howmuchhaveyoubeenemotionally affectedbyyourhealthcondition?	- There was no issue on this item		በጤናችግርዎወይምበሕመምዎምክንያትስ
Howmuchhasyourhealthbeenadrainon the financialresourcesof youoryourfamily?	- It was difficult to understand the Amharic translation of drain - Very few respondents	- We were able to find a better translation for the word “drain” in the expert consensus meeting - We trained interviewers to give some examples of financial resources for	የጤናችግርዎወይምሕመምዎየእርስዎንናየ

	asked for examples of financial resources	those who needed	
Howmuchofaproblemdidyourfamily havebecauseofyourhealthproblems?	- There was no issue on this item		**በእርስዎየጤናችግርወይምበሕመምዎምክንያ**
Howmuch ofaproblemdidyouhave indoingthingsbyyourselfforrelaxationorpleasure?	- This item was difficult to understand, and less applicable - Some simply understood it as ability to relax oneself or help oneself to get pleasure - It was even difficult for respondents to	- We did a lot of work to improve the translation and the adaptation - But, we could not improve the itemsince the concept is not applicable and relevant to this rural African context - So, this was one of the problematic items in the scale	**የሚያዝናናዎትንወይምየሚያስደስትዎትንነገ**

	understand the meaning of relaxation and pleasure since these things are not common for people in rural areas of Ethiopia		

Appendix E: Topic guide for the qualitative study (English version)

For religious healers, project outreach workers and psychiatric nurses

1. What are the most important activities / tasks that a person has to be able to do in their day-to-day life?
2. What are the tasks that men/women must do regularly to care for themselves, their family and their community?
3. When a person is affected by illness or injury, what kinds of activities can they no longer carry out?

   <u>Probe:</u>

   What about getting around (mobility)?

   What about understanding things?

   What about communicating?

   What about looking after yourself e.g. washing, eating?

   What about getting on with other people?

   What about work or housework?

   What about social activities?
4. Which of these activities is the most important?
5. For people with mental disorders, which of these areas of activity / functioning are affected by their problem?

For people with SMD and their family members /care givers

1. What day-to-day activities get affected when [you / your family member / a person with SMD] becomes unwell because of mental illness?
2. Which of these areas do you think is most important?
3. Which activities get affected first when [you / your family member / a person with SMD] starts to become ill?
4. Which get better first when [you / your family member / a person with SMD] start to recover?
5. Are there any activities that [you / your family member / a person with SMD] are unable to do all the time

Appendix F: Topic guide for the qualitative study (Amharic version)

ለሐይማኖት አባቶች፤ ለአዕምሮ ጤና ፕሮጀክት ሰራተኞች እና ለአዕምሮ ህክምና ነርሶ

1. አንድ ሰው በቀን ተቀን የኑሮ እንቅስቃሴው ሊያከናውናቸው የሚገቡ በጣም አስፈላጊ ተግባራት/ስራዎች ምንድናቸው?
2. አንድ ሰው እራሱን፣ቤተሰቡንናማሕበረሰቡን ለመርዳት ሊያከናውናቸው የሚገቡ በጣም አስፈላጊ ተግባራት/ስራዎች ምንድናቸው?
3. አንድ ሰው በበሽታ ሲጠቃ ወይም አደጋ ሲደርስበት ሊያከናውናቸው የማይችላቸው የትኖቹን አይነት ተግባራት/ስራዎች ነው?
    - ከአንድ ቦታ ወደ አንድ ቦታ መንቀሳቀስን በተመለከተ?
    - ነገሮችን በጥሞና መረዳትን በተመለከተ?
    - ከሌሎች ሰዎች ጋር መግባባትን (ሐሳብ መለዋወጥን) በተመለከተ?
    - እራሱን መጠበቅ (መንከባከብ) ለምሳ፡ መታጠብ፣መመገብ በተመለከተ?
    - ከሌሎች ሰዎች ጋር ያለውን አብሮነት በተመለከተ?
    - ስራን/የቤት ውስጥ ስራን በተመለከተ?
    - ማሕበራዊ እንቅስቃሴዎችን በተመለከተ
4. ከነዚህ ተግባራት (ስራዎች) በጣም አስፈላጊው የትኛው ነው
5. በአዕምሮ ሕመም የተጠቃ ሰው ከእነዚህ ተግባራት/ስራዎች ውስጥ በህመሙ ምክንያት ሊያከናውናቸውየማይችላቸው የትኞቹን ነው?

ለአዕምሮ ሕመምተኞች እና ለአዕምሮ ሕመምተኛ ቤተሰቦች

1. የእርስዎ/የቤተሰብዎ አባል/ የአንድ የአዕምሮ ሕመምተኛ/ የአዕምሮ በሽታ ሲነሳ ሊያከናውናቸው የማይችላቸው (ለማከናወን የሚያቅተው) የትኞቹን የቀን ተቀን ተግባራት/ስራዎች ነው?
2. ከነዚህ ተግባራት /ስራዎች/ በጣም አስፈላጊው የትኛው ነው?
3. እርስዎ /የቤተሰብ አባልዎ/አንድ የአዕምሮ ሕመምተኛ/ በሽታው ሲጀምረው ሊያከናውናቸው የማይችላቸው (ለማከናወን የሚያቅተው) የትኞቹን የቀን ተቀን ተግባራት/ስራዎች ነው?
4. እርስዎ //የቤተሰብ አባልዎ/ አንድ የአዕምሮ ሕመምተኛ/ ማገገም ሲጀምር (በሽታው ሲሻለው) በተሻለ መልኩ ማከናወን የሚችላቸው ተግባራት/ሰራዎች የትኖቹ ናቸው?
5. እርስዎ /የቤተስብዎ አባልዎ/ አንድ የአዕምሮ ሕመምተኛ/ ሁል ጊዜ (በማንኛውም ጊዜ) ሊያከናውናቸው የማይችላቸው ተግባራት /ስራዎች አሉ?

Appendix G: Butajira Functioning Scale (English version)

In the past one month, how much difficulty did you have in accomplishing the following tasks/activities compared with most other people of your age and sex?

S.N	Activity/Task	Degree of difficulty accomplishing the task/activity					
		None	Little	Moderate	A lot	Can’t do task	Not applicable
	A. Self-care						
1	Able to ask for or prepare and eat food when needed						
2	Washing own body						
3	Washing hands before and after eating						
4	Washing own clothes						
5	Cutting nails						
6	Able to change clothes when it gets dirty						
7	Able to keep oneself from danger						
8	Using the toilet properly [USETOILT]						
9	Washing hair						
	B. Work						
10	Working in the field						
11	Kitchen gardening						
12	Looking after and attending livestock during the day						
13	Cutting grass						
14	Splitting firewood						
15	Going to market						
16	Travelling for one hour						
17	Raising chickens						
18	Preparing food/ Cooking						

19	Cleaning house						
20	Going to mill house to get grain ground						
21	Washing clothes of the household						
22	Cleaning the animal area						
23	Preparing local beverages for the household (Tela/Keribu/Kinato)						
24	Doing handicraft (such as “kasha”, “mosob”, and “dantel”)						
C. Social Functioning							
25	Following up children’s health						
26	Motivating and encouraging children in their education and other activities						
27	Communicating well (living in peace and agreement) with family						
28	Discussing family issues with family members						
29	Helping parents or close elderly relatives						
30	Maintaining social contact with relatives						
31	Following up children’s hygiene						
32	Advising and disciplining children						
33	Communicating well (living in peace and harmony) with neighbors						
34	Doing different tasks in cooperation with neighbors						
35	Going and attending when there is mourning in the neighborhood						
36	Participating in “Idir”						
37	Visiting postnatal women, people who are sick, prisoners and elderly						
38	Participating in and preparing Mahiber/Senbete/Lika/Dado						
39	Attending Kebele and village meetings						
40	Going to church/mosque						
41	Giving food or money for those who are in need						

Appendix H: Butajira Functioning Scale (Amharic version)

ቡታጅራ የቀንተቀንየኑሮእንቅስቃሴመጠይቅ

ከሌሎችየእድሜእኩዮችዎእና ከርስዎ ጋር ተመሳሳይ ጾታ ካላቸውሰዎችእራስዎንሲያነፃጽሩባለፈውአንድወርጊዜውስጥየሚከተሉትንተግባራት (የእለትተእለትየኑሮእንቅስቃሴዎች) ለማከናወንምንያህልያስቸግርዎትነበር?

ተ.ቁ	**ተግባር/እንቅስቃሴ**	**ተግባሩን/እንቅስቃሴውንለመከወንምንያህልያስቸግርዎት ነበር?**				
		ምንም	በጥቂቱ	በመጠኑ	በብዛት	ሙሉበሙሉአ ለመቻል
ሀ. ራስን መጠበቅ (መንከባከብ)						
1	ምግብ መመገብ በሚያስፈልግዎ ሰዓት ምግብ ጠይቆ ወይም አዘጋጅቶ መመገብ ምን ያህል ያስቸግርዎት ነበር?					
2	ገላዎንመታጠብ ምን ያህል ያስቸግርዎት ነበር?					
3	ከምግብበፊትናበኃላእጅዎን መታጠብምን ያህል ያስቸግርዎት ነበር?					
4	ልብስዎንማጠብ ምን ያህል ያስቸግርዎት ነበር?					
5	ጥፍርዎንመቁረጥ ምን ያህል ያስቸግርዎት ነበር?					
6	ልብስዎሲቆሸሽመቀየርምን ያህል ያስቸግርዎት ነበር?					
7	እራስዎንከአደጋ መጠበቅምን ያህል ያስቸግርዎት ነበር?					
8	በአግባቡሽንት ቤት መጠቀም ምን ያህል ያስቸግርዎት ነበር?					
9	ፀጉርዎንመታጠብ ምን ያህል ያስቸግርዎት ነበር?					
ለ. ስራ						
10	የውጭ (የግብርና) ስራ መስራት ምን ያህል ያስቸግርዎት ነበር?					
11	የጓሮአትክልትማልማትምን ያህል ያስቸግርዎት ነበር?					
12	ከብትማገድና መንከባከብ ምን ያህል ያስቸግርዎት ነበር?					
13	ሳርማጨድምን ያህል ያስቸግርዎት ነበር?					
14	የማገዶእንጨትመፍለጥምን ያህል ያስቸግርዎት ነበር?					
15	ገበያመሄድምን ያህል ያስቸግርዎት ነበር?					
16	የረፋድወይምየአንድሰዓትመንገድመጓዝምን ያህል ያስቸግርዎት ነበር?					

ማሳሰቢያ፡ ከጥያቄ 17-24 ሴት ተሳታፊዎችን ብቻ የሚመለከቱ ናቸው፡፡						
ተ.ቁ	**ተግባር/እንቅስቃሴ**	**ተግባሩን/እንቅስቃሴውንለመከወንምንያህልያስቸግርዎት ነበር?**				
		ምንም	በጥቂቱ	በመጠኑ	በብዛት	ሙሉበሙሉአ ለመቻል
17	ዶሮማርባት ምን ያህል ያስቸግርዎት ነበር?					
18	ምግብማዘጋጀት (ምግብማብሰል) ምን ያህል ያስቸግርዎት ነበር?					
19	ቤትማፅዳትምን ያህል ያስቸግርዎት ነበር?					
20	ወፍጮቤትመሄድ (እህልማስፈጨት) ምን ያህል ያስቸግርዎት ነበር?					
21	የቤተሰቡንአባላትልብስማጠብምን ያህል ያስቸግርዎት ነበር?					
22	የከብቶችንቤትማፅዳት (እበትማውጣት) ምን ያህል ያስቸግርዎት ነበር?					
23	ጠላ/ቀሪቦ/ኪኔቶለቤተሰብአባላትማዘጋጀትምን ያህል ያስቸግርዎት ነበር?					
24	የእጅስራወይምስፌት (ኬሻ፤መሶብ፤ዳንቴል) መስራትምን ያህል ያስቸግርዎት ነበር?					
ሐ. ማሕበራዊተሳትፎ (ግንኙነት) **ማሳሰቢያ፡ በዚህ ክፍል ስር ያሉ ጥያቄዎች ወንድና ሴት ተሳታፊዎችን የሚመለከቱ ናቸው፡፡**						
25	የልጆችንጤናመከታተልምን ያህል ያስቸግርዎት ነበር?					
26	ልጆችንበትምሕርትናበሌሎችነገሮችማበረታታትናማነቃቃትምን ያህል ያስቸግርዎት ነበር?					
27	ከቤተሰብአባላትጋርተስማምቶናተግባብቶመኖርምን ያህል ያስቸግርዎት ነበር?					
28	ከቤተሰብአባላትጋርየቤተሰብጉዳዮችንመወያየትምን ያህል ያስቸግርዎት ነበር?					
29	ወላጆችን ወይም እድሚያቸው የገፋ የቅርብ ዘመዶችን መደገፍምን ያህል ያስቸግርዎት ነበር?					
30	ከዘመድጋርግንኙነትንመቀጠልወይምአለመልቀቅምን ያህል ያስቸግርዎት ነበር?					
31	የልጆችንንጽሕናመከታተልምን ያህል ያስቸግርዎት ነበር?					
32	ልጆችንመምከርናመቅጣትምን ያህል ያስቸግርዎት ነበር?					
33	ከጎረቤትጋርተስማምቶናተግባብቶመኖርምን ያህል ያስቸግርዎት ነበር?					
34	ከጎረቤትጋርየተለያዩስራዎችንተጋግዞበሕብረትመስራትምን ያህል ያስቸግርዎት ነበር?					
ተ.ቁ	**ተግባር/እንቅስቃሴ**	**ተግባሩን/እንቅስቃሴውንለመከወንምንያህልያስቸግርዎት ነበር?**				

		ምንም	በጥቂቱ	በመጠኑ	በብዛት	ሙሉበሙሉአ ለመቻል
35	ጎርቤትሐዘንሲኖርመሄድናማስተዛዘንምን ያህል ያስቸግርዎት ነበር?					
36	በእድርውስጥመሳተፍምን ያህል ያስቸግርዎት ነበር?					
37	አራስ፤የታመመሰውእናአቅመ-ደካሞችንመጠየቅምን ያህል ያስቸግርዎት ነበር?					
38	ማሕበር/ሰንበቴ/ሊቃ/ዳዶመሳተፍናማዘጋጀትምን ያህል ያስቸግርዎት ነበር?					
39	የቀበሌናየጎጥስብሰባመሳተፍምን ያህል ያስቸግርዎት ነበር?					
40	ቤተ-ክርስቲያን/መስጊድመሄድምን ያህል ያስቸግርዎት ነበር?					
41	ለተቸገረ ሰው ገንዘብ ወይም ምግብ መስጠት ምን ያህል ያስቸግርዎት ነበር?					

Appendix I: WHO Disability Assessment Schedule (English version)

WHODAS2.0

(World Health OrganizationDisability Assessment Schedule 2.0)

Section3 Preamble

Saytorespondent:

Theinterview is about difficultiespeoplehavebecauseofhealthconditions.

Handflashcard #1torespondentandsay:

ByhealthconditionI meandiseasesorillnesses, orother healthproblemsthat may beshortorlonglasting; injuries; mentalor emotionalproblems;andproblemswith alcohol ordrugs.

Remembertokeepallofyourhealthproblemsinmindasyouanswerthequestions. WhenI askyouaboutdifficultiesin doinganactivity thinkabout …

Pointtoflashcard#1andexplainthat"difficultywith an activity"means:

- Increasedeffort
- Discomfortorpain
- Slowness
- Changesin thewayyoudo theactivity.

Saytorespondent:

Whenanswering,I'dlikeyoutothinkbackoverthe past 30days.Iwouldalsolikeyoutoanswerthesequestions thinkingabout how muchdifficulty youhavehad, onaverage,overthepast30days, whiledoing theactivityasyouusually doit.

Handflashcard #2torespondentandsay:

Usethisscalewhenresponding.

Readthescalealoud:

None,mild,moderate,severe,extremeorcannotdo.

Ensurethattherespondentcaneasilyseeflashcards#1and #2throughoutthe interview

Section4 Domainreviews

Domain1: Cognition

Iamnow goingtoasksomequestionsaboutunderstandingandcommunicating.

Show flashcards#1 and #2torespondent

Inthepast30days,howmuchdifficultydidyouhavein:		**None**	**Mild**	**Moderate**	**Severe**	**Extremeor cannot do**
D1.1	Concentratingondoingsomethingfortenminutes?	1	2	3	4	5
D1.2	Rememberingtodoimportantthings?	1	2	3	4	5
D1.3	Analysingandfinding solutions to problems in day-to-daylife?	1	2	3	4	5
D1.4	Learninganew task,for example, learninghowtogettoanewplac	1	2	3	4	5
D1.5	Generallyunderstandingwhatpeople say?	1	2	3	4	5
D1.6	Startingand maintaining a conversation?	1	2	3	4	5

Domain2:Mobility

Iamnow goingtoaskyouabout difficulties in gettingaround.

Show flashcards#1 and #2

Inthepast30days,howmuchdifficultydidyouhavein:		**None**	**Mild**	**Moderate**	**Severe**	**Extremeor cannotdo**
D2.1	Standingforlong periodssuchas30 minutes?	1	2	3	4	5
D2.2	Standing upfromsittingdown?	1	2	3	4	5
D2.3	Moving aroundinsideyour home?	1	2	3	4	5
D2.4	Getting out ofyourhome?	1	2	3	4	5
D2.5	Walking along distancesuchasakilometre[o	1	2	3	4	5

Domain3Self-care

Iamnow goingtoaskyouabout difficultiesintakingcareofyourself.

Show flashcards#1 and #2

Inthepast30days, howmuchdifficultydidyouhavein:		**None**	**Mild**	**Moderate**	**Severe**	**Extreme orcannot**
D3.1	Washingyourwhole body?	1	2	3	4	5
D3.2	Gettingdressed?	1	2	3	4	5
D3.3	Eating?	1	2	3	4	5
D3.4	Stayingby yourself forafew	1	2	3	4	5

Domain4:Gettingalongwithpeople

Iamnow goingtoaskyouabout difficulties in gettingalongwithpeople.Please remember that I amaskingonlyaboutdifficultiesthat aredueto health problems.By thisI meandiseasesorillnesses, injuries, mentalor emotionalproblemsand problemswithalcoholordrugs.

Show flashcards#1 and #2

Inthepast30days,howmuchdifficulty didyouhavein:		**None**	**Mild**	**Moderate**	**Severe**	**Extreme orcannot do**
D4.1	Dealing with peopleyou do not know?	1	2	3	4	5
D4.2	Maintaininga friendship?	1	2	3	4	5
D4.3	Gettingalongwithpeoplewhoareclose toyou?	1	2	3	4	5
D4.4	Making newfriends?	1	2	3	4	5
D4.5	Sexualactivities?	1	2	3	4	5

Domain5:Lifeactivities

5(1) Household activities

Iamnowgoingtoaskyouaboutactivitiesinvolvedinmaintainingyourhousehold,andincaringforthepeoplewhoyoulivewithorarecloseto.Theseactivitiesincludecooking,cleaning,shopping,caringforothers andcaringforyourbelongings.

Show flashcards#1and #2

Becauseof yourhealthcondition,inthepast30days		**None**	**Mild**	**Moderate**	**Severe**	**Extreme orcannot**
D5.1	Takingcareofyourhouseholdresponsibilities?	1	2	3	4	5
D5.2	Doingyourmostimportant household tasks well?	1	2	3	4	5
D5.3	Gettingallthehouseholdworkdone thatyouneededtodo?	1	2	3	4	5
D5.4	Gettingyourhouseholdworkdoneasquickly asneeded?	1	2	3	4	5

IfanyoftheresponsestoD5.2–D5.5areratedgreaterthannone(coded as"1"),ask:

D5.01	Inthepast30days,onhowmanydaysdidyoureduceorcompletelymisshousehold workbecauseofyourhealthcondition?	***Recordnumberofdays______***

Ifrespondentworks(paid, non-paid, self-employed) orgoesto school, complete questionsD5.5–D5.10onthenext page.Otherwise,skip toD6.1onthefollowing page.

5(2): Workorschoolactivities

NowIwill asksome questionsaboutyour workorschoolactivities.

Show flashcards#1 and #2

Becauseof yourhealthcondition,inthepast30days		**None**	**Mild**	**Moderate**	**Severe**	**Extreme orcannot do**
D5.5	Yourday-to-daywork/school?	1	2	3	4	5
D5.6	Doingyourmostimportantwork/schooltasks well?	1	2	3	4	5
D5.7	Gettingalltheworkdonethatyouneedtodo?	1	2	3	4	5
D5.8	Gettingyourworkdoneasquickly asneeded?	1	2	3	4	5
D5.9	Haveyouhadtoworkatalowerlevelbecauseofahealthcondition?				No	1
					Yes	2
D5.10	Didyouearn less moneyastheresultofahealthcondition?				No	1
					Yes	2

Ifanyof D5.5–D5.8arerated greaterthannone(codedas“1”),ask:

D5.02	Inthepast30days,onhowmanydaysdidyoumiss work forhalf a day ormorebecauseofyourhealthcondition?	***Recordnumberofdays*** _______

Domain6: Participation

Now,I amgoingtoaskyouaboutyourparticipation insocietyandtheimpactofyourhealth problemson you andyourfamily. Someof thesequestionsmayinvolve problemsthatgobeyondthepast30days, howeverin answering, pleasefocusonthepast 30days.Again, I remindyoutoanswerthesequestions whilethinkingabouthealthproblems: physical, mentaloremotional,alcoholordrugrelated.

Show flashcards#1 and #2

Inthepast30days:		**None**	**Mild**	**Moderate**	**Severe**	**Extremeor cannot do**
D6.1	Howmuchofaproblemdidyouhavejoiningin community activities(for example,festivities,religiousorotheractivities)inthesamewayasanyoneelsecan?	1	2	3	4	5
D6.2	Howmuchofaproblemdidyou havebecauseofbarriersorhindrancesintheworldaroundyou?	1	2	3	4	5
D6.3	Howmuchofaproblemdidyouhaveliving with dignitybecauseofthe attitudesand actionsofothers?	1	2	3	4	5
D6.4	Howmuchtimedidyouspendonyourhealthconditionoritsconsequences?	1	2	3	4	5
D6.5	Howmuchhaveyoubeenemotionally affectedbyyourhealthcondition?	1	2	3	4	5
D6.6	Howmuchhasyourhealthbeenadrainon the financialresourcesof youor yourfamily?	1	2	3	4	5
D6.7	Howmuchofaproblemdidyourfamily havebecauseofyourhealthproblems?	1	2	3	4	5
D6.8	Howmuch ofaproblemdidyouhave indoingthingsbyyourselfforrelaxationorpleasure?	1	2	3	4	5

H1	Overall,inthepast30days,how many dayswerethesedifficultiespresent?	***Recordnumberofdays________***
H2	Inthepast30days,forhowmanydayswereyoutotally unabletocarryoutyourusualactivitiesorworkbecauseofanyhealthcondition?	***Recordnumberofdays_______***
H3	Inthepast30days,notcountingthedaysthat youwere totallyunable,forhowmanydaysdid youcutback orreduceyourusualactivitiesor workbecauseof any health condition?	***Recordnumberofdays_______***

Thisconcludestheinterview. Thank youfor participating.

Appendix J: WHO Disability Assessment Schedule (Amharic version)

መግቢያ

ለጠያቂ ማስታዎሻ፡ ካርድ ቁጥር አንድን ለተጠያቂ በመስጠት የሚከተለውን ባብራሪያ ስጥ ፡፡

ይህ ቃለመጠይቅ ሰዎች በጤና እክል ምክንያት ስለሚኖራቸው ችግር ይሆናል፡፡ የጤና እክል ስል በሽታ ወይም ህመም፤ ሌሎች ለአጭር ወይም ለረጅም ጊዜ የሚቆዩ የጤና ችግሮች፤ ጉዳቶች፤ የአዕምሮ ወይም የመንፈስ መታወክ እንዲሁም ከመጠጥ እና ከዕጽ ጋር የተገናኙ ችግሮችን ይሆናል፡፡ ቃለመጠይቁ ውስጥ ያሉ ጥያቄዎችን ሲመልሱ ሁሉንም የጤና ችግርዎን እንዲያስቡ እፈልጋለሁ፡፡

ለጠያቂ ማስታወሻ፡ ካርድ ቁጥር አንድን አመልክት ወይም ለተጠያቂው አንብብ እና የሚከተለውን ማብራሪያ ስጥ፡፡

“አንድን ተግባር ለማከናወን መቸገር” ማለት

- ስራውን ለማከናወን ተጨማሪ ጥረት ሲያስፈልግ
- ስራውን ለማከናወን አለመመቸት ወይም የሕመም ስሜት ሲፈጥር
- ስራውን ለማከናውን ብዙ ጊዜ ሲፈጅ
- ስራውን ለማከናወን ቀድሞ ከሚሰሩበት ሌላ መንገድ ለመጠቀም ሲገደዱ ማለት ነው፡፡

እንግዲህ አንድን ተግባር ለማከናወን ስለገጠመወት ችግር ስጠይቅዎት እነዚህን እያሰቡ መልስ ይስጡ፡፡

ለጠያቂ ማስተዋሻ፡ ለተጠያቂው የሚከተለውን ተጨማሪ ማብራሪያ ስጥ፡፡

ጥያቄዎቹን ሲመልሱ ያለፈውን አንድ ወር እያስታወሱ ይሁን፡፡ እንዲሁም አነዚህን ጥያቄዎች ሲመልሱ በአማካይ ባለፈው እንድ ወር ብዙ ጊዜ የሚያከናውኑትን ስራ ለመፈፀም ምን ያህል ችግር ይገጥምዎት እንደነበር እያሰቡ ይሁን፡፡

ካርድ ቁጥር ሁለትን ለመላሹ ስጥና ድምጽህን ከፍ አድርገህ መስፈርቶቹን አንብብላቸው፡፡ በመቀጠልም የሚከተለውን ተጨማሪ ማብራሪያ ስጥ፡፡

ጥያቄዎቹን ሲመልሱ እነዚህን አምስት የችግር ወይም የእክል ደረጃዎች ይጠቀሙ፡፡

1. ምንም ችግር የለም　　2. አነስተኛ ችግር　　3. መካከለኛ ችግር　　4. ከፍተኛ ችግር
5. በጣም ከፍተኛ ችግር ወይም ፈፅሞ መስራት አለመቻል

ለጠያቂ ማስታወሻ፡ መጠይቁ እስኪጠናቀቅ ድረስ ካርድ ቁጥር አንድ እና ካርድ ቁጥር ሁለት ለመላሹ እንደሚታዩ መሆን አለባቸው፡፡

ለጠያቂ ማስታወሻ፡ ለመላሹ ካርድ ቁጥር አንድንና ካርድ ቁጥር ሁለትን አሳይ፡፡

1. ነገሮችን መረዳት

ነገሮችን ስለመረዳትና ከሰዎች ጋር ያለዎትን መግባባት በተመለከተ አንዳንድ ጥያቄዎች አቀርብለዎታለሁ፡፡ ጥያቄዎቹን ሲመልሱ ከላይ የጠቀስኩልዎትን አምስቱን የችግር ወይም የእክል ደረጃዎች ይጠቀሙ፡፡ እነዚህም

1. ምንም ችግር የለም 2. አነስተኛ ችግር 3. መካከለኛ ችግር 4. ከፍተኛ ችግር
5. በጣም ከፍተኛ ችግር ወይም ፈፅሞ መስራት አለመቻል

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D1.1	በሚሰሩት ስራ ላይ **ለጥቂት ጊዜ (ለ10 ደቂቃ) ያህል ትኩረት ማድረግ** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D1.2	**ማድረግ የሚፈልጓቸውን ነገሮች አስታውሰው ለማድረግ** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D1.3	**በእለት ተእለት ሕይወትዎ ውስጥ የሚገጥምዎትን ችግሮች መንስኤ ለመለየትና መፍትሄ ለመፈለግ** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D1.4	**አዲስ ነገር ወይም ስራ ለመማር** ምን ያህል ይቸግርዎት ነበር? (ለምሳሌ፡ የእርሻ ስራ፤ ባልትና፤ የእጅ ስራ ወዘተ...)	1	2	3	4	5
D1.5	**በአጠቃላይ ሰዎች የሚሉትን ለመረዳት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D1.6	**ከሰዎች ጋር ንግግር ለመጀመርና እስከመጨረሻው ለመቆየት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5

2. እንቅስቃሴ

ለመላሹ ካርድ ቁጥር አንድንና ካርድ ቁጥር ሁለትን አሳይ፡፡

አሁን ደግሞ **ከእንቅስቃሴ ጋር የተያያዙ** ችግሮችን እጠይቅዎጣለሁ፡፡

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D2.1	ረዘም ላለ ጊዜ **ቆሞ መቆየት** ምን ያህል ይቸግርዎት ነበር? (ለምሳሌ፡ ለግማሽ ሰዓት)	1	2	3	4	5
D2.2	**ከተቀመጡበት ለመነሳት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D2.3	**እቤትዎ ውስጥ መዘዋወር** ምን ያህል ይቸግርዎት ነበር	1	2	3	4	5
D2.4	**ከቤትዎ ለመውጣት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D2.5	**የተወሰነ ርቀት መንገድ ለመጓዝ** ምን ያህል ይቸግርዎት ነበር? (ለምሳሌ፡ የሩብ ሰዓት መንገድ ወይም አንድ ኪሎ ሜትር)	1	2	3	4	5

3. እራስን መንከባከብ ወይም መጠበቅ

አሁን እራስዎትን በመንከባከብ ረገድ የሚገጥምዎትን ችግር የተመለከቱ ጥያቄዎች እጠይቅዎታለሁ፡፡

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D3.1	**ሰውነትዎን መታጠብ** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D3.2	**ልብስዎትን ለመልበስ** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D3.3	**ምግብ ለመመገብ** ምን ያህል ይቸግርዎት ነበር	1	2	3	4	5
D3.4	ያለሰው ብቻዎትን ለተወሰኑ ቀናት መቆየት ሲኖርብዎት **ብቻዎትን መቆየት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5

4. ከሰዎች ጋር መግባባት

አሁን ከሰዎች ጋር መግባባትን በተመለከተያለበዎትን ችግር እጠይቅዎታለሁ፡፡ ያስታውሱ በጤና መታወክ ምክንያት የተፈጠሩ ችግሮችን ብቻ ነው የምጠይቅዎት፡፡ ይህም ማለት በሽታ ወይም ሕመም፤ ሌሎች ለአጭር ወይም ለረዥም ጊዜ የሚቆዩ የጤና ችግሮች፤ ጉዳቶች፤ የአዕምሮ ወይም የመንፈስ መታወክ እንዲሁም ከመጠጥና ከእፅ ጋር የተገናኙ ችግሮችን ይሆናል፡፡

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D4.1	**ከዚህ በፊት ከማያውቋቸው ሰዎች ጋር ለመጀመሪያ ጊዜ ለመግባባት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D4.2	ከአንድ ሰው ጋር **በጓደኝነት ለብዙ ጊዜ መቆየት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D4.3	ከቤተሰቦችዎ፤ ከዘመዶችዎ እና ከቅርብጓደኞችዎ ጋር**ተግባብቶ መኖር** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D4.4	**አዲስ ጓደኝነት መጀመር** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D4.5	**ከተቃራኒ ፆታ ጋር የፍቅር ግንኙነት ማድረግ** ምን ያህል ይቸግርዎት ነበር?					

5. የኑሮ እንቅስቃሴ

5(1) የቤት ውስጥ ስራዎች

የሚከተሉት ጥያቄዎች እቤትዎ ውስጥ ስለሚያደርጉት እንቅስቃሴ እንዲሁም አብሮዎት የሚኖሩ ወይም ለርስዎ ቅርብ የሆኑ ሰዎችን ስለመንከባከብ ይሆናል፡፡ስራዎቹ ምግብ ማብሰል፤ ፅዳት፤ ሱቅ ወይም ገበያ መሄድ እንዲሁም ሌሎች ሰዎችን መንከባከብ እና ንብረትዎን መጠበቅ ናቸው፡፡

ካርድ ቁጥር አንድንና ካርድ ቁጥር ሁለትን አሳይ/አንብብ፡፡

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D5.1	**የቤትና የግቢ ውስጥ ስራዎችንና ሌሎች ኃላፊነቶችንመወጣት** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.2	በጣም አስፈላጊ የሚሏቸውን የቤትና የግቢ ውስጥ ስራዎች **በጥሩ ሁኔታ** መስራት ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.3	መስራት ያለብዎትን የቤትና የግቢ ውስጥ ስራዎች **ሁሉንም** ሰርቶ ለመጨረስ ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.4	የቤትና የግቢ ውስጥ ስራዎችን **በሚፈልጉት ፍጥነት** ለመስራት ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5

ከጥያቄ D5.1-D5.4 ውስጥ የችግሩ ደረጃ ከምንም በላይ (ከ1 በላይ) ምላሽ የተሰጠበት ካለ የሚከተለውን ጠይቅ፡፡

D5.01	በባለፈው አንድ ወር ጊዜ ውስጥ በጤናዎ ችግር (በሕመምዎ) የተነሳ ለስንት ቀናት **የቤት ውስጥ ስራዎችን** መስራት ቀነሱ ወይም ሙሉ በሙሉ ሳይሰሩ ቀሩ?	የቀናት ብዛት ይመዝገብ ----------------- ቀናት

መላሹ ሰራተኛ (በክፍያ፤ በነፃ፤ በግል የሚሰራ ከሆነ) ወይም ተማሪ ከሆነ ከD5.5-D5.10 ያለውን ሙላ፡፡ ካልሆነ ግን ወደ D6.1 እለፍ፡፡

5(2) **ስራ ወይም ትምህርት**

አሁን ደግሞ ስለስራዎ ወይም ስለትምህርትዎ ሁኔታ እጠይቅዎታለሁ፡፡

ካርድ ቁጥር አንድንና ካርድ ቁጥር ሁለትን አሳይ/አንብብ፡፡

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D5.5	የእለት ተዕለት **ስራዎትን ወይም ትምህርትዎትን** ለማከናወን ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.6	በጣም አስፈላጊ የሚሉትን ስራ ወይም ትምህርት **በጥሩ ሁኔታ** መስራት ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.7	መስራት ያለብዎትን ስራ ወይም ትምህርት **ሁሉንም ሰርቶ ለመጨረስ** ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.8	ስራዎትን ወይም ትምህርትዎትን **በሚፈልጉት ፍጥነት** ለመስራት ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D5.9	በሕመምዎ ምክንያት ከሚጠበቅብዎ ወይም በፊት ይሰሩት ከነበረው ባነሰ መልኩ እንዲሰሩ ተገደዋል?				የለም	1
					አዎን	2
D5.10	በሕመምዎ ምክንያት ገቢዎ ቀንሷል?				የለም	1
					አዎን	2

ከጥያቄ D5.5-D5.8 ውስጥ የችግሩ ደረጃ ከምንም በላይ (ከ1 በላይ) ምላሽ የተሰጠበት ካለ የሚከተለውን ጠይቅ፡፡

D5.02	በባለፈው አንድ ወር ጊዜ ውስጥ በጤናዎ ችግር (በሕመምዎ) የተነሳ ለግማሽ ቀን ወይም ከዚያ በላይ ስራ ሳይሰሩ የቀሩት ለምን ያል ቀናት ነበር?	የቀናት ብዛት ይመዝገብ ---------------- ቀናት

6. ማሕበራዊ ተሳትፎ

አሁን በሚኖሩበት ማሕበረሰብ ውስጥ ስላለዎት ተሳትፎ እንዲሁም የጤና ችግርዎ (ሕመምዎ) በራስዎና በቤተሰብዎ ላይ ስላስከተለው ችግር አጠይቅዎታለሁ፡፡ አንዳንዶቹ ችግሮች ከአንድ ወር በላይ የቆዩ ሊሆኑ ይችላሉ፡፡ ሆኖም ግን የሚከተሉትን ጥያቄዎች ሲመልሱ እባክዎ ባለፈው አንድ ወር ጊዜ ውስጥ ስለነበረው ብቻ ያተኩሩ፡፡ እነዚህን ጥያቄዎች ሲመልሱ ስለጤናዎ ችግር (ስለሕመምዎ) እያሰቡ እንዲሆን በድጋሚ አሳስብዎታለሁ፡፡

ካርድ ቁጥር አንድንና ካርድ ቁጥር ሁለትን አሳይ/አንብብ፡፡

	ባለፈው አንድ ወር ጊዜ ውስጥ	ምንም	አነስተኛ	መካከለኛ	ከፍተኛ	በጣም ከፍተኛ
D6.1	**በማሕበራዊ እንቅስቃሴ ውስጥ** (ለምሳሌ፡ አመት በዓል፤ ድግስ፤ ለቅሶ፤ እድር፤ ሊቃ ወዘተ…) ልክ እንደሌላው ሰው መሳተፍ ምን ያህል ይቸግርዎት ነበር?	1	2	3	4	5
D6.2	እንደ አድሎና መገለል እና ሌሎችም በአካባቢዎ ባሉ **መሰናክሎችና ምቹ ያልሆኑ ሁኔታዎች** ምክንያት ምን ያህል ችግር ገጠመዎት?	1	2	3	4	5
D6.3	ሰዎች ለእርስዎ ባላቸው መጥፎ አመለካካትና ተገቢ ያልሆኑ ድርጊቶች የተነሳ **በሰው ተከብረው** ለመኖር ምን ያህል ተቸገሩ?	1	2	3	4	5
D6.4	ለሕመምዎ መፍትሄ ለማግኘት፤ ጠያቂ ለማነጋገር፤ ስለሕመምዎ ለሌሎች ለማስረዳት **ምን ያህል ጊዜ አጥፍተዋል**?	1	2	3	4	5
D6.5	በጤና ችግርዎ ወይም በሕመምዎ ምክንያት **ስሜትዎ ምን ያህል ተረብሿ**?	1	2	3	4	5
D6.6	የጤና ችግርዎ ወይም ሕመምዎ የእርስዎንና የቤተሰብዎን **ሀብትና ንብረት ምን ያህል አራቆተ**?	1	2	3	4	5
D6.7	በእርስዎ የጤና ችግር ወይም በሕመምዎ ምክንያት **ቤተሰብዎ** ምን ያህል ተቸግሯል?	1	2	3	4	5
D6.8	**የሚያዝናናዎትን ወይም የሚያስደስትዎትን ነገር** ያለ ሌላ ሰው ድጋፍ ለማድረግ ምን ያህል ይከብድዎታል?	1	2	3	4	5

H1	በአጠቃላይ ባለፈው አንድ ወር ጊዜ ውስጥ እነዚህ ችግሮች **ለምን ያህል ቀናት ነበሩ**?	የቀናት ብዛት ይመዝገብ ------------------ ቀናት
H2	በባለፈው አንድ ወር ጊዜ ውስጥ በማንኛውም የጤና ችግር ምክንያት የተለመደ ስራዎትን ወይም እንቅስቃሴዎትን **ሙሉ በሙሉ ማድረግ ያልቻሉት** ለምን ያህል ቀናት ነበር?	የቀናት ብዛት ይመዝገብ ------------------ ቀናት
H3	በባለፈው አንድ ወር ጊዜ ውስጥ በማንኛውም የጤና ችግር ምክንያት (ሙሉ በሙሉ ምንም ስራ መስራት ያልቻሉበትን ሳይጨምር) የተለመደ ስራዎትን ወይም እንቅስቃሴዎትን **ለመቀነስ** የተገደዱባቸው ምን ያህል ቀናት ነበሩ?	የቀናት ብዛት ይመዝገብ ------------------ ቀናት

ስለተጠያቂው ተጨማሪ አስተያየት

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ቃለ-መጠይቁ በዚህ ያበቃል፡፡ ለተሳትፎዎ በጣም አመሰግናለሁ፡፡


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Addis Ababa University

What will happen if you agree to take part?

In-depth interviews

You will be invited to participate in a one-to-one interview. The interviews will usually be held at your workplace or home, or another place that is convenient for you. You will be asked some questions about normal, day-to-day activities and functioning in this area. The interview will last up to one hour. With your agreement, we will audio-tape the interview.

Discussion group

The discussion groups will be located at a central location within Butajira town. There will be between 8 and 10 people in the group, as far as possible with a similar background to you; for example, there will be separate groups for persons with mental disorders, their families and health care workers. The group will be asked some questions about normal, day to day activities and functioning among persons with severe mental disorders. You will be invited to contribute your opinion as part of the discussion, although there is no obligation for you to speak during the group. The discussion will take between 1 and 2 hours. If all participants give agreement then we will tape-record the discussion. You will be given refreshments and reimbursed for your transport costs and time.

Risks of being in the study

We don't expect that the discussion will cause you any difficulties. On rare occasions, people might be upset by the questions that are being asked. If you are distressed by the questions then you do not have to answer the question or you can leave the group at any time.

Possible benefits

We hope that the information obtained will help to improve mental health services in Ethiopia and other similar countries. Once the overall study is completed, we will let you know what we found, either by inviting you to a meeting, giving you a leaflet or publicising our findings in the district.

What we will do with your data

If you take part in the tape-recorded discussion, we will make sure that the tapes do not include your name or identifying information. If notes are taken instead of tape-recording, these notes will not include your name or identifying information. The tapes and notes will be kept in a locked cupboard. Once the interview tapes have been written down, and the data has been analysed, the tapes will be cleared. Nobody except the principal researcher will know that the information belongs to you. We will keep the questionnaires in a locked cupboard. After the end of this study, the information you tell us may be used by other researchers, but they will not be able to identify you in any way.

Main researchers:

- Kassahun Habtamu under the primary supervisoon of Dr Charlotte Hanlon.
- You can contact us at the Butajira project office on telephone number 046 151595, from Monday to Friday during working hours.

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason.

If this study has harmed you in any way you can contact the Institutional Review Board, Addis Ababa University, using the details below for further advice and information:

- Institutional Review Board, School of Medicine, Addis Ababa University
  Telephone number: 0115-5538734

- You may withdraw your data from the project at any time up until it is transcribed for use in the final report.
- If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.


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Addis Ababa University

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Addis Ababa University

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Possible benefits

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Addis Ababa University

የቡድን ውይይት

የቡድን ውይይቱ በቡታጅራ ከተማ መሐል አካባቢ የሚካሄድ ይሆናል፡፡ በእያንዳንዱ ቡድን ከስምንት እስከ አስር ሰዎች የሚሳተፉ ሲሆን የቡድኑ አባላት በተቻለ መጠን ተመሳሳይ ሰዎች እንዲሆኑ ይደረጋል፡፡ ለምሳሌ፣ ለአዕምሮ ሕመምተኞች፣ ለቤተሰቦቻቸው እና ለጤና እንክብካቤ ሰራተኞች የተለያዩ ቡድኖች እንዲኖሩ ይደረጋል፡፡

የቡድን አባላቱ የተለያዩ የተለመዱ የቀን ተቀን የኑሮ እንቅስቃሴዎችን የተመለከቱ የተወሰኑ ጥያቄዎችን ይጠየቃሉ፡፡ በሚካሄደው የቡድን ውይይት እንዲናገሩ ባይገደዱም ሐሳብ በመስጠት የበኩልዎን አስተዋፅኦ እንዲያደርጉ የሚጋበዙ ይሆናል፡፡ ውይይቱ ከአንድ እስከ ሁለት ሰዓት ይወስዳል፡፡ ሁሉም ተሳታፊዎች ፈቃደኝነታቸውን የሚሰጡ ከሆነ ውይይቱን በቴፕ ሪከርደር የምንቀርፅ ይሆናል፡፡ በውይይቱ ወቅት የሻይ ቡና አገልግሎት የሚሰጥ ሲሆን የትራንስፖርትና የውሎ አበል የሚከፈል ይሆናል፡፡

በጥናቱ በመሳተፍዎ የሚደርስብዎ ጉዳት

ውይይቱ ማንኛውም አይነት ችግር ያደርስብዎታል ብለን አናስብም፡፡ ምናልባት በጣም አልፎ አልፎ ሰዎች በሚጠየቁት ጥያቄዎች ቅር ሊሰኙ ይችላሉ፡፡ ጥያቄዎች የማይመችዎት ከሆኑ ጥያቄዎቹን አለመመለስ (መልስ አለመስጠት) ይችላሉ ወይም ደግሞ በማንኛውም ጊዜ ቡድኑን ለቀው ለመሄድ ይችላሉ፡፡

ሊገኙ የሚችሉ ጠቀሜታዎች

በቡድን ውይይቱ የሚገኘው መረጃ በኢትዮጵያና ተመሳሳይ አገራት የአእምሮ ጤና አገልግሎትን ለማሻሻል ያግዛል፡፡

በአጠቃላይ ጥናቱ ከተጠናቀቀ በኋላ በጥናቱ የተደረሰባቸውን ግኝቶች በስብሰባ ወይም ደግሞ በበራሪ ወረቀት የምናሳውቅ ይሆናል፡፡

የሚሰጡት መረጃ እንዴት ይያዛል?

በቴፕ ሪከርደር በሚቀርፅ ውይይት የሚሳተፉ ከሆነ ስምዎትን ወይም ማንነትዎን ሊገልፅ የሚችል መረጃ እንደማንቀርፅ እናረጋግጥልዎታለን፡፡ ማስታወሻ ብቻ የሚወሰድ ከሆነ ደግሞ ማስታወሻው ውስጥ ስምዎት ወይም ማንነትዎን ሊገልፅ የሚችል መረጃ እንዳይሰፍር እናደርጋለን፡፡ ማስታወሻዎችና የተቀረፁ የቴፕ ካሴቶች ሳጥን ውስጥ የሚቆለፍባቸው ይሆናል፡፡ የተቀረፁ ካሴቶች ወደ ጽሁፍ ከተገለበጡና መረጃው ከተቀናበረ በኋላ ካሴቶች እንዲወገዱ ይደረጋል፡፡

ከዋና ጥናት አድራጊው በስተቀር መረጃው የእርስዎ መሆኑን ማንም እንዲያውቅ አይደረግም፡፡ መጠይቆቹን በተቆለፈ ሳጥን ውስጥ የምናስቀምጣቸው ይሆናል፡፡

የሰጡን መረጃ ይህ ጥናት ከተጠናቀቀ በኋላ ሌሎች ተመራማሪዎች ሊጠቀሙበት ይችላሉ ነገር ግን በምንም መንገድ የእርስዎን ማንነት ሊያውቁ አይችሉም፡፡

ዋና ተመራማሪዎች

- ካሳሁን ኃብታሙ በዶ/ር ሻርሎት ሐንሎን አማካሪነት
- በስልክ ቁጥር 046 15 15 95 በስራ ሰዓት ከሰኞ እስከ አርብ ቡታጅራ ከተማ በሚገኘው የፕሮጀክት ጽ/ቤታችን ሊያገኙን ይችላሉ፡፡

በዚህ ጥናት ለመሳተፍ ወይም ላለመሳተፍ ሙሉ በሙሉ የእርስዎ ውሳኔ ነው፡፡ ለመሳተፍ ከወሰኑ በማንኛውም ጊዜ ምንም አይነት ምክንያት መስጠት ሳያስፈልግዎ ተሳትፎዎን ማቋረጥ ይችላሉ፡፡

ይህ ጥናት በማንኛውም መልኩ ጉዳት ካደረሰብዎ የአዲስ አበባ ዩኒቨርስቲን ተቋማዊ ግምገማ ቦርድ ለተጨማሪ መረጃና ምክር በሚከተለው አድራሻ ማግኘት ይችላሉ፡፡

- ተቋማዊ ግምገማ ቦርድ፣ የሕክምና ት/ቤት፣ አዲስ አበባ ዩኒቨርሲቲ
- ስልክ ቁጥር 0115 53 87 34

- ለመጨረሻው ሪፖርት ጥቅም ላይ ከመዋሉ በፊት ለፕሮጀክቱ የሰጡትን መረጃ በማንኛውም ጊዜ ማንሳት ይችላሉ፡፡
- በጥናቱ ለመሳተፍ ከወሰኑ ይህ የመረጃ ቅፅ እርስዎ ጋር እንዲሆን ይሰጥዎታል፣ የፈቃድነት መጠየቂያ ፎርም ላይም እንዲፈርሙ ይጠየቃሉ፡፡


አዲስ አበባ ዩኒቨርሲቲ
Addis Ababa University

ሊገኙ የሚችሉ ጠቀሜታዎች

በቃለ መጠይቁ የሚገኘው መረጃ በኢትዮጵያና ተመሳሳይ አገራት የአዕምሮ ጤና አገልግሎትን ለማሻሻል ያግዛል፡፡

በአጠቃላይ ጥናቱ ከተጠናቀቀ በኋላ በጥናቱ የተደረሰባቸውን ግኝቶች በስብሰባ ወይም ደግሞ በበራሪ ወረቀት የምናሳውቅ ይሆናል፡፡

የሚሰጡት መረጃ እንዴት ይያዛል?

በመጠይቁ ውስጥ ስምዎ ስለማይሰፍር ከዋና ጥናት አድራጊው በስተቀር መረጃው የእርስዎ መሆኑን ሊያውቅ የሚችል ሰው አይኖርም፡፡ መጠይቆቹን ሳጥን ውስጥ ቆልፈን የምናስቀምጥ ይሆናል፡፡ የሰጡን መረጃ ይህ ጥናት ከተጠናቀቀ በኋላ ሌሎች ተመራማሪዎች ሊጠቀሙበት ይችላሉ፡፡ ነገር ግን በምንም መንገድ የእርስዎን ማንነት ሊያውቁ አይችሉም፡፡

ዋና ተመራማሪዎች

- ካሳሁን ኃብታሙ በዶ/ር ሻርሎት ሐንሎን አማካሪነት
- በስልክ ቁጥር 046 15 15 95 በስራ ሰዓት ከሰኞ እስከ አርብ ቡታጅራ ከተማ በሚገኘው የፕሮጀክት ጽ/ቤታችን ሊያገኙን ይችላሉ፡፡

ዚህ ጥናት ለመሳተፍ ወይም ላለመሳተፍ ሙሉ በሙሉ የርስዎ ውሳኔ ነው፡፡ ለመሳተፍ ከወሰኑ በማንኛውም ጊዜ ምንም አይነት ምክንያት መስጠት ሳያስፈልግዎ ተሳትፎዎን ማቋረጥ ይችላሉ፡፡

ይህ ጥናት በማንኛውም መልኩ ጉዳት ካደረሰብዎ የአዲስ አበባ ዩኒቨርስቲን ተቋማዊ ግምገማ ቦርድ ለተጨማሪ መረጃና ምክር በሚከተለው አድራሻ ማግኘት ይችላሉ፡፡

- ተቋማዊ ግምገማ ቦርድ፣ የሕክምና ት/ቤት፣ አዲስ አበባ ዩኒቨርሲቲ
- ስልክ ቁጥር 0115 53 87 34

- ለመጨረሻው ሪፖርት ጥቅም ላይ ከመዋሉ በፊት ለፕሮጀክቱ የሰጡትን መረጃ በማንኛውም ጊዜ ማንሳት ይችላሉ፡፡
- በጥናቱ ለመሳተፍ ከወሰኑ ይህ የመረጃ ቅፅ እርስዎ ጋር እንዲሆን ይሰጥዎታል፣ የፈቃድነት መጠየቂያ ፎርም ላይም እንዲፈርሙ ይጠየቃሉ፡፡


አዲስ አበባ ዩኒቨርሲቲ
Addis Ababa University

ሊገኙ የሚችሉ ጠቀሜታዎች

በቃለ መጠይቁ የሚገኘው መረጃ በኢትዮጵያና ተመሳሳይ አገራት የአዕምሮ ጤና አገልግሎትን ለማሻሻል ያግዛል፡፡

በአጠቃላይ ጥናቱ ከተጠናቀቀ በኋላ በጥናቱ የተደረሰባቸውን ግኝቶች በስብሰባ ወይም ደግሞ በበራሪ ወረቀት የምናሳውቅ ይሆናል፡፡

የሚሰጡት መረጃ እንዴት ይያዛል?

በመጠይቁ ውስጥ ስምዎ ስለማይሰፍር ከዋና ጥናት አድራጊው በስተቀር መረጃው የእርስዎ መሆኑን ሊያውቅ የሚችል ሰው አይኖርም፡፡ መጠይቆቹን ሳጥን ውስጥ ቆልፈን የምናስቀምጥ ይሆናል፡፡ የሰጡን መረጃ ይህ ጥናት ከተጠናቀቀ በኋላ ሌሎች ተመራማሪዎች ሊጠቀሙበት ይችላሉ፡፡ ነገር ግን በምንም መንገድ የእርስዎን ማንነት ሊያውቁ አይችሉም፡፡

ዋና ተመራማሪዎች

- ካሳሁን ሐብታሙ በዶ/ር ሻርሎት ሐንሎን አማካሪነት
- በስልክቁጥር፣046151595
  በስራሰዓትከሰኞእስከአርብቡታጅራከተማበሚገኘውየፕሮጀክትጽ/ቤታችንሊያገኙንይችላሉ፡፡

በዚህ ጥናት ለመሳተፍ ወይም ላለመሳተፍ ሙሉ በሙሉ የርስዎ ውሳኔ ነው፡፡ ለመሳተፍ ከወሰኑ በማንኛውም ጊዜ ምንም አይነት ምክንያት መስጠት ሳያስፈልግዎ ተሳትፎዎን ማቋረጥ ይችላሉ፡፡

ይህ ጥናት በማንኛውም መልኩ ጉዳት ካደረሰብዎ የአዲስ አበባ ዩኒቨርስቲን ተቋማዊ ግምገማ ቦርድ ለተጨማሪ መረጃና ምክር በሚከተለው አድራሻ ማግኘት ይችላሉ፡፡

- ተቋማዊ ግምገማ ቦርድ፣ የሕክምና ት/ቤት፣ አዲስ አበባ ዩኒቨርሲቲ
- ስልክ ቁጥር 0115 53 87 34

- ለመጨረሻው ሪፖርት ጥቅም ላይ ከመዋሉ በፊት ለፕሮጀክቱ የሰጡትን መረጃ በማንኛውም ጊዜ ማንሳት ይችላሉ፡፡
- በጥናቱ ለመሳተፍ ከወሰኑ ይህ የመረጃ ቅፅ እርስዎ ጋር እንዲሆን ይሰጥዎታል፣ የፈቃድነት መጠየቂያ ፎርም ላይም እንዲፈርሙ ይጠየቃሉ፡፡


አዲስ አበባ ዩኒቨርሲቲ
Addis Ababa University

Participant's Statement:

I ____ agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signature ___________________________________ Date _______________________

Witness Statement (in event that participant is not literate):

I____ agree that the research project named above has been explained to __________________ (participant) to her satisfaction and that she agrees to take part in the study. Both the notes written above and the Information Sheet about the project have been read to her, and she understands what the research study involves.

Signature __________________________________ Date__________________________

Investigator's Statement:

I ____ confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signature ___________________________________ Date___________________________


አዲስ አበባ ዩኒቨርሲቲ
Addis Ababa University

የተሳታፊው/ዋ ቃል

እኔ ______________________________ ከላይ የተጠቀሰው የጥናትና ምርምር ፕሮጀክት ለእኔ ባረካኝ መጠን የተገለፀልኝ መሆኑን ተስማምቻለሁ እንዲሁም በጥናቱ ለመሳተፍ ተስማምቻለሁ፡፡ ከላይ የሰፈሩትን ስለ ፕሮጀክቱ የተሰጡትን ማሳሰቢያዎች እና የመረጃ ቅፅ አንብቤያለሁ እንዲሁም ጥናትና ምርምሩ ምን እንደሚይዝ (እንደሚያጠቃልል) ተረድቼአለሁ፡፡

ፊርማ ____________ ቀን ________________

የምስክርነት ቃል (ተሳታፊው/ዋ ማንበብና መፃፍ የማይችሉ ከሆነ)

እኔ ______________________________ ከላይ የተጠቀሰው የጥናትና ምርምር ፕሮጀክት ለ________ ________________ለእርሳቸው ባረካቸው መጠን የተገለፀላቸው መሆኑን ተስማምቻለሁ እንዲሁም በጥናቱ ለመሳተፍ ተስማምተዋል፡፡ ከላይ የሰፈሩት ስለ ፕሮጀክቱ የተሰጡት ማሳሰቢያዎች እና የመረጃ ቅፅ የተነበበላቸው ሲሆን ጥናትና ምርምሩ ምን እንደሚይዝ (እንደሚያጠቃልል) ተረድተዋል፡፡

ፊርማ ____________ ቀን ________________

የተመራማሪው ቃል

እኔ ______________________________ የታቀደውን ጥናትና ምርምር ባህሪ፣ ጥናትና ምርምሩ የሚጠይቀውን ነገር እና አስፈላጊ ሆኖ ሲገኝ ማንኛውም ሊከሰቱ የሚችሉ አደጋዎችን ለጥናቱ ተሳታፊ በጥንቃቄ ማብራራቴን አረጋግጣለሁ፡፡

ፊርማ ____________ ቀን ________________

Appendix O: Manuscripts (one published and two under review)[1]

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[1] The three manuscrits can be found in a separate folder

LETTER FOR DECLARATION

I, the undersigned, declared that this is my original work, has never been presented in this or any other University, and that all the resources and materials used for the dissertation, have been fully acknowledged.

Name: ____

Signature: ____

Date: ____

Place: ____

Date of submission: _______________________________________

This dissertation has been submitted for examination with my approval as University Supervisor.

Name: ____

Signature: ____

Date: ____