

Involvement of people with schizophrenia in decision-making in rural Ethiopia: a qualitative study

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Abstract

Background

The involvement of people with psychosocial disabilities in decision-making is a fundamental component of a person-centred and recovery-oriented model of care, but there has been little investigation of this approach in low- and middle-income countries. The aim of this study was to explore the involvement of people with schizophrenia in decision-making relating to their care in rural Ethiopia.

Methods

A qualitative study was conducted in rural Ethiopia as part of the Rehabilitation Intervention for people with Schizophrenia in Ethiopia (RISE) project, involving two focus group discussions (n=10) with community-based rehabilitation workers, and 18 in-depth interviews with people with schizophrenia, caregivers, health officers, supervisors and a community-based rehabilitation worker. Thematic analysis was used to examine major themes related to involvement in decision-making in this specific setting.

Results

Involvement of people with schizophrenia in decision-making in this rural Ethiopian setting was limited and coercive practices were evident. People with schizophrenia tended to be consulted about their care only when they were considered clinically 'recovered'. Caregivers typically had a prominent role in decision-making, but they also acquiesced to the views of health care professionals. People with schizophrenia and caregivers were often unable to execute their desired choice due to inaccessible and unaffordable treatment.

Conclusions

Community-based rehabilitation, as a model of care, may give opportunities for involvement of people with schizophrenia in decision-making. In order to increase involvement of people with schizophrenia in rural Ethiopia there needs to be greater empowerment of service users, wider availability of treatment choices and a facilitating policy environment. Further studies are needed to explore concepts of person-centred care and recovery across cultural settings.

1 **Keywords**

2 Decision-making - Patient participation - Community-based rehabilitation - Convention
3 on the Rights of Persons with disabilities - Schizophrenia - Psychosocial disabilities -
4 Mental health - Community mental health services - Human rights - Ethiopia -
5 Developing countries.

6 **Background**

7 The burden of schizophrenia in Ethiopia manifests in high levels of disability [1] and
8 mortality [2], a heavy burden on caregivers [3], stigma [4][5] and human rights violations
9 [6]. Many people who require treatment are not able to access it. Thus, the treatment
10 gap is huge, reaching 90% in rural areas [7], with many individuals reliant on family
11 support and traditional treatments [8]. In light of the scarcity of human and financial
12 resources, a challenge exists of how to ensure that services match international
13 recommendations in terms of promoting the use of individualized treatment [9],
14 including the involvement of people with psychosocial disabilities in decision-making
15 relating to their care. The right of people with psychosocial disabilities to make their
16 own choices is a key principle of the United Nations Convention on the Rights of Persons
17 with Disabilities (CRPD) [10], which was ratified by Ethiopia in 2010.
18 Involvement in decision-making is considered to be a fundamental component of
19 person-centred and recovery-oriented models of care [11]. These models rest on the
20 assumption that care should respect the needs, experiences and rights of the individual
21 with a mental health problem [12][13]. As such, both models are grounded in the
22 autonomy-focused value systems of the Western countries where they were developed.
23 The cross-cultural applicability of these approaches and the assumptions upon which
24 they rest have been questioned [14].
25 Shared decision-making is a model that falls between the traditional medical model and
26 the informed choice model [15][16]. Its practice ensures bidirectional exchange of

27 information between service users and care providers. Consensus is built on the
28 preferred treatment, in a supportive context of shared responsibility, whilst respecting
29 the values and preferences of service-users [15][16][17]. This differs from the informed
30 choice model, which implies that the care provider only transfers the information to the
31 patient, who will then make the decision alone [15][16][18].

32 Overall, the evidence about the impact of shared decision-making on service users'
33 outcomes in mental health is limited [19] and inconclusive [20]. However, in high-
34 income countries, interventions designed to involve people with schizophrenia in
35 decisions relating to their treatment have been associated with better outcomes,
36 especially in enhancing long-term medication adherence [21][22]; reducing re-
37 hospitalisation [23]; improving social functioning [24]; and increasing satisfaction in
38 community-based programs [24]. Moreover, a recent systematic review and meta-
39 analysis demonstrated that shared decision-making in mental health care can lead to
40 the reduced use of compulsory treatment [25]. However, that study did not find a clear
41 effect on the ability to make decisions or the quality of the therapeutic relationship [25].
42 Concerns have been raised about the capacity of people with schizophrenia to make
43 decisions about their treatment [26] and the impact of negative symptoms on their
44 motivation to be involved in the process [27]. However, there is evidence that people
45 with schizophrenia have an interest in, and are able to participate in, decision-making
46 [28][29][30], particularly in relation to choice of psychotropic medications [31]. The
47 views of people with schizophrenia on involvement, what drives participation or non-
48 participation and the impact of their preferences on service engagement and outcomes
49 remain under-researched areas [32][33][34].

50 Despite the increased interest in involving people with psychosocial disabilities in
51 decision-making, the gaps in knowledge and feasibility mean that this approach is still
52 not widely adopted in either high or low-income country settings [35]. In line with the
53 CRPD principles, the Ethiopian National Mental Health Strategy [36] aims to develop and
54 implement mental health services which respond to the needs and choices of people
55 with psychosocial disabilities and their caregivers; promote recovery and social

56 inclusion; and counter stigma, discrimination, and human rights abuses. Approaches
57 such as person-centred care, education and participation of service users, carers and
58 communities constituted the main values and principles of the strategy. In addition,
59 concepts of “informed decision-making”, “empowerment” and “peer-support groups”
60 were promoted.

61 The PRIME (PRogramme for Improving Mental healthcarE) programme [37][38] aims to
62 evaluate the integration of mental health into primary care in five low and middle
63 income countries (LMICs), including Ethiopia, guided by the WHO Mental Health Gap
64 Action Programme (mhGAP) [39][40]. Whilst the mhGAP intervention guide specifies
65 ‘the right of the person to be involved in every decision that concerns his or her
66 treatment’, it does not provide guidance on how this should be achieved. The
67 Rehabilitation Intervention for people with Schizophrenia in Ethiopia (RISE) [41][42]
68 project is nested within PRIME. In the RISE pilot study and cluster randomised trial,
69 community-based rehabilitation (CBR) [43] was delivered by trained lay workers through
70 home visits covering psycho-education , family intervention, adherence support, and
71 support to return to work and community activities, alongside community mobilization
72 [41][42]. CBR workers do not administer psychotropic medication themselves, but
73 support participants to access treatment in primary care. The CBR workers training
74 included shared decision-making as a general principle of care.

75 An understanding of the experiences of involving people with schizophrenia in decision-
76 making in Ethiopia is needed to guide efforts to improve access to care in this country
77 and other resource-constrained settings. The aim of this study was to understand the
78 extent of involvement of people with schizophrenia in decision-making relating to their
79 care in Ethiopia in the context of a CBR programme and to determine the main factors
80 influencing these processes.

81 **Methods**

82 **Setting**

83 This study was conducted as part of the RISE [41][42] 12-month pilot study in the Sodo
84 district of Ethiopia, which is also the setting of the PRIME programme [37][38]. Sodo
85 district is a rural area located 100 km south of Addis Ababa, the capital of Ethiopia,
86 which is characterized by a lack of infrastructure in terms of electricity and sanitation,
87 and a low population literacy level (45%) [44][45]. There are eight health centres, where
88 health officers and nurses deliver care, and 58 satellite health posts staffed by health
89 extension workers [45][46]. Most mental health care is provided at the health centre
90 level, with costs being out-of-pocket for the majority of the population. Access to
91 medication for people with schizophrenia is limited to first generation antipsychotics
92 (chlorpromazine and haloperidol) with sporadic access to depot injection. Medications
93 to alleviate side effects (e.g. anticholinergic medication) are rarely available [47]. A
94 psychiatric nurse-run outpatient clinic is available at Butajira, which is 30-50km from the
95 district with limited paved roads. People with psychosocial disabilities are also referred
96 to or seek inpatient care at the national referral hospital, Amanuel Specialised Mental
97 Hospital, which is located in Addis Ababa and inaccessible to most people. Traditional
98 and religious healers constitute major sources of care for people with psychosocial
99 disabilities as in the rest of Ethiopia. There are various types of traditional healers
100 (herbalists, *tanqway* ('sorcerer'), and bonesetters). However, the first port of call in the
101 case of severe psychosocial disabilities is typically holy water sites linked to the
102 Orthodox Christian church (27 sites in Sodo), where people drink the holy water or are
103 baptized in it to gain the benefits [46][48].

104 **Data Collection**

105 Data were collected between January and May 2015, after two or three month's
106 participation in the 12 month CBR programme. Two focus group discussions (FGDs) with
107 10 CBR workers and 18 in-depth interviews (IDIs) with six people with schizophrenia,
108 seven caregivers, two health officers, two supervisors and one CBR worker were
109 conducted. The age range of people with schizophrenia who participated in the IDIs was
110 18 and 70 years old and four of the six participants were male. All IDIs and FGDs were
111 based on topic guides with open-ended questions focused on the acceptability,

112 feasibility and impact of the RISE CBR program, including a set of questions on
113 involvement in decision-making. The core questions were: Who is involved in decision-
114 making about mental healthcare? How are the decisions made? What are the challenges
115 to involving people with schizophrenia and caregivers in this process?

116 Data collection was conducted in Amharic by an Ethiopian research assistant with a
117 Masters level degree and experience in qualitative research. IDIs and FGDs were audio-
118 taped, transcribed verbatim, and then translated into English. A member checking
119 meeting [49] was held with one supervisor and ten CBR workers to validate the primary
120 analysis and ensure that it accurately reflected their viewpoints. The member checking
121 was facilitated in English by LA and SS, with translation by the research assistant.

122 **Data analysis**

123 Data management and coding were conducted using NVivo 10.2.1 [50][51]. Transcripts
124 were coded independently by LA and SS, and discussed together with the research
125 assistant and CH to ensure reliability, internal coherence and consistency of the coding
126 framework, as well as capturing the cultural context. Thematic analysis was used to
127 examine major themes related to involvement in decision-making [52]. However, a
128 recursive process constantly moving back and forth between the entire data set and the
129 notes from the member checking allowed existing themes to be emphasized and
130 additional sub-themes to emerge, such as “capacity”. The accounts of the different
131 categories of participants involved in this study (e.g. people with schizophrenia,
132 caregivers, CBR workers) were also compared in relation to the themes emerging from
133 the data. Quotations from participants were embedded within the analytic narrative to
134 illustrate and support the analysis.

135 **Ethics approval and consent to participate**

136 This study received ethical approval from the LSHTM MSc Research Ethics Committee
137 [Ref.10163], the LSTHM Interventions Research Ethics Committee [Ref.7035] and the
138 Addis Ababa University College of Health Sciences Institutional Review Board
139 [Ref.083/13/Psy]. Written informed consent was obtained from all participants.
140 Participants who were non-literate gave a thumbprint and a witness signed to confirm

141 that the study had been explained according to the written information leaflet. All data
142 were de-identified to ensure anonymity of the participants.

143 **Results**

144 Three major themes were identified: how decisions are made about care; what factors
145 affect involvement; and what influences the choices made.

146 **How decisions are made about care**

147 **Communication and role of CBR workers**

148 Most CBR workers and supervisors described how they advise people with
149 schizophrenia on the available treatments, their advantages and side effects. Asking
150 people with schizophrenia what their goals are, listening to their needs and respecting
151 their opinions constituted fundamental elements of this process. CBR workers were
152 then indirectly involved in supporting treatment choices to be enacted, for example by
153 assisting individuals to attend the health centre. A supervisor described how they were
154 increasingly involving both people with schizophrenia and caregivers:

155 *“Most of the time, the patients give a special place for those who give them*
156 *attention and give them advice. I think this is what they are deprived of... we give them an opportunity to develop an interest in talking about their*
157 *issues. [Before] When we ask some questions about something, which is an*
158 *issue for the patient, the caregiver will answer and we will leave the patient*
159 *without asking that question. This should not be the way. Therefore what*
160 *we do is we ask the individual as well as the caregiver. We are now asking*
161 *both about the issue, which concerns them equally. We are also asking*
162 *questions which are for the patient only”.* (Supervisor, IDI07)
163

164 Using clear simple information and giving more time for people with schizophrenia to
165 understand their options and express their choices were underlined as effective

166 strategies to actively engage them in the decision-making process. One CBR worker
167 explained:

168 *“[The family] don’t give [the person with schizophrenia] time; I wait for her*
169 *calmly to respond and after some time she answers. Then, I show and*
170 *explain to them that she answers like this by taking her time and she should*
171 *practice like this slowly...”* (CBR worker, ID120)

172 **Adjustments to treatment plans**

173 Adjustments to treatment plans were sometimes made as a result of people with
174 schizophrenia actively requesting changes; or by being asked about their preferences at
175 the health centre or in CBR sessions. Several CBR workers and health officers
176 emphasized that the requests of people with schizophrenia are taken into account not
177 solely to enhance their involvement in decision-making, but to equally address issues of
178 non-adherence to treatment and avoid refusals of care. Health officers changed
179 treatments from oral medication to injection and CBR workers adjusted the timing and
180 frequency of CBR sessions, according to the needs of people with schizophrenia. These
181 were reported as the main mechanisms indicating ‘involvement’ according to CBR
182 workers and health officers in this study.

183 **Prominence of caregivers’ involvement**

184 The caregivers’ involvement in decision-making often took precedence over that of
185 people with schizophrenia. This prominent role in decision-making was linked to
186 caregivers’ crucial role in supporting recovery. Caregivers’ collaboration with health care
187 providers was reported to be essential to ensure service users’ access and adherence to
188 treatments. A health officer explained:

189 *“Even if we say it is the patient who is suffering, the responsibility of giving*
190 *support and care lies on the caregivers. If the caregiver didn’t participate*
191 *in the decision making process, the treatment will not give the expected*
192 *results. The caregiver is the one who gives the medicine to the patient. It is*

193 *also the caregiver who can decide on the frequency of visit and can inform*
194 *on the changes observed in the patient. The caregivers are especially*
195 *important in cases where the patient doesn't give any response...". (Health*
196 *officer, IDI18)*

197 Furthermore, caregivers were perceived to be more active in the decision-making
198 process than people with schizophrenia, for example by asking questions and expressing
199 their ideas. Thus, health officers, supervisors and some CBR workers expressed a
200 preference for the involvement of caregivers. From the perspective of people with
201 schizophrenia, the involvement of their caregivers was considered in some cases as an
202 expression of their desire to care for the person. Thus, respondents reported trusting
203 caregiver to make decisions on their behalf. Moreover, caregivers were considered to
204 have the right to be involved and make decisions as they are equally affected by the
205 burden of the illness on them. A person with schizophrenia described how his son took
206 him to the hospital as he was concerned and stressed:

207 *"It was my son who took me there [the hospital]. He was too concerned*
208 *about me. He is the one who loves me a lot. When he became too stressed*
209 *about my situation, people told him to take me to Amanuel hospital."*
210 (Person with schizophrenia, IDI02)

211 Yet in some cases, caregivers seemed to completely exclude their relatives and make
212 decisions on their behalf without even informing them. One CBR worker explained:

213 *"They [her daughter and son] don't even tell the patient what they planned*
214 *to do for her care. They were entitled with the decision making of*
215 *everything in her life. They don't consult or ask her...Even in relation to*
216 *going to church they fear taking her as she might disturb there. She is*
217 *restricted from all those freedoms."* (CBR worker, P3-FGD1)

218 A person with schizophrenia expressed his frustration of not being informed or having
219 the choice in relation to his care:

220 *“If I knew [we were going to holy water] I wouldn’t go, but they [his mother*
221 *and another person] decided. I don’t like that! ... They would take me either*
222 *by force or politely”.* (Person with schizophrenia, ID117)

223 **Coercive care**

224 Facing relapse due to the refusal of care and non-adherence to treatment, some
225 caregivers adopted coercive approaches. These included scaring service users to
226 influence their treatment choices; mixing medication into food without telling the
227 person with schizophrenia; and physical restraint. There was a consensus among health
228 officers, CBR workers and supervisors that coercive approaches are ethically
229 inappropriate. However, they all acknowledged the usefulness of such approaches to
230 guarantee that the person is taking medication. Thus, they argued that the use of
231 coercion as a last resort, after exhausting all other alternatives, was justified as long as it
232 was not harmful and used for the benefits of the service users. Health officers
233 supported their views by explaining how some service users, who were given
234 medication without their consent, later recovered and took the medicine by themselves:

235 *“There are cases where the medication is given with food and injection*
236 *medicines are administered by use of force...without the patients will. The*
237 *patients will thank you when they recover and stabilize. I know patients*
238 *who were treated like that and have returned to their normal life and work.*
239 *This shows that we might not get this result if we had waited for the*
240 *patients consent and tried to understand their feelings...”.* (Health officer,
241 ID116)

242 A divergent view from one caregiver favoured persuasion over the use of force to
243 convince people with schizophrenia to follow treatment:

244 *“Yes, the use of force doesn’t work at all. There is nothing could be done*
245 *with force. He is not cooperative. It is helpful to convince him and let*
246 *himself decide. I think that is the better way...though he might not be*
247 *willing at the beginning, at last he will be convinced...but, it is after a series*
248 *of discussions and arguments...”.* (Caregiver, IDI01)

249 Additionally, one supervisor explained how CBR could play a role in creating awareness
250 among caregivers on how to respect the dignity and ensure the safety of the person
251 with schizophrenia when the use of coercion, such as physical restraint, is needed.

252 **What affects involvement in decision-making**

253 A number of individual factors (capacity, intellectual disability, motivation and financial
254 capacity) and service delivery factors (setting and CBR worker fear of failure) were
255 identified as affecting involvement in decision-making.

256 **Individual factors**

257 **Capacity**

258 Perceived mental capacity to make decisions emerged as an important factor that
259 determined whether attempts were made to involve people with schizophrenia in
260 decision-making. Views varied across the respondents on whether having schizophrenia
261 per se necessarily indicated lack of mental capacity. However, health officers tended to
262 consider schizophrenia as synonymous with incapacity. There was a strong belief that
263 illness severity impacted on the capacity of people with schizophrenia to be involved.
264 Symptoms such as confused thoughts, delusions and lack of insight were considered to
265 hinder people with schizophrenia from participating effectively in decision-making.

266 *“As the illness becomes severe, even when [the person with schizophrenia]*
267 *is asked about decision-making, what she says is outside of the issue we*
268 *want to decide about. She simply talks on her own. We couldn’t understand*
269 *what she says as her talk is not normal. I think that this might influence the*
270 *judgment that she has no capacity to decide”.* (CBR worker, P3-FGD1)

271 Health officers, CBR workers and supervisors suggested that capacity is enhanced after
272 receiving treatment and recovering, enabling people with schizophrenia to participate
273 more actively and make decisions that they viewed as 'better'. People with
274 schizophrenia who had recovered clinically were reportedly given more opportunities to
275 be involved in decision-making. Instead of imposing opinions on them, respondents
276 reported that they often asked them what they wanted and listened to how they would
277 prefer to be helped. In recovery, the choices of the person were considered to be
278 trustworthy and thus more respected.

279 Nevertheless, attitudes of caregivers towards the capacity of people with schizophrenia
280 were not consistent with those claimed by health officers. In some cases, caregivers'
281 attitudes appeared not to change over time; irrespective of the person's recovery. The
282 person with schizophrenia appeared to be stigmatized and their capacity was judged
283 based on previous situations when their symptoms were worse. Equally, the type of
284 decisions made by people with schizophrenia seems to influence the judgment of their
285 capacity not only by caregivers but also by CBR workers. It was implied that 'better'
286 decisions involved adherence to medication and compliance with health professionals'
287 advice. CBR workers underlined how the concerns of people with schizophrenia about
288 their medications and/or a decision not to attend treatment are sometimes dismissed as
289 signs of relapse and considered as irrational and reflective of lack of capacity.

290 In addition, the limited abilities of the two CBR participants with comorbid intellectual
291 disability to understand and communicate were seen as a major obstacle towards their
292 involvement in decision-making. Thus, in these cases, caregivers, CBR workers and
293 health officers tended to make decisions on behalf of the person. One CBR worker
294 explained:

295 *"As she also has intellectual disability, she is not conscious about her overall*
296 *situation. Therefore, she couldn't decide by her self. We are the ones who*
297 *decide on behalf of her. We are deciding whether she has to go to Holy*
298 *water or health centre instead of her. It is because she doesn't say anything,*
299 *it is only her family who decides with us". (CBR worker, P5-FGD2)*

300 **Motivation and expectations**

301 Motivation and expectations of people with schizophrenia and caregivers also appeared
302 to affect the extent of their involvement. One CBR worker reported that people with
303 schizophrenia tend to keep their opinions to themselves and lack motivation to be
304 involved in decision-making due to pervasive stigma. A health officer highlighted how it
305 is difficult to engage people who are not motivated and willing to express themselves.
306 They also underscored how unmet expectations of care can affect the judgement of
307 people with schizophrenia and their caregivers to make the “right” treatment decision:

308 *“If the treatment didn’t bring the result they [the person with schizophrenia*
309 *and the caregiver] wanted; and the illness became worse, the patient might*
310 *try to escape or think you have misled him and try to attack you, because*
311 *he spent a lot of money and didn’t see any change. This will create*
312 *prejudices for the caregiver and the patient and they will not be able to*
313 *make the right decision”.* (Health officer, IDI18)

314 **Age and position in the family**

315 The age and position of people with schizophrenia and caregivers in the family was
316 discussed as influential on their perceived decision-making ability. One supervisor
317 explained that from the perspective of the family, a father, who is responsible for the
318 family, would be given the opportunity to make his own decisions. In contrast a son or
319 daughter living with their parents might have less power within the family and therefore
320 not be considered capable of making decisions.

321 **Financial capacity and power**

322 The financial capacity of people with schizophrenia and caregivers was discussed as an
323 important factor in determining who is involved in decision-making. Household finances
324 were typically in the hands of caregivers; therefore they held the power to make
325 decisions regarding treatment. When families were under financial constraints, other
326 family or community members were sometimes involved and influenced on the
327 decisions made to access treatment.

328 *“At the beginning, it was me [the caregiver] who decided, as the Holy water*
329 *doesn’t require any money, so I could take her [the person with*
330 *schizophrenia] there easily. However, for the later [treatment at the health*
331 *centre], it was him [her nephew] who decided, as I don’t have money”.*
332 (Caregiver, IDI03)

333 CBR workers highlighted some exceptions where people with schizophrenia decided
334 independently about their treatment and bought medication with their own money.
335 These were people who were working and had gained back their productivity and
336 financial independence.

337 **Service delivery factors**

338 **Setting**

339 The setting where decision-making takes place was considered to affect the feasibility
340 and acceptability of involvement. The high staff workload at health centres was
341 discussed as an obstacle. However, the greater time capacity of CBR workers and the
342 provision of home-visits were perceived to enhance the participation of people with
343 schizophrenia and caregivers. One CBR worker described how home visits increase
344 confidentiality; and thus, they offer people with schizophrenia the possibility to interact
345 more freely in the decision-making process:

346 *“People with schizophrenia and their caregivers want confidentiality about*
347 *their illness. Through home visits, they could feel free to express their views.*
348 *They could express their opinions and concerns freely as there is only them*
349 *and us there”.* (CBR worker, P2-FGD2)

350 Moreover, the support received during home visits was greatly appreciated and
351 accepted by people with schizophrenia and caregivers, who felt engaged in these visits
352 especially because the timing and frequency were tailored to their convenience.

353 **CBR workers fear of failure**

354 Fear of failure due to refusal of care by people with schizophrenia was indicated as a
355 major concern for some CBR workers. They described the stressful and demoralizing
356 feeling associated with a person's lack of improvement and that refusal of care
357 negatively influenced their motivation and relationships with people with schizophrenia.
358 Thus, some CBR workers adopted a persuasive approach to convince participants to
359 continue treatment and CBR by re-emphasising the benefits and potential impact on
360 their lives. In some cases, CBR workers mustered the support of caregivers and health
361 officers in both evaluating the risks and stressing the benefits of treatment and CBR
362 sessions, based on their insights into the person's situation and care plan.

363 **Influences on the choices made**

364 **Clinical recovery**

365 There was a strong belief among CBR workers that symptomatic improvement affects
366 the way people with schizophrenia perceive their need to continue the care. They
367 explained how people with schizophrenia started to refuse care including CBR,
368 medication, and attending the health centre, once they began feeling better. For some
369 people, these treatments were considered as options to be sought only in case of
370 relapse or severe illness. Lack of improvement might equally affect the motivation of
371 people with schizophrenia and caregivers to continue the treatment. A health officer
372 explained:

373 *"People get bored when they don't see changes...The treatment of mental*
374 *illness needs long follow up. You might not see changes sometimes. This is*
375 *a big challenge in the treatment of the illness...Some patients recover from*
376 *their illness. Some do not recover. The families of the patients who haven't*
377 *recovered have a tendency to be demoralized. The caregivers may bring*
378 *the patient from remote areas; villages might not have access to transport.*
379 *In addition, the cost of transport and treatment is very high...". (Health*
380 *officer, IDI18)*

381 **Side effects of medication**

382 Despite recognising the importance of medication in treating their symptoms, the side
383 effects of anti-psychotic medication remained a major concern, which frequently led to
384 non-adherence. People with schizophrenia and caregivers were often concerned about
385 sedating side effects affecting their daily life and productivity, in particular the ability to
386 do manual labour, whilst one family were concerned the side effects might prove to be
387 life threatening. From their side, CBR workers and health officers underlined their
388 responsibility to clearly explain the side effects of medication to people with
389 schizophrenia and caregivers.

390 *“...As the medication created fatigue on her situation they suspect that this*
391 *might lead to death. They stopped the medication and went to other*
392 *treatment options because of that. However, after trying other options,*
393 *they returned back [to medication]”.* (CBR Worker, P3 FGD1)

394 **Poverty and lack of access to free medicine**

395 In the absence of free medication, lack of financial capacity to pay for medication was
396 discussed by all participants in this study as a major obstacle, which often guided
397 decisions relating to the care of people with schizophrenia.

398 *“The patient whom I am working with is from a poor family. The medication*
399 *prescribed for him needs one hundred forty five birr [approximately US\$ 5].*
400 *.... What I want to add here is about the challenge which the caregiver is*
401 *facing and even she was on the way to decide to stop [the medication]*
402 *because of the economic challenge. She even asked me to find support for*
403 *her as she couldn't be able to help her children. The father of the patient*
404 *has nothing to support her”.* (CBR worker, P4 FGD2)

405 **Relationship with health professionals**

406 In the context of this study, there appeared to be a power dynamic, in which the
407 knowledge and opinions of health professionals (health officers and CBR workers) were
408 usually considered valuable and trustworthy. In some cases, even when asked about

409 their preferences and given the choice to decide, people with schizophrenia and
410 caregivers seemed to trust the opinions of health professionals and delegate them to
411 make the decisions. Good communication, attention and respect towards the person
412 with schizophrenia were identified to play an important role in enhancing this
413 confidence.

414 *“All the health professionals have a good attitude towards [the person with*
415 *schizophrenia]. Especially [xxxx], ... at the health centre, gives him good*
416 *attention. [The health officers] ask him his preference whether it is better*
417 *to take medication or injection, while he tells them that he is okay with*
418 *both options. When they ask him to have an injection, he takes the injection*
419 *without any resistance. He has no problem in this respect. He tells him that*
420 *he could take medication if they think that is appropriate or if they think*
421 *injection is appropriate respectively” (Caregiver, IDI10)*

422 **Traditional treatments**

423 Decisions to use traditional treatments appeared to be most often driven by the beliefs
424 of people with schizophrenia and caregivers and also influenced by relatives, the local
425 community and religious leaders.

426 *“It was both of us [caregiver and person with schizophrenia] together [who*
427 *decided to go to Holy water]. Other people also recommended the Holy*
428 *water. So, It was all of us who decided with the people who has seen his*
429 *situation...as it might be an evil spirit...It was with the assumption of*
430 *treating the illness with Holy water. I took him after a discussion. Then, he*
431 *attended the Holy water treatment for some days”.* (Caregiver, IDI01)

432 Nevertheless, there were some divergent opinions regarding traditional treatments
433 among people with schizophrenia and caregivers, who refuse to seek these types of
434 treatments, despite them being recommended by others.

435 *"I couldn't go to such places [Traditional treatments]. I can't attend this*
436 *"Chida" [traditional] treatment. I believe in one God who created the earth.*
437 *I worship only one God not any other... I haven't tried any Holy water. I*
438 *don't want to go there although they [his family] asked me to". (Person*
439 *with schizophrenia, IDI08)*

440 **Discussion**

441 This study shows that in practice there is limited operationalization of involvement of
442 people with schizophrenia in decision making in this rural Ethiopian setting. Coercive
443 practices are not uncommon. A CBR programme may give service users more
444 opportunities for involvement compared to a primary care setting. However in general
445 people with schizophrenia tend to be consulted about their care only when they are
446 considered clinically 'recovered' and in the absence of comorbid intellectual disability.
447 These practices may reflect a pervasive stigma towards people with mental illness.
448 Caregivers typically have a more prominent role in decision-making, but even they often
449 acquiesce to the views of health care professionals. People with schizophrenia and
450 caregivers are often unable to execute their desired choice due to inaccessible and
451 unaffordable treatment.

452 **Strengths and Limitations**

453 This is among the first studies to explore the involvement of people with schizophrenia
454 in decision-making relating to their care in a low-income country setting. Comparing the
455 perspectives of people with schizophrenia, caregivers and service providers allowed a
456 holistic and comprehensive understanding of current involvement, and enabled us to
457 identify the roles of each stakeholder in the process. The study also sought to
458 understand involvement across the spectrum of functioning, by including caregivers and
459 CBR workers of people with schizophrenia who were included in the pilot, but could not
460 participate in the interviews due to cognitive impairment. In addition, conducting
461 member-checking increased the validity of the findings.

462 However, there are limitations to this study. First, this was an exploratory study
463 conducted in the specific setting of a pilot study of CBR. The findings may not be
464 generalisable to other settings where CBR does not exist. Furthermore, data on
465 decision-making were collected at one time point early in the RISE pilot study so do not
466 allow understanding of how perceptions may have changed over time during the course
467 of treatment or CBR. The broader RISE pilot evaluation, which drew on qualitative and
468 process data over 12 months, also identified excessive persuasion to take medication
469 amongst a minority of CBR workers. Second, information bias may have occurred due to
470 CBR workers and supervisors emphasizing their efforts to involve people with
471 schizophrenia and caregivers in compliance with the RISE study protocol. The intimate
472 involvement of one of this study's authors in the RISE project might also have led to a
473 more favourable depiction by the CBR workers. Equally, despite the anonymity of the
474 interviews, people with schizophrenia and caregivers might have been reluctant to
475 criticize CBR workers and health officers for fear of damaging their relationships with
476 them. Furthermore, socio-cultural norms and the financial dependency from caregivers
477 may have potentially influenced the frankness with which people with schizophrenia
478 discussed their relationship with caregivers. An observational approach could have
479 reduced this response bias. Third, despite triangulating the data, the analysis was mostly
480 shaped by opinions of CBR workers, supervisors and health officers, which were
481 generally more clearly articulated than those of people with schizophrenia and
482 caregivers. Nonetheless, even in this context which would be expected to lead to more
483 favourable depictions of service user involvement, the extent of involvement in shared
484 decision-making appeared to be limited.

485 **Comparison of findings**

486 In this study only limited evidence of shared decision-making [15][53] was identified.
487 This supports findings from a previous qualitative study in rural Ethiopia, which showed
488 that people with psychosocial disabilities and caregivers are often poorly informed
489 about their rights, the illness, available treatments and their risks and benefits [54][55].
490 Moreover, the decision-making model identified in our study was in some cases

491 dominated by caregivers and health professionals. Discussions regarding treatments
492 tend to be characterized by asymmetric interactions, where health officers and CBR
493 workers seemed to control the exchange of information. However, this needs to be
494 understood within the context of Ethiopian society, where health professionals are
495 trusted and are expected, as in many cultures, to assume an authoritative and
496 prescriptive role [14]. Furthermore, both service users and caregivers in rural Ethiopia
497 may fear expressing their opinions if they include criticism of mental health providers, as
498 this could jeopardize their access to care [55]. Mayston et al. underlined that the extent
499 to which people with psychosocial disabilities in this setting express their opinions is
500 likely limited by their marginalized role in their community [56]. Women in Ethiopia also
501 have low status and have fewer rights than men (for example, less control over
502 household decisions and lower access to education and employment) [57][58][59][60].
503 Thus, it is conceivable that gender norms might constrain the involvement of females,
504 whether it is the person with schizophrenia and/or the caregivers, in decision-making.
505 In one case decision-making power apparently shifted to the nephew of a woman with
506 schizophrenia because her mother was unable to pay for treatment. However, there
507 was insufficient data from our study to draw firm conclusions on the role of gender.
508 In common with other LMICs, caregivers in this study were often the main decision-
509 makers, rather than a contributor to the process [54]. It has been proposed that in
510 Ethiopian society the rights of families are not separate from those of people with
511 mental illness and that the 'smallest autonomous unit' is the family rather than the
512 individual [61]. Thus a collective approach to decision-making is dominant [54], though
513 in our study this did not typically extend to the wider community. In settings where
514 there is limited access to care, caregivers may be forced to over-ride the autonomy of
515 the person with psychosocial disabilities to ensure that they receive effective treatment
516 and that other people are protected [54]. The potential for these relationships to
517 become abusive has been noted [54]. However, in our study, caregivers framed their
518 actions as taking moral responsibility for their family member: in such a context, to give
519 the person freedom to decide whether to take treatment or not might be perceived as

520 irresponsible and even unethical. Similarly, the physical restraint of people with
521 schizophrenia by family members has been conceptualized as a form of care
522 pragmatically employed to protect individuals and the wider community [6]. The
523 tensions between respecting autonomy and ensuring protection from harm equally exist
524 in high-income countries. Yet in rural Ethiopia the dominant mode of personhood is
525 arguably socio-centric, where value is given to reliance on one another and mutual
526 responsibility [62][63][14], in contrast to conceptions of disability in Western cultures,
527 which emphasize autonomy and independence. The prominence of caregivers'
528 involvement in our study was also attributed to the heavy caring and financial burden. It
529 has previously been noted that people with mental illness would not usually seek
530 treatment without the family's backing [61] and if the family refuses to pay, then the
531 person would often not have access to treatment [54].

532 It has been proposed that decision-making capacity is considered an 'all or nothing'
533 phenomenon in many African countries [64]. People with mental illness, who are found
534 to be lacking capacity, are deprived of their rights and meaningful involvement in the
535 management of their lives on the basis of minimal evidence and their capacity is re-
536 assessed rarely if at all by health professionals [64]. Concerns about mental capacity are
537 often highlighted as a major barrier to individuals' involvement in decision making [26]
538 and this was a key finding in our study. The CRPD indicates that all persons with
539 disabilities, even those who lack mental capacity, should receive care only on the basis
540 of free and informed consent, and should be offered support to reach autonomous
541 decisions [10]. Article 12 of the CRPD [10] indicates that persons with disabilities have
542 the right to exercise legal capacity according to their own will and preferences at all
543 times [65]. However, it has been argued that the inability of health professionals to
544 override personal autonomy in any circumstances undermines critical rights for people
545 with psychosocial disabilities, including the enjoyment of the highest attainable
546 standard of health [66]. Freeman et al suggest that the likelihood of recovery, and the
547 resumption of capacity to make treatment decisions in an informed manner, is often
548 diminished without treatment [66]. This reasoning is supported by our study, which

549 found that people with schizophrenia who were clinically recovered were reportedly
550 offered more opportunities for involvement.

551 Studies from high-income countries, where treatment is widely accessible, have
552 demonstrated that a high proportion of people with schizophrenia are competent to
553 make decisions in relation to their care [67][68], and illness severity does not necessarily
554 influence participation [69]. However, in our study in which treatment uptake was
555 variable, stage and severity of the illness and comorbid intellectual disability were
556 highlighted as factors associated with low decision-making capacities. Bearing in mind
557 the impact negative symptoms are believed to have on motivation and engagement in
558 the decision-making process [27], findings from our study supported the use of
559 individualized approaches by CBR workers, for example involving service users by giving
560 them more time to express themselves [69].

561 In this study, involvement of people with schizophrenia was often undermined by
562 caregivers and health professionals focusing on the decision made, rather than the
563 entire process [70]. The legitimacy of decisions not to adhere to medication or to refuse
564 care was often questioned, in light of a perceived lack of capacity. This is consistent with
565 studies from the US reporting that non-adherence is often perceived to be symptomatic
566 of the illness, rather than indicative of patient preferences [71], and a sign of
567 incompetence [72]. Finally, our findings align with recent research in rural Ethiopia,
568 which identified poverty and intolerable side effects of anti-psychotic medication as key
569 reasons for disengagement with mental healthcare [73].

570 **Implications**

571 The overall findings of this study suggest that the nature and setting of CBR
572 interventions and the role of CBR workers hold substantial promise in enhancing the
573 participation of people with schizophrenia and caregivers in decision-making by
574 facilitating their understanding and encouraging them to express their opinions.

575 However, the feasibility of involvement remains challenging in Ethiopia. Poverty, lack of
576 affordable medications and access to psychosocial care means that real choices for
577 treatment in the context of biomedical care are limited. This hinders the process of

578 decision-making and can lead people with schizophrenia and caregivers to reject care.
579 Thus, the over-riding priority in LMIC is to expand access to care so that people with
580 schizophrenia and caregivers have meaningful choices at an earlier stage in the illness
581 [54]. Such choices might include access to a wider range of psychosocial interventions
582 and anti-psychotic medications with a more acceptable side effect profile.

583 The establishment of community-based mental health services is a major focus of the
584 Ethiopian National Mental Health Strategy [36] but implementation is patchy due to
585 workforce and funding constraints. CBR has historically been delivered by NGOs in
586 Ethiopia and at present this is the most feasible route for wider implementation.

587 Once accessing care, people with schizophrenia should be actively involved by being
588 informed of their treatments options and given the right to choose their preferred
589 treatments. This may include on one hand reassurance that care provision will not be
590 affected by expressing an opinion or preference about treatment. On the other hand, it
591 should also include orientation to the notion that people with psychosocial disabilities
592 can still have capacity even if their decision does not accord with health workers
593 recommendations.

594 Guidance on how to involve people with schizophrenia in decision-making should be
595 included in the mhGAP Implementation Guide, and implemented as part of wider efforts
596 to scale up mental healthcare in primary care in LMIC. Such guidance should be
597 contextualised and acknowledge variations in decision-making norms and values across
598 cultures, and mental health systems, especially where choices are very limited and may
599 be influenced by age, gender, position in the family and socio-economic status. Specific
600 guidance on decision-making involvement in times of crisis may be valuable.

601 In Ethiopia, the National Mental Health Strategy needs to be supported by mental
602 health legislation and context-specific policies and procedures on implementing,
603 monitoring and evaluating the involvement and addressing stigma and discrimination of
604 people with psychosocial disabilities in inpatient and outpatient care. Legislation should
605 guide capacity assessment and informed consent and should be designed to protect
606 people with psychosocial disabilities who are not consenting to treatment [74].

607 Legislation could also guide the use of advance directives, which document a person's
608 preferences for treatment should they lose the capacity to make decisions in the future.
609 However implementation of such approaches may be challenging in the absence of
610 specialist input and appropriate oversight mechanisms.

611 The empowerment of service users, for example through self-advocacy organisations,
612 may support a broader shift towards people with psychosocial disabilities being aware
613 of their rights [56], and also contribute to their involvement in strengthening the mental
614 health system [55].

615 Cultural, social and religious values remain key to individual decision-making,
616 exemplified by the prominent role of caregivers and the use of religious and traditional
617 treatments. These values need be acknowledged and respected. Increased involvement
618 in decision-making by the individual should not result in the exclusion of caregivers from
619 the process. Indeed, removing caregivers and families from decision-making may
620 amount to the imposition of Western values and is likely to be both unacceptable and
621 unfeasible in the Ethiopian setting. Thus, health professionals should focus on how to
622 orient this involvement to be for the benefit of the person with schizophrenia, who is
623 usually dependent on caregiver support. The process should aim to support the balance
624 between protection from harm and preservation of autonomy [75].

625 Further studies are needed in LMIC to explore how concepts of person-centred care and
626 recovery as well as the process of involvement in decision-making could be
627 contextualised and adapted to ensure local validity and acceptability across cultural
628 settings [13][14] and in under-resourced health systems. Of particular interest is how
629 decision-making processes function in settings in Ethiopia and elsewhere where CBR
630 does not exist, and where involvement may be less feasible due to the high workload of
631 care providers and limited emphasis on empowering service users. Future research
632 could also explore how involvement in decision-making can be measured in LMIC, using
633 self-report by service users [76] or as part of broader assessment of healthcare worker
634 competence [77]. The RISE pilot evaluation identified involvement in decision-making as
635 a potential intermediate outcome in the pathway to improved functioning. Future

636 evaluations could further explore the impact of shared decision making on outcomes
637 such as treatment engagement and adherence, functioning and personal recovery.
638 Equally, there is a need to define the mechanisms through which involvement in
639 decision-making could go beyond individual-level care to wider involvement in the
640 system, where people with schizophrenia would be more represented in the planning
641 and delivery of services and their role might be transformed into peer support,
642 empowerment and advocacy [78][79][80].

643 **Conclusion**

644 In this study setting in rural Ethiopia, involvement of people with schizophrenia in
645 decision-making about their care was limited and challenging. Caregivers and health
646 care professionals have prominent roles in the process compared to people with
647 schizophrenia. Decision-making was often hindered by absence of real choices and care
648 was sometimes rejected due to poverty and lack of affordable and accessible
649 medications. In this context, CBR represents a promising model of care that may
650 facilitate and enhance involvement and participation of people with schizophrenia in
651 decision-making about their care. This involvement needs to be supported by greater
652 empowerment of service users, wider availability of treatment choices and a facilitating
653 policy environment.

654 **List of abbreviations**

655 **CRPD:** Convention on the Rights of Persons with Disabilities
656 **PRIME:** PRogramme for Improving Mental healthcarE
657 **LMIC:** Low and middle-income countries
658 **mhGap:** Mental Health Gap Action Programme
659 **RISE:** Rehabilitation Intervention for people with Schizophrenia in Ethiopia
660 **CBR:** Community-based rehabilitation
661 **FGD:** Focus groups discussion
662 **IDI:** In-depth interview

663 **Declarations**

664 **Ethics approval and consent to participate**

665 Ethical approval was obtained from the Addis Ababa University College of Health
666 Sciences Institutional Review Board (reference 039/13/PSY) and from the London School
667 of Hygiene and Tropical Medicine Research Ethics Committee (reference 6408). Written
668 informed consent, or a witnessed thumbprint for those who were illiterate, was
669 obtained from all study participants. Prior to conducting the interviews with people
670 with mental illness, capacity to consent to participation in the study was evaluated by a
671 psychiatrist.

672 **Consent for publication**

673 Written informed consent for publication was obtained from all participants in this
674 study. The consent form is held by Addis Ababa University and is available for review by
675 the Editor-in-Chief.

676 **Availability of data and materials**

677 The datasets analysed during the current study are part of the RISE project and are
678 available from LA on reasonable request.

679 **Competing interests**

680 The authors declare that they have no competing interests.

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697

698 **Authors contributions**

699 SS and LA conceived and designed the study. SS led the analysis with support from LA
700 and CH. SS drafted the manuscript. All authors commented on all the drafts of the
701 paper. All approved the final draft.

702

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707

708 **Authors information**

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710 **References**

- 711 1. Kebede D, Alem A, Shibre T, Negash A, Deyassa N, Beyero T, et al. Short-term
712 symptomatic and functional outcomes of schizophrenia in Butajira, Ethiopia.
713 *Schizophr Res.* 2005;78:171–85.
- 714 2. Fekadu A, Medhin G, Kebede D, Alem A, Cleare AJ, Prince M, et al. Excess mortality
715 in severe mental illness: 10-year population-based cohort study in rural Ethiopia. *Br*
716 *J Psychiatry* [Internet]. 2015;206:289–96. Available from:
717 <http://bjp.rcpsych.org/content/206/4/289>

- 718 3. Shibre T, Kebede D, Alem a, Negash a, Deyassa N, Fekadu a, et al. Schizophrenia:
719 illness impact on family members in a traditional society--rural Ethiopia. Soc
720 Psychiatry Psychiatr Epidemiol [Internet]. 2003;38:27–34. Available from:
721 <http://www.ncbi.nlm.nih.gov/pubmed/12563556>
- 722 4. Shibre T, Negash A, Kullgren G, Kebede D, Alem A, Fekadu A, et al. Perception of
723 stigma among family members of individuals with schizophrenia and major affective
724 disorders in rural Ethiopia. Soc Psychiatry Psychiatr Epidemiol. 2001;36:299–303.
- 725 5. Assefa D, Shibre T, Asher L, Fekadu A. Internalized stigma among patients with
726 schizophrenia in Ethiopia: a cross-sectional facility-based study. BMC Psychiatry.
727 2012;12:239.
- 728 6. Asher L, Fekadu A, Teferra S, De Silva M, Pathare S, Hanlon C. “I cry every day and
729 night, I have my son tied in chains”: Physical restraint of people with schizophrenia
730 in community settings in Ethiopia. Global Health. 2017;13.
- 731 7. Alem A, Kebede D, Fekadu A, Shibre T, Fekadu D, Beyero T, et al. Clinical course
732 and outcome of Schizophrenia in a predominantly treatment-naive cohort in rural
733 ethiopia. Schizophr Bull. 2009;35:646–54.
- 734 8. Alem A, Jacobsson L, Araya M, Kebede D, Kullgren G. How are mental disorders
735 seen and where is help sought in a rural Ethiopian community? Acta Psychiatr
736 Scand. 1999;100:40–7.
- 737 9. Fleischhacker WW, Arango C, Arteel P, Barnes TRE, Carpenter W, Duckworth K, et
738 al. Schizophrenia-Time to commit to policy change. Schizophr Bull. Oxford
739 University Press; 2014;40.
- 740 10. United Nations. Convention on the Rights of Persons with Disabilities. Article 12:
741 Equal recognition before the law and Article 25: Health. 2006.
- 742 11. Weinstein J. Mental health, service user involvement and recovery. Ment Heal
743 Serv user Involv Recover 224 pp London, Engl Jessica Kingsley Publ Engl [Internet].
744 2010. Available from:
745 <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc6&AN=2010-02424-000>
746
- 747 12. Gask L, Coventry P. Person-centred mental health care: The challenge of
748 implementation. Epidemiol Psychiatr Sci. 2012;21:139–44.
- 749 13. Morgan S, Yoder LH. A Concept Analysis of Person-Centered Care. J Holist Nurs.
750 2012;30:6–15.
- 751 14. Bayetti C, Jadhav S, Jain S. The Re-covering Self: a critique of the recovery-based
752 approach in India’s mental health care. Disabil Glob South. 2016;3:889–909.
- 753 15. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter:
754 what does it mean?(or it takes at least two to tango). Soc Sci Med [Internet].
755 Elsevier; 1997;44:681–692. Available from:
756 <http://www.sciencedirect.com/science/article/pii/S0277953696002213>
- 757 16. Charles C, Gafni A, Whelan T. Revisiting the shared treatment decision-making
758 model. Soc Sci Med [Internet]. 1999;49:651–61. Available from:

- 759 <http://www.ncbi.nlm.nih.gov/pubmed/10452420>
- 760 17. Edwards A, Elwyn G. Inside the black box of shared decision making:
761 Distinguishing between the process of involvement and who makes the decision.
762 *Heal Expect.* 2006;9:307–20.
- 763 18. Gafni A, Charles C, Whelan T. The physician-patient encounter: The physician as
764 a perfect agent for the patient versus the informed treatment decision-making
765 model. *Soc Sci Med.* 1998;47:347–54.
- 766 19. Duncan E, Best C, Hagen S. Shared decision making interventions for people with
767 mental health conditions. *Cochrane Database Syst Rev* [Internet]. 2010. Available
768 from: <http://doi.wiley.com/10.1002/14651858.CD007297.pub2>
- 769 20. Slade M. Implementing shared decision making in routine mental health care.
770 *World Psychiatry.* 2017;16:146–53.
- 771 21. Lloyd C, King R, Moore L. Subjective and objective indicators of recovery in
772 severe mental illness: a cross-sectional study. *Int J Soc Psychiatry.* 2010;56:220–9.
- 773 22. Warner R. Recovery from schizophrenia and the recovery model. *Curr Opin*
774 *Psychiatry.* 2009;22:374–80.
- 775 23. Hamann J, Cohen R, Leucht S, Busch R, Kissling W. Shared decision-making and
776 long-term outcome in schizophrenia treatment. *J Clin Psychiatry* [Internet].
777 2007;68:993–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17685733>
- 778 24. Malm U, Ivarsson B, Allebeck P, Falloon IRH. Integrated care in schizophrenia: a
779 2-year randomized controlled study of two community-based treatment programs.
780 *Acta Psychiatr Scand.* 2003;107:415–23.
- 781 25. Stovell D, Morrison AP, Panayiotou M, Hutton P. Shared treatment decision-
782 making and empowerment-related outcomes in psychosis: Systematic review and
783 meta-analysis. *Br. J. Psychiatry.* 2016. p. 23–8.
- 784 26. Seale C, Chaplin R, Lelliott P, Quirk A. Sharing decisions in consultations
785 involving anti-psychotic medication: A qualitative study of psychiatrists’
786 experiences. *Soc Sci Med.* 2006;62:2861–73.
- 787 27. Tambuyzer E, Pieters G, Van C, Phdà A. Patient involvement in mental health
788 care: one size does not fit all. *John Wiley Sons Ltd Heal Expect.* 2011;17:138–50.
- 789 28. Hamann J, Coden R, Leucht S, Busch R, Kissling W. Do patients with
790 schizophrenia wish to be involved in decisions about their medical treatment? *Am J*
791 *Psychiatry.* 2005;162:2382–4.
- 792 29. Hill SA, Laugharne R. Decision making and information seeking preferences
793 among psychiatric patients. *J Ment Heal.* 2006;15:75–84.
- 794 30. Puschner B, Becker T, Mayer B, Jordan H, Maj M, Fiorillo A, et al. Clinical decision
795 making and outcome in the routine care of people with severe mental illness across
796 Europe (CEDAR). *Epidemiol Psychiatr Sci* [Internet]. 2016;25:69–79. Available from:
797 http://www.journals.cambridge.org/abstract_S204579601400078X
- 798 31. O’Neal EL, Adams JR, McHugo GJ, Van Citters AD, Drake RE, Bartels SJ.

- 799 Preferences of older and younger adults with serious mental illness for involvement
800 in decision-making in medical and psychiatric settings. *Am J Geriatr Psychiatry*
801 [Internet]. 2008;16:826–33. Available from:
802 <http://www.ncbi.nlm.nih.gov/pubmed/18827229>
803 [http://dx.doi.org/10.1097/
JGP.0b013e318181f992](http://dx.doi.org/10.1097/JGP.0b013e318181f992)
- 804 32. Eliacin J, Salyers MP, Kukla M, Matthias MS. Patients' Understanding of Shared
805 Decision Making in a Mental Health Setting. *Qual Health Res* [Internet].
806 2014;25:668–78. Available from: <http://qhr.sagepub.com/content/25/5/668?etoc>
- 807 33. Wills CE, Holmes-Rovner M. Integrating Decision Making and Mental Health
808 Interventions Research: Research Directions. *Clin Psychol (New York)* [Internet].
809 2006;13:9–25. Available from:
810 [http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1466549&tool=pmcen
811 trez&rendertype=abstract](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1466549&tool=pmcentrez&rendertype=abstract)
- 812 34. Cooper LA. Commentary: At the center of decision making in mental health
813 services and interventions research: Patients, clinicians, or relationships? *Clin.*
814 *Psychol. Sci. Pract.* 2006. p. 26–9.
- 815 35. Shared Decision-Making in Mental Health Care: Practice, Research, and Future
816 Directions. Center for Mental Health Services, Substance Abuse and Mental Health
817 Services Administration; 2010.
- 818 36. Federal Democratic Republic of Ethiopia Ministry of Health. National mental
819 health strategy 2012/13–2015/16. Addis Ababa, Ethiopia.;
- 820 37. Lund C, Tomlinson M, de Silva M, Fekadu A, Shidhaye R, Jordans M, et al. PRIME:
821 A Programme to Reduce the Treatment Gap for Mental Disorders in Five Low- and
822 Middle-Income Countries. *PLoS Med.* 2012;9.
- 823 38. PRIME: Programme for Improving Mental Health Care.
824 <http://www.prime.uct.ac.za>.
- 825 39. World Health Organization. mhGAP Intervention Guide for Mental, Neurological
826 and Substance Use Disorders in Non-Specialized Health Settings: Mental Health Gap
827 Action Programme (mhGAP). [Internet]. *mhGAP Interv. Guid. Ment. Neurol. Subst.*
828 *Use Disord. Non-Specialized Heal. Settings Ment. Heal. Gap Action Program.* 2010.
829 Available from:
830 [http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:mhGAP+Interven
831 tion+Guide#1%5Cnhttp://scholar.google.com/scholar?hl=en&btnG=Search&q=intit
832 le:mhGAP+intervention+guide#1%5Cnhttp://www.ncbi.nlm.nih.gov/pubmed/237
833 41783](http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:mhGAP+Intervention+Guide#1%5Cnhttp://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:mhGAP+intervention+guide#1%5Cnhttp://www.ncbi.nlm.nih.gov/pubmed/23741783)
- 834 40. World Health Organization. WHO | WHO Mental Health Gap Action Programme
835 (mhGAP). WHO. 2014.
- 836 41. Asher L, Fekadu A, Hanlon C, Mideksa G, Eaton J, Patel V, et al. Development of a
837 community-based rehabilitation intervention for people with schizophrenia in
838 Ethiopia. *PLoS One.* 2015;10.
- 839 42. Asher L, De Silva M, Hanlon C, Weiss HA, Birhane R, Ejigu DA, et al. Community-
840 based Rehabilitation Intervention for people with Schizophrenia in Ethiopia (RISE):

841 study protocol for a cluster randomised controlled trial. *Trials* [Internet].
842 2016;17:1–14. Available from: <http://dx.doi.org/10.1186/s13063-016-1427-9>

843 43. World Health Organization. Social Component: CBR Guidelines. World Heal.
844 Organ. 2010.

845 44. Hanlon C, Luitel NP, Kathree T, Murhar V, Shrivasta S, Medhin G, et al. Challenges
846 and opportunities for implementing integrated mental health care: a district level
847 situation analysis from five low- and middle-income countries. *PLoS One* [Internet].
848 2014;9:e88437. Available from:
849 <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0088437>
850 7

851 45. Fekadu A, Medhin G, Selamu M, Shiferaw T, Hailemariam M, Rathod SD, et al.
852 Non-fatal suicidal behaviour in rural Ethiopia: A cross-sectional facility- and
853 population-based study. *BMC Psychiatry* [Internet]. 2016;16:1–9. Available from:
854 [http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=2016-14717-](http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=2016-14717-001&lang=fr&site=ehost-live)
855 001&lang=fr&site=ehost-live

856 46. Selamu M, Asher L, Hanlon C, Medhin G, Hailemariam M, Patel V, et al. Beyond
857 the biomedical: Community resources for mental health care in rural Ethiopia
858 [Internet]. *PLoS One*. 2015. p. no pagination. Available from:
859 [http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.p](http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0126666&representation=PDF%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=2015093238)
860 [one.0126666&representation=PDF%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS](http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0126666&representation=PDF%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=2015093238)
861 [&PAGE=reference&D=emed13&NEWS=N&AN=2015093238](http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0126666&representation=PDF%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=2015093238)

862 47. Teferra S, Hanlon C, Beyero T, Jacobsson L, Shibre T. Perspectives on reasons for
863 non-adherence to medication in persons with schizophrenia in Ethiopia: a
864 qualitative study of patients, caregivers and health workers. *BMC Psychiatry*
865 [Internet]. 2013;13:168. Available from:
866 [http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3686587&tool=pmcen](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3686587&tool=pmcentrez&rendertype=abstract)
867 [trez&rendertype=abstract](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3686587&tool=pmcentrez&rendertype=abstract)

868 48. Shibre T, Spångéus A, Henriksson L, Negash A, Jacobsson L. Traditional
869 treatment of mental disorders in rural Ethiopia. *Ethiop Med J* [Internet].
870 2008;46:87–91. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18711994>

871 49. Koelsch L. Reconceptualizing the Member Check Interview. *Int J Qual Methods*
872 [Internet]. 2013;12:168–79. Available from:
873 <http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/12327>

874 50. NVivo qualitative data analysis Software. QSR International Pty Ltd.;

875 51. Welsh E. Dealing with data: Using NVivo in the qualitative data analysis process.
876 *Forum Qual Soc Res* [Internet]. 2002;3:Art 26. Available from:
877 [http://www.qualitative-](http://www.qualitative-research.net/index.php/fqs/article/view/865/1880%5Cnhttp://www.qualitative-research.net/index.php/fqs/article/viewArticle/865)
878 [research.net/index.php/fqs/article/view/865/1880%5Cnhttp://www.qualitative-](http://www.qualitative-research.net/index.php/fqs/article/view/865/1880%5Cnhttp://www.qualitative-research.net/index.php/fqs/article/viewArticle/865)
879 [research.net/index.php/fqs/article/viewArticle/865](http://www.qualitative-research.net/index.php/fqs/article/viewArticle/865)

880 52. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*.
881 2006;3:77–101.

882 53. Hamann J, Leucht S, Kissling W. Shared decision making in psychiatry. *Acta*

883 Psychiatr Scand. 2003;107:403–9.

884 54. Hanlon C, Tesfaye M, Wondimagegn D, Shibre T. Ethical and professional
885 challenges in mental health care in low- and middle-income countries. *Int Rev*
886 *Psychiatry* [Internet]. 2010;22:245–51. Available from:
887 <http://www.tandfonline.com/doi/full/10.3109/09540261.2010.482557>

888 55. Abayneh S, Lempp H, Alem A, Alemayehu D, Eshetu T, Lund C, et al. Service user
889 involvement in mental health system strengthening in a rural African setting:
890 qualitative study. *BMC Psychiatry* [Internet]. 2017;17:187. Available from:
891 <http://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-017-1352-9>

892 56. Mayston R, Alem A, Habtamu A, Shibre T, Fekadu A, Hanlon C. Participatory
893 planning of a primary care service for people with severe mental disorders in rural
894 Ethiopia. *Health Policy Plan*. 2016;31:367–76.

895 57. Central Statistical Agency [Ethiopia] and ORC Macro. Ethiopia Demographic and
896 Health Survey 2005. Addis Ababa, Ethiopia and Calverton, Maryland, USA; 2006.

897 58. Ethiopia society of population study. Gender Inequality and Women’s
898 Empowerment; In- depth Analysis of the Ethiopian Demographic and Health Survey
899 2005. Addis Ababa, Ethiopia.; 2008.

900 59. International CSA [Ethiopia] and I. Ethiopia Demographic and Health Survey
901 2011. Addis Ababa, Ethiopia and Calverton, Maryland, USA; 2012.

902 60. Moreda TA. Nature of Women Empowerment in Ethiopia (Constitutional and
903 Policy Provisions). 2017;

904 61. Alem A, Jacobsson L, Lynöe N, Kohn R, Kullgren G. Attitudes and practices among
905 Ethiopian health care professionals in psychiatry regarding compulsory treatment.
906 *Int J Law Psychiatry*. 2002;25:599–610.

907 62. Whyte SR, Ingstad B. Help for people with disabilities: do cultural differences
908 matter? *World Health Forum* [Internet]. 1998;19:42–6. Available from:
909 [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=9610240)
910 [=Citation&list_uids=9610240](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=9610240)

911 63. McKevitt C. Disability in local and global worlds – Edited by Benedicte Ingstad &
912 Susan Reynolds Whyte. *J R Anthropol Inst* [Internet]. 2008;14:690–1. Available
913 from: [http://10.0.4.87/j.1467-](http://10.0.4.87/j.1467-9655.2008.00525_23.x%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=33717215&site=eds-live&scope=site%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?dire)
914 [9655.2008.00525_23.x%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscoho](http://10.0.4.87/j.1467-9655.2008.00525_23.x%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=33717215&site=eds-live&scope=site%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?dire)
915 [st.com/login.aspx?direct=true&db=a9h&AN=33717215&site=eds-](http://10.0.4.87/j.1467-9655.2008.00525_23.x%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=33717215&site=eds-live&scope=site%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?dire)
916 [live&scope=site%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com](http://10.0.4.87/j.1467-9655.2008.00525_23.x%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=33717215&site=eds-live&scope=site%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?dire)
917 [/login.aspx?dire](http://10.0.4.87/j.1467-9655.2008.00525_23.x%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=33717215&site=eds-live&scope=site%0Ahttp://ludwig.lub.lu.se/login?url=http://search.ebscohost.com/login.aspx?dire)

918 64. Bartlett P, Hamzic V. Reforming Mental Disability Law in Africa: Practical Tips
919 and Suggestions. 2010.

920 65. Minkowitz T. Prohibition of Compulsory Mental Health Treatment and Detention
921 Under the CRPD. Available SSRN <https://ssrn.com/abstract=1876132> or
922 <http://dx.doi.org/102139/ssrn1876132>. 2011;

923 66. Freeman MC, Kolappa K, de Almeida JMC, Kleinman A, Makhshvili N, Phakathi S,

- 924 et al. Reversing hard won victories in the name of human rights: A critique of the
925 General Comment on Article 12 of the UN Convention on the Rights of Persons with
926 Disabilities. *The Lancet Psychiatry*. 2015;2:844–50.
- 927 67. Appelbaum BC, Appelbaum PS, Grisso T. Competence to Consent to Voluntary
928 Psychiatric Hospitalization : A Test of a Standard Proposed by APA. *Psychiatr Serv*.
929 1998;49:1193–6.
- 930 68. Saks ER, Jeste D V, Granholm E, Palmer BW, Schneiderman L. Ethical issues in
931 psychosocial interventions research involving controls 283. *Ethics Behav*.
932 2002;12:87–101.
- 933 69. Hamann J, Kruse J, Schmitz FS, Kissling W, Pajonk FG. Patient participation in
934 antipsychotic drug choice decisions. *Psychiatry Res*. 2010;178:63–7.
- 935 70. Matthias MS, Salyers MP, Frankel RM. Re-thinking shared decision-making:
936 Context matters. *Patient Educ. Couns*. 2013. p. 176–9.
- 937 71. Deegan PE. The lived experience of using psychiatric medication in the recovery
938 process and a shared decision-making program to support it. *Psychiatr Rehabil J*.
939 2007;31:62–9.
- 940 72. Leo RJ. Competency and the Capacity to Make Treatment Decisions: A Primer for
941 Primary Care Physicians. *Prim Care Companion J Clin Psychiatry* [Internet].
942 1999;1:131–41. Available from:
943 [http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=181079&tool=pmcent](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=181079&tool=pmcentrez&rendertype=abstract)
944 [rez&rendertype=abstract](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=181079&tool=pmcentrez&rendertype=abstract)
- 945 73. Hailemariam M, Fekadu A, Prince M, Hanlon C. Engaging and staying engaged: A
946 phenomenological study of barriers to equitable access to mental healthcare for
947 people with severe mental disorders in a rural African setting. *Int J Equity Health*.
948 2017;16.
- 949 74. Mall S, Hailemariam M, Selamu M, Fekadu A, Lund C, Patel V, et al. “Restoring the
950 person’s life’: a qualitative study to inform development of care for people with
951 severe mental disorders in rural Ethiopia. *Epidemiol Psychiatr Sci* [Internet].
952 2017;26:43–52. Available from:
953 [https://www.cambridge.org/core/product/identifier/S2045796015001006/type/j](https://www.cambridge.org/core/product/identifier/S2045796015001006/type/journal_article)
954 [ournal_article](https://www.cambridge.org/core/product/identifier/S2045796015001006/type/journal_article)
- 955 75. United Nations. Convention on the rights of persons with disabilities. *Treaty Ser*
956 [Internet]. 2006;2515:3. Available from: <http://www.un.org/disabilities/>
- 957 76. Williams J, Leamy M, Bird V, Le Boutillier C, Norton S, Pesola F, et al.
958 Development and evaluation of the INSPIRE measure of staff support for personal
959 recovery. *Soc Psychiatry Psychiatr Epidemiol*. 2015;50:777–86.
- 960 77. Kohrt BA, Jordans MJD, Rai S, Shrestha P, Luitel NP, Ramaiya MK, et al. Therapist
961 competence in global mental health: Development of the ENhancing Assessment of
962 Common Therapeutic factors (ENACT) rating scale. *Behav Res Ther*. 2015;69:11–21.
- 963 78. Abayneh S, Lempp H, Alem A, Alemayehu D, Eshetu T, Lund C, et al. Service user
964 involvement in mental health system strengthening in a rural African setting:

965 qualitative study. BMC Psychiatry. 2017;17:187.

966 79. Semrau M, Alem A, Abdulmalik J, Docrat S, Evans-Lacko S, Gureje O, et al.
967 Developing capacity-building activities for mental health system strengthening in
968 low- and middle-income countries for service users and caregivers, service
969 planners, and researchers. Epidemiol Psychiatr Sci. 2018;27:11–21.

970 80. Lempp H, Abayneh S, Gurung D, Kola L, Abdulmalik J, Evans-Lacko S, et al.
971 Service user and caregiver involvement in mental health system strengthening in
972 low- and middle-income countries: A cross-country qualitative study. Epidemiol
973 Psychiatr Sci. 2018;27:29–39.

974