

Stakeholder perspectives on an integrated package of care for lower limb disorders caused by podoconiosis, lymphatic filariasis or leprosy: a qualitative study

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1 Stakeholder perspectives on an
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3 limb disorders caused by podoconiosis,
4 lymphatic filariasis or leprosy: a
5 qualitative study

6 Bethany Davies^{1,*}, Mersha Kinfel², Oumer Ali^{1,2}, Asrat Mengiste², Abraham Tesfaye², Mossie Tamiru
7 Wondimeneh³, Gail Davey^{1,4}, Maya Semrau^{1,*} and EnDPoINT Research Team and Consortium^{1,2,4}

8 ¹Centre for Global Health Research, Brighton and Sussex Medical School, Brighton, UK

9 ²Center for Innovative Drug Development and Therapeutic Trials for Africa (CDT-Africa), Addis Ababa
10 University, Addis Ababa, Ethiopia

11 ³Ministry of Health, Addis Ababa, Ethiopia

12 ⁴School of Public Health, Addis Ababa University, Addis Ababa, Ethiopia

13 Membership of EnDPoINT Research Team and Consortium is provided in the acknowledgments

14 *b.davies@bsms.ac.uk (BD), *m.semrau@bsms.ac.uk (MS)

15

Abstract

Background Lower limb disorders including lymphoedema create a huge burden for affected persons in their physical and mental health, as well as socioeconomic and psychosocial consequences for them, their families and communities. As routine health services for the integrated management and prevention of lower limb disorders are still lacking, the 'Excellence in Disability Prevention Integrated across Neglected Tropical Diseases' (EnDPoINT) study was implemented to assess the development and delivery of an integrated package of holistic care – including physical health, mental health and psychosocial care – within routine health services for persons with lower limb disorders caused by podoconiosis, lymphatic filariasis and leprosy.

Methodology/Principal Findings This study was part of the first of three phases within EnDPoINT, involving the development of the integrated care package. Focus group discussions and key informant interviews were undertaken with 34 participants between January – February 2019 in Awi zone, Ethiopia, in order to assess the draft care package's feasibility, acceptability and appropriateness.

Persons affected by lower limb disorders such as lymphoedema experience stigma, exclusion from families, communities and work as well as physical and financial hardship. Beliefs in disease causation inhibit affected persons from accessing care. Ignorance was a barrier for health care providers as well as affected persons. Training and education of affected persons, communities and caregivers is important in improving care access. It also requires time, space, materials and financial resources. Both top-down and grass roots input into service development are key, as well as collaboration across stakeholders including charities, community leaders and "expert patients".

Conclusions/Significance This study highlighted the need for the EnDPoINT integrated care package and provided suggestions for solutions according to its three aspects of integrated care (integration into routine care; integration of mental health and psychosocial care; and integration of care across the three diseases), thereby giving support for its feasibility, acceptability and appropriateness.

41 Author Summary

42 Lower limb disorders including lymphoedema are prevalent in Ethiopia as a common endpoint of varying
43 causes such as podoconiosis, leprosy and lymphatic filariasis. This study involved the development of a
44 comprehensive integrated and holistic care package for lower limb disorders into routine health care
45 services. It used interviews and focus groups to assess feasibility, acceptability and appropriateness of the
46 draft care package. We found that persons affected by lower limb disorders had many negative
47 experiences due to their condition, especially related to stigma, that included physical, financial and
48 psychological sequelae. Neglect was paramount, with financial neglect in central budgets, a lack of
49 knowledge by care givers and a lack of awareness among affected persons and their communities, all
50 contributing to inadequate care provision and access. Affected persons, communities and caregivers may
51 benefit from provision of learning opportunities about the prevention and treatment of lower limb
52 disorders; and resources are crucial in engendering change, including material goods, time to provide care,
53 and collaborative work to create a culture shift and address stigma.

54 Introduction

55 Lower limb disorders including lymphoedema, resulting from neglected tropical diseases (NTDs) such as
56 lymphatic filariasis (LF), podoconiosis and leprosy, are a substantial problem carried disproportionately by
57 a few highly endemic countries, such as Ethiopia [1]. LF is caused by chronic parasitic infection, leprosy by
58 mycobacterial infection and podoconiosis results from the long-term exposure of bare feet to irritant
59 mineral particles in red clay soil of volcanic origin [2]. Lymphoedema occurs when the lymphatic system
60 sustains damage with impaired drainage of lymphatic fluid. Accumulation of lymphatic fluid in the affected
61 limb causes a chronic progressive swelling. Over time, there is fibrosis and thickening of the subcutaneous
62 tissues. This may be disfiguring, painful and there is a risk of recurrent infections due to the stagnant
63 interstitial fluid [3]. Many of the care needs for established limb lymphoedema are the same regardless of
64 aetiology – for example, a self-care routine, foot hygiene, skin care with emollients, wound care,
65 appropriate footwear and management of acute flares or superadded infections [4].

66 Globally, it is estimated that there are nearly 15 million cases of LF with lower limb lymphoedema [5], at
67 least 3 million of podoconiosis [6] and just over 200,000 new leprosy cases annually [7]. However, the
68 prevalence and the predominant aetiological cause vary widely dependent on locality. Ethiopia is
69 comprised of diverse topographical areas with climatically different conditions. Its population is over 93
70 million, 79% of whom live in rural areas (world bank) [8]. A disproportionate number of its population
71 suffers from lymphoedema. Mapping by Deribe et al in Ethiopia in 2015 found that 6.2% of their study
72 population of 129,959 individuals across the country were living with lymphoedema [9]. In contrast to the
73 relative proportion globally, podoconiosis is responsible for over 60% of lymphoedema cases in Ethiopia.
74 However, there is also significant geographical variation within Ethiopia itself, as prevalence varies
75 between health districts from zero to 8.6% [9]. Three hundred and forty-five (of 839) *woredas* are
76 endemic for podoconiosis; 112 for LF; and of these, 53 are co-endemic for podoconiosis and LF [6].

77 The World Health Organisation (WHO) launched the Global Programme to Eliminate Lymphatic Filariasis in
78 2000, with a 2011 position statement on morbidity management and disability prevention (MMDP) [10].
79 This recognized that, in addition to the interruption of disease transmission, the management of morbidity
80 and prevention of disability is a core component of care. To improve quality of life and alleviate suffering,
81 WHO recommends a basic package of care for affected persons, including ongoing access to continuing
82 care and support. Although the position statement urges members to consider a combined approach with
83 other disease-specific programmes tackling similar chronic disease, the toolkit focuses on LF rather than
84 lower limb disorders more generally. This is problematic in an area where LF is only one of several
85 possible aetiologies. In areas where LF, leprosy and podoconiosis are all endemic such as in many parts of
86 Ethiopia, differentiating between causation is not straightforward and so a care package that incorporates
87 all three NTDs may be more useful.

88 Ethiopia has had foot care for people affected by leprosy embedded into routine care since 2001, but
89 services for podoconiosis or LF related disease are fragmented and only patchily provided by external
90 contributors [6]. In contrast, the Ethiopian Federal Ministry of Health (FMOH) developed integrated
91 guidelines for MMDP related to podoconiosis and LF. However, these omit leprosy, and neglect any
92 mental health or psychosocial care. Recognizing that there can be overlaps between the two terms, here
93 we take mental health care to mean services that aim to improve a person's psychological or emotional

94 wellbeing, for instance interventions aiming to reduce depression or anxiety; we take psychosocial care to
95 mean interventions that explicitly take into account interrelating social and individual factors – stigma
96 reduction interventions could be an example of this. Realizing the opportunities afforded by integration
97 (i.e. integration, 1) across diseases; 2) into routine health care; and 3) incorporating mental health and
98 psychosocial interventions), the Ethiopian FMOH has identified podoconiosis and LF as priority NTDs and
99 included them in the first two National NTD Master Plans (2013-15 & 2016-20) and within the Health
100 Sector Transformation Plan (HTSP) 2015/2016–2019/2020. These are moving away from disease-specific
101 vertical programmes (as are currently implemented as part of the national health structure, and which
102 have fallen out of favour to a degree due to their lack of integration, lack of efficacy and potential for
103 harm) [11] and towards cross-cutting interventions integrated with non-NTD programmes.

104 The current healthcare system in Ethiopia consists of a mixture of public, private and nongovernmental
105 organisations. The public health strategy is for fair access to health services for all, with a tiered structure
106 of service provision, from specialised hospitals (regional/general hospitals and primary/district hospitals),
107 through to primary health care units (health centres with satellite health posts). The health service
108 extension programme was introduced in 2003 to bring “high-impact primary care and community-based”
109 healthcare into households, especially in rural areas, countering the previous imbalance and neglect [12].
110 Before the reforms, Ethiopia was not only in the lowest quintile of African nations for healthcare workers
111 (HCW) per population, but these were unevenly distributed in terms of number and skills, with major gaps
112 in essential services in rural areas, which carry the greatest burden of lymphoedema and its consequences
113 [12].

114 The study is part of Phase 1 of the ‘Excellence in Disability Prevention Integrated across NTDs’ (EnDPoINT)
115 implementation research study, whose overall aim was to develop and implement an integrated,
116 comprehensive and holistic care package – including physical health, mental health and psychosocial care
117 – for lower limb disorders across the three diseases into routine health services in Awi zone in North-West
118 Ethiopia. This particular study aimed to explore the perspectives of a range of stakeholders to harness
119 their views on the feasibility, acceptability and appropriateness of such integrated care. For the purposes
120 of this study: feasibility is conceptualized as the capability for successful completion of the project;

121 acceptability, as pre-intervention prospective treatment acceptability [13]; and appropriateness, the
122 suitability of the project for the needs identified.

123

124 **Methods**

125 **Ethics statement**

126 Ethical approval was obtained from the Brighton and Sussex Medical School Research Governance and
127 Ethics Committee, UK (ref. ER/BSMS9D79/1) and the Institutional Review Board of the College of Health
128 Sciences at Addis Ababa University, Ethiopia (ref. 061/18/CDT). All participants were given a participant
129 information sheet (PIS) in Amharic and were required to give written informed consent before taking part,
130 if literacy allowed. If they were unable to read the PIS or sign the consent form due to illiteracy, then the
131 form was read out, and they were asked to give witnessed oral consent. Participants were able to
132 withdraw from the study at any time without detriment or reason up until the point at which data had
133 been aggregated. In the event that any participant was deemed to need immediate assistance or support,
134 for instance because they disclosed mental distress, appropriate action was established according to local
135 resources and capacities.

136 **Study setting**

137 The EnDPoINT study was conducted in three districts (of 12) in Awi zone, Amhara Region, north-west
138 Ethiopia. The Awi zone in the central highlands of Amhara has the red clay soil, seasonal rainfall and
139 altitude that are necessary for the development of podoconiosis,[14] and 87.5% of its population live
140 rurally [15]. The EnDPoINT research team together with the Ethiopian FMOH selected the particular
141 districts for the study based on a combination of their accessibility, previous or ongoing work in the area
142 and their co-endemicity of podoconiosis, LF and leprosy. The pilot study was conducted in Guagusa
143 Shikudad *woreda* (district).

144 Study design

145 This study was guided by both the Medical Research Council (MRC) framework for complex interventions
146 and the Context and Implementation of Complex Interventions (CICI) framework [16,17], building through
147 three phases with an iterative approach, and with “Theory of Change” embedded for the development
148 and feasibility/piloting phases [18]. Further details on these frameworks and how the EnDPoINT project
149 maps onto them are provided elsewhere [19].

150 Phase 1 of EnDPoINT, which this study was part of, entailed a number of research activities to inform the
151 development of the holistic care package. This care package was based on an established MMDP (physical)
152 self-care package for podoconiosis and LF, but building in mental health and psychosocial components,
153 and including leprosy care for lower limb disorders. This paper reports on one element of these Phase 1
154 activities: key informant interviews and focus group discussions with stakeholders. These were intended
155 to assess feasibility, acceptability and appropriateness of the draft care package as viewed by the
156 stakeholders, as well as assessing key aspects of the Theory of Change, such as assumptions made, for
157 example the willingness and availability of key stakeholders to participate in and engage with the various
158 care package interventions.

159 Three focus group discussions (FGD) and 11 individual key informant interviews (KII) were conducted in
160 January and February 2019 by researchers MK, OA and AM, involving 34 participants in total (25 male and
161 9 female). Three participant groups were recruited: regional health office NTD staff, staff members at
162 Injibara hospital working on NTDs, and community members including affected persons. Purposive
163 sampling with snowballing was used to identify and recruit key stakeholders based on their role/position
164 in the community; the sample size was guided by the number of key stakeholders who were identified to
165 take part and available, as per the original study protocol [19]. Participants had to be at least 18 years of
166 age.

167 Each of the three focus groups were separated according to a different stakeholder group, as follows: 1)
168 community representatives (*kebele* administrators, religious leaders, affected persons, health extension
169 workers); 2) health professionals (nurses, health officers, general practitioners and specialists); and 3)
170 decision-makers (NTD focal, NTD officer, TB-Leprosy officer, programme managers). There were three

171 affected persons (two female and one male) in the community representative groups. The sample size
172 during focus groups was limited to ensure that all participants have the opportunity to speak.

173 The KIIs included participants from the FMOH (officers for leprosy and podoconiosis), staff members from
174 International Orthodox Christian Charities (IOCC), a dermatologist from Felegehiwot hospital, and several
175 focal team members from Awi zone (NTD focal, leprosy focal, mental health focal), staff from the Guagusa
176 Shikudad health office, the head and vice head of the *woreda* office, as well as the *woreda* NTD focal
177 person.

178 Open-ended questions with follow-up clarification and further enquiry were used [see S1 Text for the
179 topic guide]. Questions were based around participants' experiences regarding affected persons with
180 lower limb disorders secondary to podoconiosis, LF or leprosy. All participants were encouraged to
181 contribute and be heard; the discussion facilitators set ground rules for behaviour to support participants
182 to feel safe; they also actively tried to include all participants in the discussion and to make the
183 participants feel their contribution was welcome and worthwhile. Those participants who were not highly
184 verbal were encouraged to share their views. The interviews and focus groups were conducted in
185 Amharic, audio recorded, transcribed and checked for accuracy. Unique identifying numbers were
186 assigned during transcription, and names of specific people removed if mentioned. A meaning-based
187 translation of transcripts into English was made before coding.

188 Data analysis

189 Data were thematically analysed using a combination of manual coding and nVivo software. Two
190 researchers (BD and MK) independently reviewed the data from the focus groups and the first few
191 interviews initially, ensuring detailed knowledge before using within-case analysis, close text analysis and
192 cross-case analysis to develop initial themes. These were then compared and integrated to form a coding
193 framework which was then applied to the remainder of the data. Examples of disconfirming evidence
194 were also sought, as well as comparing responses about different stakeholders. Data collection continued
195 until no new themes emerged.

196 Confidentiality and anonymity of data were ensured by using allocated identifiers instead of names, and
 197 with identifying data kept separately. Data were fully anonymized before data analysis. Data were stored
 198 in a secure OneDrive folder with access limited to members of the study team for whom it was essential.

199 Quotations below are identified as follows: Key informant interviews were labelled K1 – K11 in
 200 chronological order of their interviews; focus group participants are identified by the focus group
 201 attended and their allocated number at the start of the session. For example, [P2, FG3] was participant
 202 number two in the third focus group.

203 Results

204 In total, 34 adults between 24 and 52 years of age participated in focus groups and individual interviews.
 205 The majority of the participants were male (74%).

206 Overall, the focus group discussions and key informant interviews highlighted the need for the EnDPoINT
 207 integrated care package and provided suggestions for how it might provide solutions according to its three
 208 aspects of integrated care (integration into routine care; integration of mental health and psychosocial
 209 care; and integration of care across the three diseases), thereby giving support for its feasibility,
 210 acceptability and appropriateness. Table 1 and Fig 1 summarise the main themes and subthemes
 211 identified.

212 **Table 1: Themes and sub-themes identified through qualitative analyses of focus group discussions**
 213 **(FGDs) and key informant interviews (KIIs)**

High level themes	Sub-themes	
Establishing a need for the new integrated care package	The disease burden in the community and its consequences	The size of the problem: the large number of persons affected with lower limb disorders, as well as a need to identify those affected
		The financial consequences on affected persons and their dependents

		The physical burden of disease on an individual: mobility, smell, swelling
		The psychosocial effects of disease: stigma – affected persons, families, community and healthcare providers; effects on intimate relationships, immediate family and exclusion from key social events
	Current and anticipated challenges and barriers to care	Distance as a problem: the geographical spread of disease and affected persons
		Knowledge deficit: a lack of knowledge among healthcare workers, affected persons and community, inhibiting care and leading to stigma.
		Causation beliefs: religious, contagious, hereditary
	Neglect: lack of treatment provision in current model of care, including space, budget, time to provide care and staff turnover	
Solutions		
Integration into routine care	Training needs	Community and affected persons: expert patients, demonstrable change, what constitutes care
		Healthcare workers
	Material matters	Sourcing and funding material goods: shoes including fit, clean water, perception of materials
	Space matters	Separate room to provide care: prioritizing to enhance engagement, stigma between clinic patients
	Time as a resource	Long consultations

	Who contributes	Cascade of care, external organizations, patient associations, community leaders, self-care: collaborative approach, top down or bottom up
Integration of mental health and psychosocial care		
Integration of care across the diseases		

214

215 Fig 1. Themes and sub-themes identified through qualitative analyses of focus group discussions (FGDs)

216 and key informant interviews (KIIs)

217 Establishing a need for the new integrated care package

218 Disease burden and its consequences

219 The **magnitude of the problem** in the study districts due to the numbers of affected individuals with lower
220 limb disorders was described:

221 *“It was one [] disease that the community is suffering a lot with”* (FG1, P2, 59-year-old male
222 community representative)

223 *“We have treated fifty thousand, it is entered in the data base, and the Ministry of Health also knows
224 about this [...], there are these many people but we only addressed about fifteen and sixteen
225 woredas.”* (K4)

226 Even then, these numbers did not reflect the true extent of disease burden, due to cases that had not yet
227 been identified or brought into services.

228 *“There are so many people... more than 500 people have come to get the service. And there are also
229 people with the problem who didn’t come to the health facility yet.”* (K8).

230 Participants described the **consequences borne by individuals and families** as a result of living with
231 lymphoedema in Ethiopia, *“having this problem and living in sorrow”* (FG1, P1, 48-year-old female
232 community representative).

233 Three main categories were offered: **physical, psychosocial and financial:**

234 *“Physical impairment brings social impact that leads to psychological impairment”* (FG3, P2, 37-year-
235 old male decision-maker).

236 The predominant **physical burden** resulted from **limb swelling restricting mobility**:

237 *“...they cannot wear a shoe and walk freely because of the swollen limb/leg. Even the size of the shoes*
238 *didn’t fit their leg. They are suffering a lot because of this.”* (FG1, P5, 52-year-old male community
239 representative).

240 For many there was an additional burden attributed to an **offensive smell**:

241 *“People didn’t consider them even as a human being and make them sit away from the gathering*
242 *because they think they have a bad smell.”* (FG1, P2, 59-year-old male community representative).

243 Participants reported that affected persons **struggle financially** as a result of their limb disorders. Physical
244 impairment limits their ability to work as they had formerly: *“There is a high chance, because of their*
245 *disability, that they face economic problems and go out to the streets to beg.”* (K3). Farmers especially
246 were disadvantaged as the work predisposes to disease, and disease prevents physical work such as
247 farming: *“The disease itself banned them from their farm”* (K4). There was also the indirect contribution of
248 stigma and discrimination: *“Some of them can’t even work because of the severe injury or because of the*
249 *social stigma”* (K11). In addition to the financial difficulties resulting from the effects of disease on the
250 ability to work and earn, the conditions themselves incurred additional costs:

251 *“Health insurance, that small amount of 200 [roughly US\$5], there were those who were not able to*
252 *pay that amount; the reason is the disease itself”* (K4)

253 Participants reported **stigma** in all aspects of an affected person’s life:

254 *“Due to their degree of disability, they feel ashamed/ embarrassed and such feelings to eat with other*
255 *people, to get medical record and proper treatment, to express their views in the proper way like any*
256 *other person.”* (K3).

257 This is enacted by themselves, their families, their communities and the health professionals providing
258 their care:

259 *“The stigma comes from different angles, including first from health care providers, second caregivers*
260 *including family and community and also it’s observed that the patients stigmatize themselves.”* (FG3,
261 P2, 37-year-old male decision-maker)

262 Participants described how affected persons felt “ashamed”, stay “hidden” and “isolate” themselves, and
263 of a “feeling of inferiority”. **Close personal relations** were affected, with disease leading to divorce or
264 preventing marriage in the first place: *“We found divorced husband and wives because of the diseases”*
265 (K4). They were excluded from **key social events**, such as weddings, funerals and other religious services:
266 *“They can’t go anywhere, even to express their condolences at the mourning ceremonies.”* (FG1, P2, 59-
267 year-old male community representative). Communities contribute to the discrimination and isolation of
268 individuals: *“Most of the time they get social rejection from the community and from their neighbours. This*
269 *made them psychologically tortured.”* (K11). This impacted not only on the affected person themselves,
270 but also on their **dependents**: *“Finally, these kids start to decrease with their grades because of the social*
271 *stigma.”* (FG2, P8, 38-year-old male health professional). Stigma also negatively affected physical health
272 in addition to mental health, with individuals reportedly not engaging with healthcare due to the stigma
273 and shame that they felt: *“Most patients coming to health institutions for services raised stigma as main*
274 *reason for not seeking health care.”* (FG3, P3, 39-year-old male decision-maker).

275 Challenges and barriers to care

276 **Distance as a problem:** the physical size of the country and the current infrastructure (both in transport
277 and within healthcare) was recognised as potentially problematic,

278 *“We must think about reaching the community for treatment because as you see it is a big country.”*
279 (FG2, P6, 34-year-old male health professional);

280 *“it is difficult for health professionals to reach them.”* (FG3, P7, 49-year-old male decision-maker).

281 The spatial distribution of affected persons across large geographical areas was noted to be especially
282 difficult (although not insurmountable) for those with lower limb disorders for whom mobility may be
283 restricted, painful or even harmful:

284 *"It is not common to treat these chronic cases or such cases at hospital or centralized hospital or*
285 *referral hospital, for those cases a long journey is not appropriate - to move that long way that may*
286 *cause some harm to them."* (FG3, P7, 49-year-old male decision-maker).

287

288 **Knowledge deficit:** A lack of knowledge or awareness around lower limb disorders was reported by a wide
289 range of participants, including affected persons, families, communities, care managers and caregivers.

290 There was widespread misunderstanding of the **underlying causes of the disease process** among affected
291 persons, their families and wider society. Not only was a lack of knowledge noted, *"There is still a*
292 *knowledge gap in the community about the causes of the disease and the ways of disease transmission."*

293 (K5); but beliefs ascribing causation to religious, contagious or social practices were reported to be widely
294 held which actively hindered the engagement of affected persons and their families with medical care:

295 *"They believe only God can heal them but no other treatment...If they go to the health facilities, they*
296 *could get better but they don't believe. They think it is given by God and cannot be treated in the*
297 *health facility."* (FG1, P3, 36-year-old female community representative);

298 *"Traditionally, the community assumes the disease is hereditary or a curse from God. This hinders*
299 *them from treatment in the health facilities."* (K1)

300 *"The main challenge in the community is the perception of people to the disease itself. They perceived*
301 *it as a curse from God and not a treat[able] disease."* (K9);

302 *"They only think it is because of their genes and did not think of getting better through treatment."*
303 (FG1, P2, 59-year-old male community representative)

304 **Neglect:** These diseases were also neglected within all levels of the health care system:

305 *"It is a very important issue but no attention was given before."* (K8);

306 *"In the meetings we hold, they say they are forgotten by the government and are denied attention,*
307 *these issues are raised a lot [...] it is also a problem I witnessed in practice."* (K3)

308 This lack of attention or awareness manifested for affected persons as **a lack of adequate healthcare**

309 **provision**, *"There was no treatment for the disease neither in the health facilities nor in the health centre*

310 *until now.*" (FG1, P5 52-year-old male community representative) Healthcare workers were insufficiently
311 aware or trained to deal with such cases, *"People with podoconiosis might come to the OPD [outpatient*
312 *department] but the health workers didn't give attention for it, they would rather assess and treat other*
313 *cases and let the patient go by completely ignoring the podoconiosis."* (K7). If staff were trained, then
314 **turnover** was frequently cited as a problem: *"The other challenge is staff turnover. Those who have*
315 *already trained and who have the skill to provide the service also leave the health facility and go to other*
316 *places. So, this is a major problem."* (K5) This appeared to be a widespread problem across the
317 participants' areas of work. One participant ascribed it to a low salary, but the majority did not expound
318 on the reasons for this turnover, nor on ways to address it, rather on its consequences alone:

319 *"He or she may be the only professional person in that place. So, once he or she transfers, it causes a*
320 *problem."* (FG3, P4, 38-year-old male decision-maker)

321 It was also difficult to establish **space to provide care** for those who were keen to do so:

322 *"When we started work at the beginning around 2010, even in Amhara region, health centres were*
323 *not happy to give us a working place."* (K4)

324 The lack of attention within the health system also featured within **budget planning** and financial
325 resources. Participants involved in health centre services reported struggling with limited financial
326 resources to maintain adequate supplies and carers:

327 *"There are so many things which we don't achieve from our plans because [...] there is no finance."*
328 (K3)

329 **Solutions: Integration into routine care**

330 **Training needs**

331 Engaging people with greater understanding and awareness of the diseases through training and
332 education was felt to be essential.

333 *"The next thing is to change the old perception of the health professionals at the health centre level*
334 *and to give treatment. In addition to this the religious leaders, the health extension workers and those*
335 *influential community leaders need to teach the society so the community accept these people."* (K1)

336 A culture shift was described as a key goal, both within the community and in healthcare services,
337 *“Changing the mind of the society is what needs to be done.”* (P2, FG1). Participants for the most part
338 thought that there would be a willingness to engage with such an agenda rather than “resistance”, *“I also*
339 *believe the community is willing too”* (FG2, P2, 59-year-old male community representative).

340 Raising awareness was thought to be of benefit through enhanced care-seeking and improved self-care,
341 *“If we teach the community changes can happen.”* (K1) **Affected persons** would be more likely to seek
342 care once they were aware that there are services and effective treatment available: *“By giving*
343 *community awareness to go to health institutions and believe [they can] be cured and that the*
344 *management works.”* (FG3, P3, 39-year-old male decision-maker). Once affected persons had been
345 registered and engaged with available services, they would also benefit from understanding more about
346 their underlying disease process, why self-care measures are important and how to manage self-care:
347 *“They need to know what causes the problem, how to prevent it and how to treat it. If we can teach them*
348 *that they can get back to their previous health condition, I think they can get rid of the problem.”* (K8). A
349 wider knowledge of causation and prevention measures was also thought to be required: *“When we talk*
350 *about control and management of these diseases, the first thing we need to focus on is on the prevention.*
351 *Because prevention is better way of management.”* (FG2, P5, 30-year-old male health professional).

352 Snowballing of awareness as it may be shared onwards was recognised to have beneficial effects: *“if the*
353 *community understand it clearly, they will also teach others.”* (FG3, P1, 32-year-old male decision-maker)

354 Many participants reported that **“expert patients”** (i.e. individuals who themselves had previously been
355 successfully treated for lower limb disorders) would be an invaluable source of teaching and information
356 for new or current patients. They recognised that such people may have a better appreciation and
357 understanding of the problems encountered in living with these conditions. This allows a better shared
358 understanding with affected persons still learning about their condition: *“Use people who were cured as a*
359 *result of your project. They can teach the before and after changes and this may help others to understand*
360 *the treatment mechanism in a better way.”* (K4). They would also act as positive role models, advocating
361 the gains and positive outcomes of treatment, *“To bring others, those with good management outcome*
362 *works by giving their testimony at some Woredas”* (FG3, P3, 39-year-old male decision-maker)

363 Some participants felt that there would be better understanding and uptake of measures across groups if
364 they were able to see a **demonstrable change**. As with the expert patients, the reinforcement for both
365 healthcare workers and affected persons in being able to see a positive outcome at first hand was thought
366 to have a more powerful effect on their engagement with the program.

367 *“The community cannot accept it only because they are told. However, with the awareness we create,*
368 *if we involve them in jobs and when they can become independent and change their lives, that is when*
369 *we can make the community believe and accept it.” (K3).*

370 Equally, there were concerns that an absence of any demonstrable effect could be detrimental. Along
371 similar lines, healthcare workers identified that patient perceptions of **what constitutes care** may impede
372 their engagement. The simplicity of the tools and the actions needed for successful care, such as washing
373 their leg, and wearing shoes meant that patients may not accept that that was all that was required,

374 *“They expect injection and when you tell them that washing is the method that we use to treat their*
375 *disease, they will not accept it.” (K4).*

376 Shifting that mindset was an important part of engaging people with their treatment, *“we have to*
377 *convince them that it is medical treatment.” (FG3, P1, 32-year-old male decision-maker)*

378 A lack of good working knowledge among healthcare workers also needed to be addressed to enable
379 quality care to be delivered. **Training of the healthcare workers** was repeatedly brought up as an
380 absolute necessity,

381 *“Because one’s knowledge won’t be enough unless someone else with better knowledge trains. That*
382 *way I could get to work easily. But if there is no one to train me, I would be useless.” (FG2, P2, 48-year-*
383 *old male health professional)*

384 **Health extension workers** were identified as having a key role in disseminating awareness at a community
385 level, identifying cases and engaging them with care: *“if we can capacitate the health care providers and if*
386 *we can create awareness up to the level of health extension workers, there will be increased health seeking*
387 *behaviour among people who are affected by these problems.” (K6).* They reported making efforts to
388 identify all cases within their care remit, both to establish the true extent of disease burden as well as to

389 ensure individual patients were encouraged and supported to engage in care: *“The need of the patients*
390 *comes next after seeing how many they are in number.”* (K11)

391 **Material matters**

392 Participants were clear about **essential material resources** and their conspicuous absence in the delivery
393 of care to people with lower limb disorders. Shoes, medicines, and moisturisers were most commonly
394 identified, *“The most important thing for these three diseases is pair of shoes.”* (K10). **Clean water** was
395 also raised as a key rate-limiting step for delivering care: *“If you say to them to wash at home and if you*
396 *ask them the availability of clean water, most of the times their response is clean water is not there.”* (K4).
397 The current situation in obtaining material goods to provide care, including the funding needed as well as
398 secure supply chains was thought inadequate. **Shoes** in particular were a cause for concern. The main
399 issues arising were where appropriate footwear could be sourced (in addition to who would cover the
400 costs), and of the additional difficulties posed by the need for shoes to actually fit – one size does not fit
401 all:

402 *“Lack of shoes, so this is a common problem everywhere. Because of their unique size and shape, there*
403 *is a shortage of access for shoes for Podo, LF and Leprosy patients.”* (FG3, P4, 38-year-old male
404 decision-maker)

405 As well as the material goods themselves, a change in affected persons’ approach to the items was seen to
406 be important, **shifting their perception** from this being an everyday item, **to considering it as a treatment**.
407 Achieving this would support affected persons in procuring and safeguarding these resources themselves:

408 *“The soap and the basin, there is a tendency to use these materials for something else. When you give*
409 *them these supplies, you have to tell them not to use the materials for other purposes and you should*
410 *tell them to consider these supplies as medication”* (K4)

411 **Space matters**

412 **Space and place** were recognised as being an important component of care. An increase in the number of
413 affected persons receiving care necessitates an expansion in the spaces available to deliver that care.
414 However, this did not seem to be an obstacle that concerned participants: *“There is no problem regarding*

415 *the room;*" (K2). Providing care in the affected person's own home was a helpful factor in this regard,
416 *"They did this in their house so for working place we didn't expect to have that much challenge."* (K2)

417 Participants were also keen that services at the treatment centres should be separated out from
418 mainstream care, *"If we are integrating these three cases together then we need to assign a specific room*
419 *for a better work."* (FG2, P5, 30-year-old male health professional). They predicted that with the burden
420 already carried by these individuals, they may be more likely to engage with care and to have a more
421 positive experience with separate care facilities.

422 *"I thought there will be discomfort among patients if they assigned in a same [general] OPD. These*
423 *patients may feel ashamed even when they sit together with other patients. So in my opinion it is*
424 *better for them to have a different treatment room."* (FG1, P4, 46-year-old female community
425 representative)

426 *"It helps them to discuss their problems freely with the health care givers which could give them some*
427 *relief."* (FG1, P5, 52-year-old male community representative)

428 A **separate facility** with trained staff could provide benefits in affected persons being prioritised both
429 physically and psychologically.

430 *"It is good to give them priority and a chance to get the treatment first."* (FG1, P5, 52-year-old male
431 community representative)

432 *"There is a heavy patient flow in the health centre as you all know. If we make these people wait for*
433 *the service as others do in OPD, sometimes they might not get the care they want and go back to their*
434 *homes. Because of the long list of cards for a day in our health centre, there are some patients who*
435 *could not get treatment service. If these people are left to sit and wait for the line in OPD they might*
436 *not come back again. So like the ART [HIV service] clinic clients must get the service they needed any*
437 *time they came and every person knows from where to get the treatment he needed. They won't get*
438 *frustrated and the service is active. They are properly treated."* (FG1, P4, 46-year-old female
439 community representative)

440 Time as a resource

441 These are complex conditions and even with training, consultations may not be straightforward or quick:

442 *“In the others case you will sit in your outpatient department and treat your patient. You have a*
443 *prescription and you ask your patient what his illness is, whether it is his foot and then you just write*
444 *for him and tell him to go and buy the medication, but in the cases of these diseases it is not*
445 *something like that. You might be expected to sit down and demonstrate on how to wash their leg. [...]*
446 *you won’t just write down and say the patient, go: you put a basin and with water wash your leg and*
447 *then you do it at home and use Vaseline and do like this and then put on a shoe. If you say the patient*
448 *to do in this way and if you write it down and give him, he won’t do it.” (K4)*

449 **Time to provide appropriate care** was also a concern for an already busy care team,

450 *“The main concern providers raised during the training was that they have no time and are busy with*
451 *other competing priorities.” (FG3, P3, 39-year-old male decision-maker).*

452 Improving care for people living with lower limb disorders was seen to need more personnel with the
453 corresponding time to provide care once trained: *“The biggest struggle in the first place is human*
454 *resource.” (K1).* However, others disagreed and were more confident that this would not be a barrier: *“In*
455 *regard to the manpower also we don’t have a problem.” (K9)*

456 Who contributes to care

457 The governmental health system is central to care delivery, with its tiered structure facilitating **cascades of**
458 **care**, *“we want them to be addressed by the available structure of the health system.” (K6).* This allows
459 access up towards increasingly specialised services:

460 *“The trained professionals work in areas where cases are presented. If they find any case that is*
461 *beyond their and the health centre’s capacity, they immediately refer the cases to the hospital*
462 *because there are more professionals with advanced material for treatment and good knowledge.”*
463 *(K11)*

464 and out to wide-reaching disseminated local care. This was thought to allow for the greatest number of
465 affected persons to be reached, while maintaining access to specialist care when needed.

466 *“When we implement it directly by ourselves, we couldn’t cover large areas but when we change our*
467 *strategy and gave the responsibility to the health centres after we gave them appropriate training, we*
468 *could cover very large areas.”* (K4)

469 Participants felt that a **top-down approach** to initiate and embed widespread change is necessary: *“I think*
470 *direction should be given at a national level”* (K7); *“I believe that the ministers’ attention for the program is*
471 *a major input to control and eliminate these diseases on the anticipated period of time.”* (K6). Additionally,
472 they felt there was benefit to feeding in the experience and knowledge of those actually receiving and
473 delivering care to improve services: *“The ones who are more knowledgeable about the program are the*
474 *experts who are implementing the program. Because, they know how the program can benefit the*
475 *community, how to address the community and how the program can be strengthened.”* (K5)

476 **“Collaboration”** between stakeholders allows for better outcomes – heightened awareness, sharing of
477 resources and sustainability of services: *“For the sake of the community, the zonal health department, the*
478 *regional health bureau and the woreda health office should work in collaboration.”* (K1)

479 Other **external organisations** are essential contributors to initiating, establishing and sustaining a
480 successful program for improved healthcare services for people with lower limb disorders. In addition to
481 raising awareness and instigating change, partner organisations provide training to carers and affected
482 persons: *“The IOCC in collaboration with the Health Bureau are providing training.”* (FG3, P2, 37-year-old
483 male decision-maker); as well as material resources: *“the first thing the Carter Centre did was giving MDA*
484 *[mass drug administration] for lymphatic filariasis.”* (K1).

485 **Religious and community leaders** work to raise awareness and are seen as being “influential” within
486 society: *“Even at the grass roots level, influential peoples like leaders, religious leader’s engagement would*
487 *be the best way to bring change at community level.”* (K9). They share information on prevention and
488 treatment, *“We religious leaders were also teaching and counselling them to take medical treatment and*
489 *to wear shoes.”* (FG1, P2, 59-year-old male community representative), as well as work towards shifting
490 attitudes towards acceptance and away from stigma: *“The religious leader, the health extension workers*
491 *and those influential community leaders need to teach the society so that the community give acceptance*
492 *for these people.”* (K1)

493 **Patient associations** are not regarded so universally as positive. There is an advocacy role, *“it will help*
494 *their voice [be] heard and protect their rights”* (FG3, P1, 32-year-old male decision-maker), and more
495 directly for affected persons, helping them to establish links with healthcare services as well as with other
496 people living with the same condition: *“They help each other out and disseminate useful information*
497 *easily.”* (K10). However, associations may struggle due to internal and external factors: *“The existing*
498 *associations are not strong enough and not well functioning”* (K9), *“There are situations where one sees*
499 *the other as a rival”* (K3). Also for the individual, costs of joining the associations [10 Ethiopian Birr / US
500 \$0.22 per person] could be prohibitive; *“When they told us how much to pay for being a member of the*
501 *association it was shocking.”* (FG2, P1, 33-year-old male health professional) and affected persons outside
502 the associations may be excluded from benefits meant for all.

503 Finally, affected persons are expected to participate actively in their treatment and recovery, once they
504 have been taught how to do so, through ongoing **self-care**: *“the lifetime care is done by the patients*
505 *themselves.”* (K3)

506

507 **Solutions: Integration of mental health and psychosocial care**

508 Historically, routine care has not included psychological aspects of care: *“The social, psychological,*
509 *physical and financial therapy is somewhat forgotten. The biggest gap of the country for not achieving the*
510 *2020 goal is also these.”* (K10). This lack of psychological care was viewed as a critical deficit, due to an
511 intrinsic link: *“Physical impairment brings social impact that leads to psychological impairment. These are*
512 *linked and working together is very important and effective.”* (FG3, P2, 37-year-old male decision-maker).
513 This applies to all three diseases in the integrated care package: *“Stigma is so common and bad among all*
514 *the three diseases”* (FG3, P2, 37-year-old male decision-maker); *“It is clear that the three diseases need*
515 *psychosocial support.”* (FG3, P7, 49-year-old male decision-maker). Participants supported combining
516 psychosocial care with routine medical care: *“While doing the integrated treatment of those three*
517 *diseases it will be even better to include mental health on it because mental health is mostly neglected.”*
518 (FG2, P8, 38-year-old male health professional)

519 Participants thought that this could be one way of better addressing the problems experienced due to
520 stigma,

521 *“They need to have psychological support in order to avoid the stigma and discrimination they face*
522 *due to their physical disability.”* (K5)

523 *“The disease by itself can bring social discrimination. But counselling and developing their mental*
524 *capacity during rehabilitation sessions can be effective. So this integration idea is a good opportunity*
525 *for policy makers.”* (FG2, P4, 36-year-old female health professional)

526 Other ideas on how to specifically address stigma mirror the themes already discussed: collaborative
527 work, *“We can control the stigma and discrimination if all of us including those from different sectors like*
528 *health centres, woreda office or hospitals can take full commitment.”* (FG2, P7, 33-year-old female health
529 professional); involving influential community leaders, *“if we can use schools and religious organizations”*
530 (K8); addressing the knowledge gap: *“the stigma and discrimination will change if their knowledge about*
531 *the thing is advanced.”* (K11) and using expert patients: *“It is better if those who are cured and saved give*
532 *witness and awareness about stigma on the stage face to face to the people.”* (FG3, P7, 49-year-old male
533 decision-maker).

534

535 Solutions: Integration of care across the causes of lower limb 536 disorders

537 The EnDPoINT care package was seen as a way to improve the services delivered for people living with
538 lower limb disorders and consequently their outcomes. These would benefit the affected persons
539 themselves, their families, and wider society. *“People were isolated then, we brought them [...], and after*
540 *six months they came to know the disease is not communicable and they [are] able to have family, close*
541 *friends and even life partners.”* (FG3, P2, 37-year-old male decision-maker). Healthcare providers also
542 gained through professional satisfaction in achieving good care outcomes: *“Some providers [who] get*
543 *[made] aware and start treatment and management, [and] start seeing improvement within three months*
544 *are considering their jobs as blessings.”* (FG3, P5, 42-year-old male decision-maker)

545 The majority of participants were in favour of integrating services across the three diseases due to the
546 shared elements of the disease and treatment process:

547 *“Though there are different positive agents of the three diseases they have many things in common.*
548 *For example, the three diseases can result in disability, foot care can reduce their burden, all are prone*
549 *to stigmatization. Therefore, providing integrated foot care is very important”* (FG3, P4, 38-year-old
550 male decision-maker)

551 *“Both lymphatic filariasis and podoconiosis manifest with leg swelling and the case management is*
552 *similar. That means it’s necessary to have integrated management.”* (K6)

553 An integrated service may be easier for people living with lower limb disorders in **gaining initial access** to
554 foot care services, at a stage when they may not know what is causing their disease: *“We told them to*
555 *accept all cases of foot swelling [...] if the cases are not LF or Podo, we will not tell the patients to return to*
556 *their home but the health professional will give the treatment that he can.”* (K4); and may encourage
557 greater engagement: *“If three of them are integrated, the health seeking behaviour of the community will*
558 *also increase.”* (K11); *“when we are able to give common service for those people without differentiating*
559 *one from another”* (K2).

560 Most participants thought that integration would allow a more **efficient and cost-effective** service: *“There*
561 *is nothing to lose by working in an integrated way. We can reach the community with an integrated*
562 *package of services, this will improve staff efficacy, reduce wastage and redundancy. Generally, for me it is*
563 *a great way.”* (K9). *“If we apply these packages together, this is a process by which we can bring big*
564 *changes. Leprosy, podoconiosis and lymphatic filariasis are foot-related problems, therefore, by providing*
565 *more integrated service, there is the possibility that integrated care will make us more effective.”* (FG3, P1,
566 32-year-old male decision-maker) Such outcomes would make the integrated care package an attractive
567 option for service provision:

568 *“Decision makers will not oppose if you mobilize and integrate resources and man power because you are*
569 *going to minimize loss of resources and give care service for many patients.”* (K2)

570 Uniting the separate patient associations may also benefit in the same way: *“If the two or three come*
571 *together, it will play a crucial role in terms of human resource utilization and knowledge transfer.”* (P6,

572 FG3); *“If patients of all the three diseases come together and establish one large association, it will benefit*
573 *all patients [...] If we integrate it, considering the resource, there is a chance we can get more things.”*
574 (FG3, P1, 32-year-old male decision-maker).

575 Not all were optimistic or supportive of integration across the three diseases. Some were worried that
576 integration may be detrimental in some regards, due to **competing priorities** when resources are limited,
577 *“they may think there will be resource sharing ...I also think that way.”* (K5). There were concerns that
578 integrating care across the three diseases may **negatively affect uptake of care** by some with
579 podoconiosis or LF, due to the **stigma** associated with leprosy.

580 *“If leprosy is integrated with the other disease, those patients taking podoconiosis and LF treatment*
581 *could dropout.”* (K1);

582 *“From what I have seen they may refuse to take the treatment together because they think leprosy is*
583 *communicable even by sitting together.”* (FG1, P2, 59-year-old male community representative)

584 Others were concerned that the current government health care strands could be problematic for
585 successful integration: *“The problem in integrating leprosy treatment with others is the overall*
586 *government structure problem and it is not designed in such a way.”* (K1). This was mostly related to
587 separating leprosy from its current integration with tuberculosis: *“We shouldn’t lose our experts...because,*
588 *we have already integrated TB and leprosy and it has a good outcome... the one who is trained on TB is*
589 *also trained on leprosy and it demands extra resources if we are trying to separate those providers or*
590 *experts from the TB program.”* (K5). Another participant was worried that there were aspects of leprosy
591 care that were not covered by the integrated package, such as ulcer management and specific medical
592 treatment: *“In leprosy, the most probable disability is going to be neurological ulceration rather than*
593 *lymphoedema.”* (K10)

594 This same participant expressed anxiety that integrated services rather than vertical ones **reduced**
595 **expertise**: *“There are no vertical clinics in this village. These days every service is considered to be an*
596 *integrated service [...] The health professionals don’t have the ability to detect these diseases.”* (K10); and
597 that they were already struggling to provide health care due to lack of resources and infrastructure: *“For*
598 *treating podoconiosis patients, we even beg for materials from the cleaning staff. We can’t even*

599 *accommodate this kind of minor materials.” As a result: “I don’t see the feasibility of the integration.”*
600 *(K10), even though they supported the ideal: “Wound care clinics linked with psychiatric care and social*
601 *work issues done by social workers need to be established”.*

602

603 Discussion

604 This qualitative study explored the feasibility, acceptability and appropriateness of implementing an
605 integrated holistic care package for people with lower limb disorders caused by podoconiosis, LF or
606 leprosy in a region of northwest Ethiopia where disease is highly prevalent. The EnDPoINT care package
607 addresses three types of integration - integration into routine care; integration of mental health and
608 psychosocial care (alongside limb care); and integration of care across the three diseases.

609 Is it necessary and appropriate?

610 Our findings describe a significant burden of disease related to lower limb disorders including
611 lymphoedema in the endemic districts of Ethiopia studied. This study found that individuals with lower
612 limb disorders suffer a great deal, from the physical aspects of the disease as well as the psychosocial
613 consequences with stigma and discrimination resulting in social isolation for affected persons and their
614 families [20]. These lead to further consequences for their finances and health, in a vicious cycle. This
615 burden – whether physical, psychological or financial – was similar regardless of which of the three
616 diseases had caused the lower limb disorder, providing support for an integrated approach to providing
617 care across the three diseases.

618 Like other studies, communities and individuals held beliefs about causation that hindered engagement
619 with medical care and which perpetuated the stigma of affected individuals and their families. Consistent
620 with other studies, experience and enactment of stigma was influenced by beliefs about the causes of
621 lower limb lymphoedema, including ascribing the disease to religious retribution, genetics and
622 transmissible infection [21,22]. As elsewhere, this affected interpersonal relationships [23] including
623 divorce and exclusion from social events. Our study highlights the absence of sufficient psychosocial
624 support for affected persons within current care provision. This supports the appropriateness of an

625 intervention that integrates mental health and psychosocial care as well as addressing stigma and lack of
626 knowledge among those living in endemic areas [24].

627 Some of the challenges noted by our study participants was the spatial distribution of affected persons
628 across large geographical areas in potentially hard-to-reach rural areas, and a general neglect for people
629 affected by lower limb disorders within the health care system. This supports integration of services for
630 lower limb disorders into routine care, particularly within primary health facilities and outreach in the
631 community by health extension workers.

632 **Is it feasible?**

633 Assessing feasibility of the program requires us to identify hurdles and how those can be overcome.
634 Financial restraints, lack of material resources (including their supply chains and appropriate treatment
635 spaces) and training of healthcare workers all need to be prioritised within current healthcare structures
636 in order to facilitate the integration of services within routine care. Although there may be concerns that
637 the package adds a burden of work, both integration of care across diseases and integration of holistic
638 care (as opposed to vertical programmes) may improve the efficiency and cost-effectiveness of care, since
639 resources – financial, material and human – are shared. Reassuringly, although the desire to provide a
640 separate clinic to mitigate stigma would require extra space, this was not seen as a barrier of note by our
641 participants. Collaboration between the health service, charities and community leaders was viewed
642 constructively by our study participants, as urged by Engelman et al [25]; interestingly patient associations
643 were seen as less helpful. However, some caution should be applied due to the limited inclusion of
644 affected persons in this study; further exploration from their perspective on the role of patient
645 associations would be helpful.

646 This study adds to the existing knowledge about barriers of care by highlighting the dearth of knowledge
647 and experience amongst healthcare workers and care planners. Health care providers were inadequately
648 prepared with either knowledge or resources to be able to manage people with lower limb disorders
649 effectively. This is similar to a recent Rwandan study which demonstrated poor knowledge around
650 podoconiosis as well as minimal clinical experience in treating affected persons [26]; this was
651 compounded by shortages of supplies and drugs as in our study. Another recent study which explored the

652 inclusion of podoconiosis in medical undergraduate studies across all endemic countries in Africa found
653 there was insufficient specific teaching on podoconiosis [27], mirroring our respondents, along with earlier
654 Ethiopia-specific reports [28] of high levels of misconceptions among health care professionals. Education
655 interventions targeted to healthcare workers in endemic areas should be a component of any planned
656 intervention to aid success. One advantage of implementing integrated programmes is that such
657 interventions can be streamlined for training cohorts; within EnDPoINT, for example, health workers
658 receive MMDP training for all three diseases combined as well as mental health training.

659 Vertical interventions requiring sufficient expertise to differentiate between the causative conditions may
660 also be a barrier to care [29], and one of the benefits of our integrated care package is that it offers
661 holistic treatment to people affected by lower limb disorders regardless of its cause.

662 **Is it acceptable?**

663 Barriers to accessing and ongoing engagement with care are most commonly ascribed to stigma and
664 financial reasons [30,31], however there are other important obstacles. Our study showed that making the
665 intervention acceptable may require a reframing of what counts as “treatment”. The materials as well as
666 the clinical interaction suffer in affected persons’ regard due to their intrinsic simplicity, which results in a
667 failure to engage with care. Non-engagement (with a specific focus on non-use of footwear by people
668 living in endemic areas) has also been explored [32,33], but less is known about other reasons for poor
669 adherence. Misconceptions of care have been touched on elsewhere, such as in Tsegay et al’s study in
670 2014 where disappointment with the simplicity of care on offer was related to discontinuing care [31].
671 Changing understanding of their importance and clinical value may facilitate better engagement with care
672 by affected persons. Along with a focus on the “aetiology, preventability and treatability of the disease”
673 [22], this could be included with the education and awareness initiatives. Our participants also felt that
674 engagement would be improved by demonstrating success stories – actively through the use of expert
675 patients [34,35]; and that failure to demonstrate a good response would have a negative effect, another
676 “misconception of care” [30]. Setting realistic expectations for treatment response along with support by
677 those who have been through the process themselves would be valuable in making the intervention
678 acceptable to affected persons and their families.

679 In contrast to earlier reports of stigmatizing beliefs among healthcare workers [28], the attitudes of those
680 interviewed in this study were much more positive about the conditions, recognised the stigma and were
681 keen to work towards changing this. Participants were enthusiastic that an integrated program would
682 provide tangible benefits for affected individuals and their families, while delivering better and more
683 holistic care to a wider cohort of people living with lower limb disorders, done in a more efficient and
684 cost-effective way.

685 However, there were also some concerns mentioned by our study participants, particularly in regard to
686 integration of care for leprosy, since: leprosy programmes have traditionally been linked with those for
687 tuberculosis in Ethiopia; leprosy can manifest itself in ways other than lower limb lymphoedema; and
688 misinformation about the transmissibility of leprosy possibly limits acceptability of integrated services by
689 people with podoconiosis and LF. Disentangling leprosy care from its current place within the TB
690 programme may have negative sequelae, such as loss of expertise, and a requirement for extra resources,
691 unless carefully managed. These kinds of challenges and concerns need to be addressed when planning
692 and implementing integrated programmes. Interestingly, since completion of the EnDPoINT project, the
693 Ethiopian Federal Ministry of Health has included leprosy into the priority NTD list /group in the 3rd
694 National NTD Master Plan.

695 **Strengths and limitations of study**

696 The inclusion of a variety of stakeholders from an endemic region, with the combined use of focus groups
697 to stimulate discussion and in-depth interviews to probe in depth were strengths of this study. This study
698 is part of a bigger project underpinned with implementation research concepts which will allow a wide
699 range of mixed method approaches to explore fully the processes and outcomes involved in integrated
700 care. Furthermore the inclusion of implementers and policy makers alongside other stakeholders as part
701 of the consortium means that they have been kept abreast of research findings throughout the study and
702 any concerns raised have been fed into later stages of the project.

703 There are limitations to this study. Firstly, this study was conducted in one area of northwest Ethiopia and
704 the results may not be generalizable to other settings. Secondly, the data comes from self-reporting
705 rather than observed or witnessed behaviours. Thirdly, due to language limitations, one of the two

706 researchers analysing data could not listen to the audio recordings; however, translations were done by
707 the second researcher, who also conducted the interviews and contributed to data analysis; and we went
708 back to the original data to settle queries about nuances. Due to the phased nature of the overall project,
709 data collection in this study was limited by time constraints rather than primarily by data saturation.

710 An additional consideration is the limited inclusion of affected persons as participants. This was
711 compounded by the merged nature of focus group 1, which held both affected persons and community
712 members. While this could stimulate discussion, there is the risk that, despite the ground rules and the
713 facilitators, affected persons may have felt restricted from fully sharing their experiences due to the
714 presence of those by whom they may be stigmatized. In retrospect, including affected persons within the
715 key informant interviews could have offset this, as well as recruiting more affected persons as
716 participants.

717 The EnDPoINT care package was restricted to lower limb disorders and co-morbid mental health problems
718 caused by podoconiosis, LF and leprosy. It may be interesting for future research to explore the feasibility
719 and effectiveness of broadening the provision of integrated care to limb disorders caused by other non-
720 communicable diseases, for example diabetic foot.

721 However, despite these limitations, the results provide support for the roll out of an integrated care
722 package in the endemic areas of Ethiopia where the study was conducted.

723

724 Conclusion

725 In conclusion, these findings support the introduction of an integrated holistic care package for lower limb
726 disorders caused by podoconiosis, LF and leprosy in endemic areas in Ethiopia. Incorporating education of
727 care givers and care recipients into any package would be essential as would prioritisation by decision-
728 makers to enable allocation of time, resources and attention. It also suggests the need for further enquiry
729 into factors that inhibit engagement with care in order to develop supportive strategies.

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831

832 **S1 Text. Topic guide questions.** English and Amharic versions of the questions used for the key informant
833 interviews and focus group discussions.

834