

1 **Full Title**

2 Inclusive medical rehabilitation for persons with disability due to leprosy, lymphatic
3 filariasis, and diabetes mellitus: Mapping the gap in three leprosy endemic districts in
4 Indonesia

5

6 **Short Title**

7 Inclusive medical rehabilitation for disabilities

8

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41

42 **Abstract**

43 Medical rehabilitation for person with disability in Indonesia is still an issue. This research aimed to
44 explore Inclusive medical rehabilitation for persons with disability due to leprosy, lymphatic
45 filariasis, and diabetes mellitus in three regions in Indonesia. The qualitative study was
46 employed to gather data from disability patients, health workers in PHCs, medical rehabilitation
47 services for leprosy, DM, and LF in hospitals.

48 The results indicated that the gap on medical rehabilitation for person with disability due to
49 leprosy, lymphatic filariasis and diabetes mellitus in three regions were due to some
50 differences in their geographical aspects, availability of referral hospital for treating leprosy
51 and filariasis, supervision, human resource competencies.

52

53 **Introduction**

54 Medical rehabilitation in Indonesia remains limited in terms of availability and accessibility
55 to the majority of people needing it [1,2]. There are medical rehabilitation centres in all major
56 cities, and even district hospitals must offer basic rehabilitation services. This however does
57 not mean that all the relevant services are obtainable nationwide, that the professional staff is
58 available, or that patients or persons with disabilities are adequately informed about their
59 options. For persons with disability living in poverty, lack of funds or information about their
60 rights may cause them to go without any rehabilitative interventions their whole life [3].

61

62 The right to receive health services contains the elements of availability, accessibility,
63 acceptability, and appropriateness (or quality) [2]. In Indonesia, people with leprosy often
64 experience barriers in obtaining rehabilitation services [4]. For example, a previous study
65 described barriers to medical rehabilitation services for persons with disability due to leprosy

66 [5]. There are seven leprosy hospitals available throughout Indonesia, but only one offers the
67 most relevant medical rehabilitation (e.g. surgery, prosthetics & orthotics, physiotherapy,
68 occupational therapy, including here also guidance to home-based self-care) [3]. Long
69 distance to reach the nearest leprosy hospital limits the access for most leprosy-affected
70 persons. Furthermore, access to general hospitals is often restricted by stigmatising and
71 discriminating attitudes of hospital staff [4]. Furthermore, information accessibility is
72 constrained for many people in remoter areas and with low level of education [6].

73

74 Many persons affected by leprosy are not members of any insurance scheme as they do not
75 have valid identity cards [7]. Additionally, economical access or affordability is often not
76 ensured when people have to stay for prolonged times in leprosy hospitals waiting for
77 services, or have to bring family members to care for them, both reducing family income [8].
78 Acceptability of medical services is low in some leprosy hospitals where facilities and
79 services hardly respect human dignity, as clearly evident when visiting these hospitals.
80 Appropriateness or quality for services differs and may only benefit those who have the
81 resources.

82

83 Other diseases such as lymphatic filariasis (LF) and diabetes mellitus (DM) can cause
84 disabilities similar to leprosy in several aspects [9–11]. All require care and self-care to deal
85 with chronic impairments especially to lower limbs [12–14]. Both in leprosy and DM,
86 peripheral neuropathy is common, which may lead to wounds when pain is not felt, and
87 ultimately to amputations [9,11]. Simple interventions such as wearing protective footwear
88 may prevent worsening of impairments for people with insensitive feet caused by neuropathy,
89 while tendon transfers in leprosy restore function and mobility [12]. On the other hand,
90 people with LF develop lymphedema on their limbs, which could be reduced and kept from
91 worsening through home-based lymphedema management [13]. In later stages surgery might
92 be beneficial [15].

93

94 Medical rehabilitation plays an important role in all three diseases [16,17]. For the diseases,
95 self-care is essential, which ideally should be taught by hospitals and primary health cares
96 (PHCs) [12–14]. Thus, it is important to develop models used for advocacy and
97 implementation of inclusive medical rehabilitation for persons affected by leprosy, LF and
98 DM. The aim of this study is to generate knowledge on the gap of medical rehabilitation

99 services in three leprosy endemic areas, in order to improve comprehensive rehabilitation
100 services.

101

102 **Materials and Methods**

103 **Study design**

104 This was a qualitative study designed as baseline data to map the gap of inclusive medical
105 rehabilitation for leprosy, LF, and DM. The aim of this study is to systematically and
106 comprehensively collect information regarding the enabling and disabling factors influencing
107 the successful provision of inclusive medical rehabilitation services for persons with
108 disability due to leprosy, LF and DM.

109

110 **Study site**

111 Selection of the study site was based on endemicity of leprosy according to data from
112 Ministry of Health. The study was carried out in three leprosy districts, namely: Pekalongan
113 District, PALI District, Bima District (leprosy prevalence was 1.33 %, 1.73%, and 2.2 %
114 respectively).

115

116 **Informant**

117 The informants of this study were disability patients, health workers in PHCs, medical
118 rehabilitation services for leprosy, DM, and LF in hospitals. The informants were selected
119 purposively in Penukal Abab Lematang Ilir (PALI) District (Sumatera Selatan Province),
120 Pekalongan District (Jawa Tengah Province), and Bima District (Nusa Tenggara Barat
121 Province). The informant of this study consisted of three groups: 29 patients, 41 health
122 workers, and 17 experts.

123

124 **Conceptual Research Framework and Variables**

125 The conceptual framework implemented the Innovative Care for Chronic Condition (ICCC)
126 approach. The framework was initially published by World Health Organization (WHO) as an
127 innovative method to manage current care and prevent future chronic condition [18]. The
128 approach consists of 3 dimensions: from the point of view of health services, community, and
129 patients and their families. All the three dimensions were obtained from DM, leprosy, and LF
130 patients.

131

132 **Data Collecting Technique**

133 Data was collected by indepth interview. Instruments for data collection consisted of
134 questionnaire and observation list. The instruments were tested in a district that has similar
135 characteristics with the study locations.

136

137 **Data Analysis**

138 Data was analysed by content analysis according to the response from the informants, which
139 then was attributed to the context of variables. The data was analyzed to describe the gap
140 between each variable of the three programs (LF, DM, and Leprosy) and also the three
141 locations of study.

142

143 **Ethics Statement**

144 Ethical approval was issued by the Committee of Public Health Research Ethics, Diponegoro
145 University (233/EC/FKM/2016). Writtien informed consent was acquired from all subjects.
146 For subject under 18 years old, informed consent was provided by a parent on behalf of the
147 subject.

148

149 **Result**

150 **Characteristics of informants (patients, health workers, experts)**

151 The number of patients in Pekalongan, PALI, and Bima was 29 respondents (10, 11, and 8
152 respectively), consisted of 16 females and 13 males. The average age was 51 years old
153 (ranged 14-72 years old). The patients had several types of occupation but mostly were
154 housewives (27.6%), followed by farmer (13.8%). Sixty seven point nine percent of patients
155 were married while 37.0% did not graduate from elementary school. The duration of illness
156 was 2-15 years for Leprosy, 5 years for DM, and 32 years for LF.

157

158 The mean age of health workers was 39 years old, and the majority of them were female. The
159 majority of health workers were graduated from Diploma of Nursing (44.7%), married
160 (92.1%), and were the native of the district. The average distance from the residence of health
161 worker respondents to their workplace is 4.6 km with the closest distance 15 meters and the
162 longest distance 25 km. 88.6% of respondents ride motorcycle as transportation to the
163 workplace. Respondents have worked in their respective workplace on average of 12 years.

164

165 In this study, experts consisted of physiotherapist (22.2%), internist (22.2%), dermatologist
166 (11.1%), surgeon (22.2%), general practitioner (11.1%), and professional nurses (11.1%).
167 The majority of experts were male (55.6%). The average age of respondents is 47 years old
168 with the youngest is 45 years old and the oldest is 51 years old. 4 of 9 respondents are known
169 to have studied the disease for an average of 15 years, with the shortest time to explore the
170 field of disease is 2 years and the longest is 24 years.

171

172 **The Gap of Health Services for Leprosy, Diabetes Mellitus, and Lymphatic Filariasis**

173

174 **Infrastructures**

175 Leprosy, DM, and LF patients reported similar statement about the PHC infrastructure for
176 which the patients are sufficiently satisfied with the building condition and the facilities of
177 health services. The positive response was reported by patients in Pekalongan and Bima
178 Districts that the facilities are sufficient and helpful. In a similar comment, a patient from
179 outside Java stated the facility in health service was convenient. Other patients felt grateful
180 for the services.

181

182 Health workers reported that the building condition had been a major concern for the health
183 management, which was addressed by continuous effort to improve the condition. However,
184 there were occasions when examinations were conducted where the health workers were on
185 duty, for example, if the health worker is responsible for treating the leprosy and also TB,
186 then the examination for both diseases will be conducted in the same room. It was also
187 known that the total building area in the PHCs affected the availability of examination rooms.
188 With regards to the temporary room for DM patients, one health worker addressed the
189 importance of renovating the health facility. A health worker informed that while the medical
190 rehabilitation for LF in Pekalongan District was not yet available, the mass drug
191 administration had been launched. The annual launching is scheduled in October. She also
192 added that the ideal facility for combining the treatment of Leprosy, LF and DM should be in
193 the form of a rehabilitation room. Rehabilitaion for TB and Leprosy patients should be
194 isolated in a special room and the care givers assigned should also be separated for each
195 disease.

196

197 **Inputs and Equipment**

198 Health workers stated that connection to the sewage in the PHCs is available along with the
199 water system. Data regarding the availability of basic equipment for the diagnosis and
200 therapeutic in the PHC facilities was obtained from a checklist filled out by the health
201 workers. The results can be seen in the following table.

202 Table 1 Percentage of availability of the basic equipment for the diagnosis and therapeutic

District	Leprosy	DM	LF	Average
Pekalongan	76	95	35	68.7
PALI	52	67	42	53.7
Bima	52	70	n/a	61.0
Average	60	77.3	38.5	

203
204 The availability of basic equipment for the diagnosis and therapeutic is presented in Table 1.
205 It can be seen that the availability of basic equipment for the LF diagnosis and therapeutic is
206 the most incomplete when compared to others. In detail, the average of the availability of
207 basic equipment for LF diagnosis and therapeutic is only 38.5%, creating a 21.5% gap with
208 Leprosy and 38.8% with DM. Based on district, it can be seen that Pekalongan has more
209 equipment, although only a slight gap was found between three district. In detail, the average
210 of the equipment availability in Pekalongan is 68.7%, creating a small gap of 7.7% with Bima
211 and 15% with PALI. In contrast to the health worker, patients described how the equipment
212 always available and there were no signs of deficiency. In contrast to the data given by the
213 health workers, patients described how the equipment was always available and that there
214 were no perceived signs of a deficiency. Other patient also informed that the availability of
215 the service material was complete.

216
217 In terms of laboratory availability for the clinical checkup, all PHCs observed in Pekalongan
218 have a laboratory despite its lack of equipment. Meanwhile, both in PALI dan Bima Districts,
219 patients acknowledged that the laboratory function in the PHCs was not optimal. Leprosy
220 patients in Bima District, are therefore required to use the service of private laboratory which
221 sometimes involves considerable amount of money. In addition, in all the three study sites,
222 each healt centre has at least one ambulance to help services. Most patients were also aware
223 that there was ambulance available in each PHC.

224

225 **Pharmaceutical**

226 Data regarding the availability of generic and supporting drugs in the PHC was obtained from
227 a checklist filled out by the health worker. Results can be seen in the following table.

228

229 Table 2. The percentage of availability of the generic and supporting drugs

Districts	Leprosy	DM	LF	Average
Pekalongan	68	16.7	70	51.57
PALI	100	41.9	50	63.97
Bima	100	16.7	n/a	58.35
Average	89.3	25.1	60	

230

231 The result indicated the availability of generic and supporting drugs for leprosy is more
232 complete than DM and LF. However, it should be taken into account that some types of drugs
233 were not available at PHC. There were significant differences between the percentages gap
234 with LF (29.3%) and with DM (64.2%). It can also be seen that the drugs availability in PALI
235 District were more complete than in Pekalongan and Bima Districts. However, there was only
236 a small gap found between the three districts.

237

238 The Government of Indonesia is organizing programs to provide medicines for leprosy, DM,
239 and LF covered by the BPJS Health program, in the form of health insurance. DM drugs are
240 included in the *Prolanis Program*, associated with other non-communicable diseases. While
241 the drug for LF patients only exist in PHC, therefore the hospitals often repatriate LF
242 patients. This was the reason hospitals were not as knowledgeable in treating LF patients.

243

244 **Human Resources**

245 According to the patients, the presence of health workers serving the PHC patients is
246 sufficient. The human resources in PHC and in the hospital are very different. In PHC, health
247 workers are usually given the task of holding one or more programs in addition to their main
248 program. For example in DM, the program is incorporated in the other non-infectious disease
249 program. There are leprosy officers who are also responsible for tuberculosis programs, some
250 are assigned concurrently with LF. This is due to the limited number of qualified health

251 workers that can be given the responsibility. As a result, the program officers were not able to
252 share the attention of both programs fairly and harmoniously.

253

254 On the other hand, health workers at referral hospitals such as Dr. Rehatta Hospital in Jepara-
255 Central Java and Dr. Rivai Abdullah Hospital in Palembang-South Sumatra at least consist of
256 a general practitioner, a dermatology specialist (for leprosy), an internist specialist (for DM),
257 nurses, a physiotherapist, officers in orthotic prosthetic, and medical rehabilitation doctors.
258 Unfortunately LF expert are not found in these two hospitals. However, an expert from Dr.
259 Rivai Abdullah Hospital, who is a surgeon, stated that he was able to perform surgery for LF
260 patients who already suffered swollen lymph nodes.

261

262 **Supervision**

263 Supervision for the implementation of the program of DM, leprosy, and LF in PHC is
264 provided by the District Health Office (DHO). PHCs provide oral and written reports every
265 three months to DHO. Unfortunately, not all officers are able to make quick and complete
266 reports. This was stated by a health worker in Sape PHC (Bima District). In addition to
267 reporting every three months, the PHC also holds internal monthly workshops for staffs
268 aimed to increase the vigilance of the stakeholders of the other programs as well. It also
269 reaffirms and indicates that, in fact, tracking and management of each disease is the
270 responsibility of an individual officer.

271

272 **Referral**

273 Referral sites for leprosy rehabilitation exist only in Central Java and South Sumatra. Dr.
274 Rehatta Hospital in Jepara, Central Java, became a reference only for Central Java Province,
275 while Dr. Rivai Abdullah Hospital became a reference throughout Sumatra and West
276 Kalimantan. Bima District, on the other hand, has no experience to refer leprosy patients to
277 medical rehabilitation due to the long distance to the location of leprosy referral hospitals in
278 Mataram or in Makassar.

279

280 Referrals for medical rehabilitation of DM in Central Java and South Sumatra may be
281 targeted at local public hospitals in each district or in the same place as leprosy referral
282 hospitals, since they receive services for medical rehabilitation with other causes such as
283 stroke and traffic accidents. While in Bima District, there is no place for medical
284 rehabilitation referral for DM as well as LF, and leprosy diseases. Referrals for medical

285 rehabilitation due to LF have not been officially established in all three provinces, but an
286 informant in South Sumatra stated that he may be able to handle the rehabilitation of LF
287 patients.

288

289 **Discussion**

290 The gaps can be seen in the three research areas (Pekalongan, Bima, and PALI Districts). The
291 condition of health facilities and infrastructure in Central Java is relatively better than in
292 South Sumatra and West Nusa Tenggara. Nevertheless, in areas directly adjacent to the Java
293 Sea in Pekalongan District, many are experiencing floods [19], so the PHC is inundated by
294 sea water forcing many health workers to wear boots. Therefore, several PHCs in Pekalongan
295 District are rebuilt, having more than one floor. The condition of most PHCs in Bima District
296 does not meet the standard/is not adequate, however there is one PHC in Sape with adequate
297 building and facilities. On the other hand, seven PHCs in PALI District are acceptable.

298

299 According to the previous findings, it could be understood that the gaps on medical
300 rehabilitation for leprosy, DM, and LF remain exist [19,20]. In this study, the gaps are mainly
301 illustrated on self-care management and referral system. The LF and DM do not have self-
302 care program, which is available for leprosy program. In LF and DM, the program only deal
303 with passive finding and treatment only. Likewise, referral schemes for rehabilitation and
304 advanced treatment are of no special nature as can be found in leprosy programs. Leprosy
305 programs show special programs i.e. from active case finding such as contact surveys, RVS
306 and school surveys.

307

308 Treatment of leprosy patients is also always accompanied by a self-care mechanism taught by
309 the officer to the patient, in order to prevent the disease from worsening [21]. There is also a
310 mechanism of rehabilitation through reconstruction, physiotherapy and the provision of aids
311 (prosthesis) for people with disabilities level 1 or 2 [22]. DM program is managed in
312 conjunction with other non-infectious diseases program, so there is no specificity of the DM
313 program. If anyone is disabled by DM, there is no specific scheme for rehabilitation. This is
314 also the case with LF, although it is a separate program in PHC the rehabilitation or self-care
315 efforts do not become the focus in the treatment of patients. This self-care gap, as well as
316 rehabilitation efforts, can actually be overcome by combining the care of disabled DM and
317 LF patients into the treatment of leprosy patients which are currently underway [20]. In this

318 case, medically self-care efforts and medical rehabilitation that have been applied to leprosy
319 patients can also be applied to LF and DM patients.

320

321 This study indicated that in the region there are variations in leprosy referral system
322 implementation inter-regional, especially from the aspect of availability of referral facilities
323 and referral system. Referral medical rehabilitation was only available in leprosy programs.
324 The best referral system only exists in Java Island. In the research area in Central Java, they
325 have referral hospital with a system to pick up patients who are ready to be rehabilitated by
326 coordinating the Leprosy Supervisor in DHO and PHC. In South Sumatra, the leprosy referral
327 hospital does not have a system such as in Central Java. RS is passively waiting for referrals
328 from the region. In West Nusa Tenggara research area there is no clear referral mechanism
329 nor any case of PHC referring leprosy patients to undergo rehabilitation as there is no leprosy
330 hospital in the area.

331

332 Regional policies greatly affect the implementation of medical rehabilitation services in the
333 regions. National policy is required on the best referral mechanism for leprosy patients.
334 Policy making also needs to be accompanied by the provision of facilities along with the
335 division of working area, so that the reference facilities are easily accessible by the patient. It
336 is also necessary to consider the infrastructures to the hospital, such as public transportation
337 and good road conditions, for easy public access once the hospital is announced as able to
338 treat disabled patients due to DM and LF. We suggest Leprosy Hospital may also use existing
339 hospitals, with additional training for staffs. The hospital can also be equipped with therapists
340 to assist the recovery of the patient. This policy should be executed considering the
341 distribution of health services for rehabilitation should be implemented in all parts of
342 Indonesia.

343 Limitation of this study such as information bias could be occurred in some translations of
344 the specific indigenous dialect such as the name of the disease in the local.dialect. For
345 example, "Ncola" in Bima refers to Leprosy. Therefore, the investigators asked the local
346 health officer to make sure that the term of the disease in a local dialect was translated
347 correctly.

348

349 **Conclusion**

350 Gap of medical rehabilitation services remains exist between leprosy, diabetes, and filariasis.
351 Medical rehabilitation program of leprosy is better than the other diseases. There was also a
352 gap of medical rehabilitation services between Java and non-Java Islands.

- 353 1. Availability of facilities and referral system in Java Island was better. The worst services
354 were found in east Indonesia (Nusa Tenggara Barat Province).
- 355 2. Availability of facilities, health officer conformity, and community acceptance are factors
356 to minimize stigma and are key factors of inclusive medical rehabilitation service.
- 357 3. Model of integrated medical rehabilitation between leprosy, filariasis, and diabetes may
358 be developed by involving puskesmas as treatment and selfcare unit, and leprosy hospital
359 as referal unit of reconstruction and rehabilitation.
- 360 4. Government should develop national policy and universal coverage for health insurance,
361 which will be an operational reference in puskesmas and hospital level. Puskesmas,
362 hospital and government should be oriented to community empowerment, with final goal
363 to decrease leprosy stigma and increase community awareness on the importance of
364 medical rehabilitation for leprosy, diabetes, and filariasis.

365

366 **Acknowledgments**

367 The authors would like to thank all the participants of this study. The authors would also like
368 to thank the corresponding Public Health Centers, Hospitals, and Distric Health Offices.

369

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432

433 **Supporting Information Legends**

434 S1 Checklist: STROBE Checklist