

1 Perception, awareness and treatment experiences about Onchocerciasis in a 2 rural community in Cross River State, Nigeria: implications for control

3 4 5 **Abstract**

6 **Background:** Onchocerciasis a disease of poverty continues to place huge health, economic and
7 social burden on communities at risk. Understanding critical factors that impact on access to
8 treatment, acceptance and overall control measures are pivotal to the march towards its
9 elimination.

10
11 **Objective:** To assess Onchocerciasis perception and treatment experiences in a rural community
12 in Cross River State, Nigeria

13 14 **Methodology:**

15 A cross-sectional descriptive study using mixed method was undertaken. Data were collected
16 using pretested questionnaire and in-depth interview guide. Quantitative data were analysed
17 using SPSS while the in-depth interviews were audio taped, transcribed verbatim and thematic
18 analysis done. Findings were presented in frequencies, charts, percentages, tables and quotes.
19 Tests of significance were determined using Chi-square (χ^2) at significance level of 5%

20
21 **Results:** Ignorance, myths and negative perception about the cause of Onchocerciasis pervade
22 in 64 (31.2%) of the respondents that did not know that the bite of infected Blackfly is the cause.
23 Some attributed the disease to curse from the gods (45.3%) and witchcraft (23.4%). This poor
24 knowledge is associated with lower highest attained level of education ($p = 0.01$). Non-
25 availability of drugs (23.9%) and lack of knowledge on where to access ivermectin (9.8%) were
26 the major challenges to ivermectin uptake. Inequity in treatment access was identified from the
27 thematic analysis.

28
29 **Conclusion:** Poor knowledge of the cause of the disease, non-availability of ivermectin and
30 misconceptions about cause of onchocerciasis had negative influence on health- seeking
31 behaviors, discriminatory practices and treatment coverage. By integrating contextual knowledge
32 awareness creation about Onchocerciasis into the design of control strategies will facilitate the
33 vantage march towards achieving elimination target.

34
35 **Key words:** Onchocerciasis, Access, ivermectin treatment, Perception, Awareness, Nigeria

36 **Running Title:** Perception of Onchocerciasis and ivermectin treatment experiences
37

38 39 **Introduction**

40 Onchocerciasis or river blindness is a disease of poverty that continues to place huge health,
41 economic and social burden on communities at risk. The disease is a major problem among rural

42 communities living in close proximity to rivers in sub-Saharan African countries. An estimated
43 25 million people were infected with about 1.3 million people visually impaired or blind as a
44 result of the disease [1, 2]. Nigeria is estimated to bear a significantly high burden of the disease
45 with 32 endemic states including Cross River State [3, 4]. In Cross River State, almost all the 18
46 local government areas (LGAs) are endemic for the disease and the prevalence was estimated to
47 be 10% in 2012 [5], which may be gross underestimation given lack of credible population data.

48
49 Community Directed Treatment with Ivermectin (CDTI) is the major control strategy adopted in
50 African countries by the African Program for Onchocerciasis Control (APOC). CDTI primarily
51 involves yearly mass drug administration (MDA) of Ivermectin. Despite the successes this
52 strategy has engendered [6,7,8], meeting target goal set for elimination of Onchocerciasis seems
53 far-fetched [9,10,11]. However, ignorance, myths and misconceptions about Onchocerciasis have
54 been implicated in the drag to elimination. These have equally been acknowledged to lead to
55 negligence in prevention and control measures and causes acceptance of inappropriate treatment
56 regimen.

57
58 It has been recognised that knowledge of history and cause of a health condition including the
59 whole continuum of epidemiology of the disease often promotes health-seeking behaviours and
60 encourages reduction of effects or elimination of the disease [9,11,12,13,14]). Silumbwe *et al*
61 [14] opined that often programme implementation strategies do not take into account the
62 contextual factors that impact on overall programme success. Some of the key factors that have
63 been suggested by many studies include; knowledge of cause and transmission of the infection,
64 perception of disease symptoms, socioeconomic burdens of the disease, first point of call or

65 source of treatment, factors affecting treatment regimen such as willingness to pay for treatment
66 or otherwise, acceptance of treatment and prevention/control measures [8,11,12,13,15].

67
68 In addition, lack of knowledge of transmission of Onchocerciasis can also manifest in
69 discriminatory and stigmatizing attitudes towards those affected [10,15]. This in turn may
70 negatively affect the health-seeking behaviours of those affected by Onchocerciasis [8,16]. This
71 may further limit access to ivermectin, acceptance of treatment and overall treatment coverage
72 [13,17].

73
74 Another crucial factor could be lack of close monitoring of drug treatment and distribution by
75 community –directed distributors (CDD) often occasioned by technical and logistic limitations in
76 their ability to deliver interventions [1, 2, 5, 18]. It has been equally suggested that poor
77 compliance to treatment may not be unrelated to long treatment duration (10 – 15 years), interval
78 between doses (one year) that can easily be forgotten and thus missed, adverse events in
79 ivermectin treatment often leading to rejection of treatments by communities [1,3,6]. Reinvasion
80 caused by limited treatment coverage area has also been implicated in low CDTI programme
81 success [15,17,19]. Perhaps this could be attributed to the inconsistent availability of ivermectin
82 in states and government’s inability to complement the efforts of APOC leading to poor
83 distribution and follow-up in affected communities [2,5,18].

84
85 To attain community participation and design socially/locally acceptable control strategies,
86 health program planners and implementers should be familiar with people’s knowledge, attitude
87 and practice in relation to Onchocerciasis and other cultural innuendos that impact **access to**
88 treatment, coverage and other control measures [8,10]. The successful use of ivermectin at
89 community level requires a broad public health program designed to address barriers to

90 treatments. Understanding the peoples' knowledge and perceptions of Onchocerciasis may stand
91 as important promoters of effective Onchocerciasis control strategies [4,16,20]; especially in
92 gaining the community's buy-in and confidence to participate in control programme
93 [11,12,16,19]. There is paucity of information as few studies have been carried out to understand
94 these issues in this environment. Therefore, this study was aimed at assessing Onchocerciasis
95 perception, awareness and ivermectin treatment experiences among residents of a rural endemic
96 community in Cross River State, Nigeria.

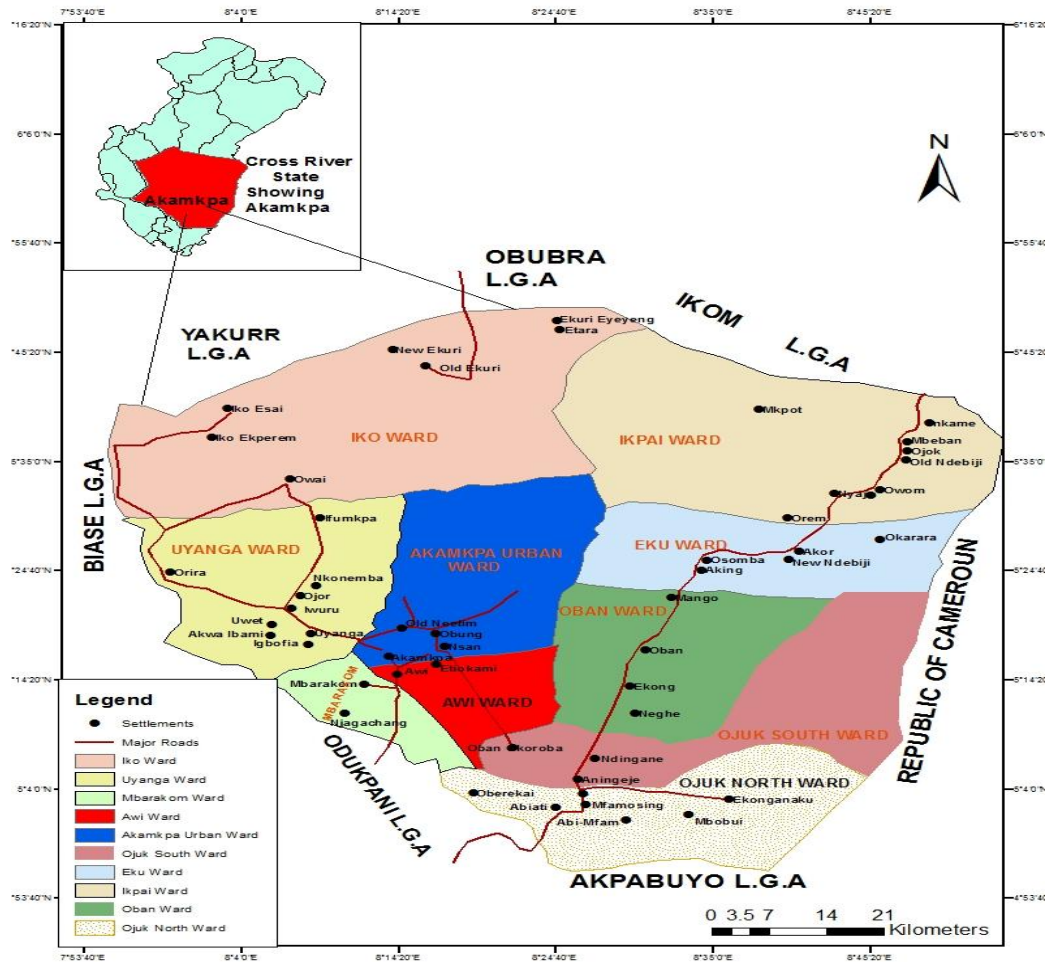
97

98 **Research Methodology**

99 *Study setting*

100 The study setting was Akamkpa Local Government Area (LGA) of Cross River State in the
101 South-South region of Nigeria (Figure 1). It is one of the Onchocerciasis endemic foci in the
102 State. Akamkpa LGA lies within longitude 5°25', East of the Greenwich Meridian and latitude
103 8°31' North of the equator. It has a projected population from the 2006 census figures to 2017 of
104 about 203,705 using annual growth rate of 3.0%. The study area has the largest forest area in the
105 state and a very fertile land, watered by many rivers, streams and springs; that serves as veritable
106 breeding ground for blackflies.

107



108

109 **Figure 1: Map of Akamkpa Local Government Area, Cross River State, Nigeria**

110 *Study design, sample size and sampling method*

111

112 This study is a cross-sectional descriptive study using a mixed method approach comprising both
 113 quantitative and qualitative data collection methods. The study population was limited to
 114 individuals residing within Akamkpa LGA of Cross River State aged 15years and above. The
 115 sample size for this study was 205 for the quantitative data. The sample size was determined
 116 using the formula for dichotomous descriptive study [21]; employing the 10% prevalence of

117 Onchocerciasis in Cross River State estimated by Cross River State Neglected Tropical Disease
118 (NTD) Programme (Eyo, 2016) at 95% confidence interval and 5% precision. Simple random
119 sampling technique was employed to select the respondents for the quantitative aspect. A total of
120 25 respondents participated in the in-depth interviews comprising two from the NTD centre in
121 Calabar, the Primary Healthcare Coordinator for Akamkpa LGA, Officers in-charge of the 10
122 PHCs, two active ivermectin CDDs and 10 community leaders one from each ward.
123 The instrument for data collection was semi-structured interviewer-administered questionnaire. It
124 comprised of four sections. Section A elicited information on the socio-demographics of the
125 respondent; Section B was on knowledge, perceptions and beliefs about Onchocerciasis. Both
126 sections C and D covered Onchocerciasis treatment and factors influencing Onchocerciasis
127 treatment respectively. In-depth Interview guide was designed to explore the experiences of
128 participating individuals residing within Akamkpa LGA. Each interview session lasted for about
129 90minutes.

130
131

132 *Data analysis*

133 Quantitative data obtained from the study were entered, coded, cleaned and analysed using
134 Statistical Package for the Social Sciences (SPSS version 20). Quantitative data was presented
135 using descriptive statistics. Categorical variables were reported as frequencies (and percentages)
136 while normally distributed continuous variables reported as means and standard deviations. Tests
137 of significance were determined using chi-square (χ^2). Each in-depth interview was tape
138 recorded. All audiotapes from the key informants interviewed were transcribed verbatim into

139 word documents. The transcripts and notes were analysed by themes described in the literature
140 review as well as novel opinions expressed during the data collection process.

141

142 *Ethical considerations*

143 Ethical clearance for conduct of this study was obtained from the Cross River State Ministry of
144 Health, Health Research Ethics Committee. The research participants were briefed on the
145 purpose of the study and verbal consent was obtained from those who volunteered to be enrolled
146 in the study. Participants who did not wish to participate in the research were excluded from the
147 study. Participants were provided all the necessary information about the research and were
148 assured of strict confidentiality and anonymity of data to be collected.

149

150 **RESULTS**

151 *Socio-demographic characteristics of respondents*

152

153 A total of 205 respondents responded to all the items in the survey questionnaire; giving a
154 response rate of 98%. There was a slight preponderance of males; 105 (51.2%) with the
155 respondents having a mean age of 31.9 ± 12.3 years. The number of respondents were married is
156 103 (50.7%). Respondents with a household size between of 4- 6 were in the majority (104;
157 50.7%) followed distantly by respondents with 1 – 3- member household 52 (25.4%). Most of
158 the respondents had attained secondary level of education 113 (55.1%) with those with no formal
159 education being the least 6 (2.9%). The highest proportion of the respondents were self-
160 employed 65 (31.7%), followed by civil servants and farmers which were equally proportioned
161 40 (19.5%) amongst the respondents. Most of the respondents had lived in the study area for

162 more than 15 years 74 (36.1%). The detailed data on socio-demographic characteristics of the
 163 respondents is shown on Table 1.

164
 165 **Table 1**
 166 **Socio demographic characteristics of respondents, Akamkpa LGA, Cross River State**
 167

Variables	Frequency (n = 205)	Per cent (%)
Sex		
Male	105	51.2
Female	100	48.8
Family Size		
1 - 3	52	25.4
4 - 6	104	50.7
7- 9	35	17.1
>10	14	6.8
Marital Status		
Single	97	47.3
Married	103	50.2
Widowed	3	1.5
Divorced	2	1.0
Educational level		
No formal education	6	2.9
Primary	37	18.1
Secondary	113	55.1
Tertiary	49	23.9
Occupation		
Civil Servant	40	19.5
Farmer	40	19.5
Self-employed	65	31.7
Student	46	22.4
Others	14	6.8
Duration of stay in Akamkpa LGA		
<2 years	17	8.3
2 - 5 years	28	13.7
6 – 10 years	60	29.3
11 – 15 years	26	12.7
>15 years	74	36.1
	Mean	Standard Deviation (SD)
Age (Years)	31.9	12.3

168
 169 ***Knowledge and perception of onchocerciasis***
 170 Ignorance, myths and negative perception about the cause of Onchocerciasis still persist as 64
 171 (31.2%) of the respondents did not know that the bite of infected Blackfly is the cause (Table 2).

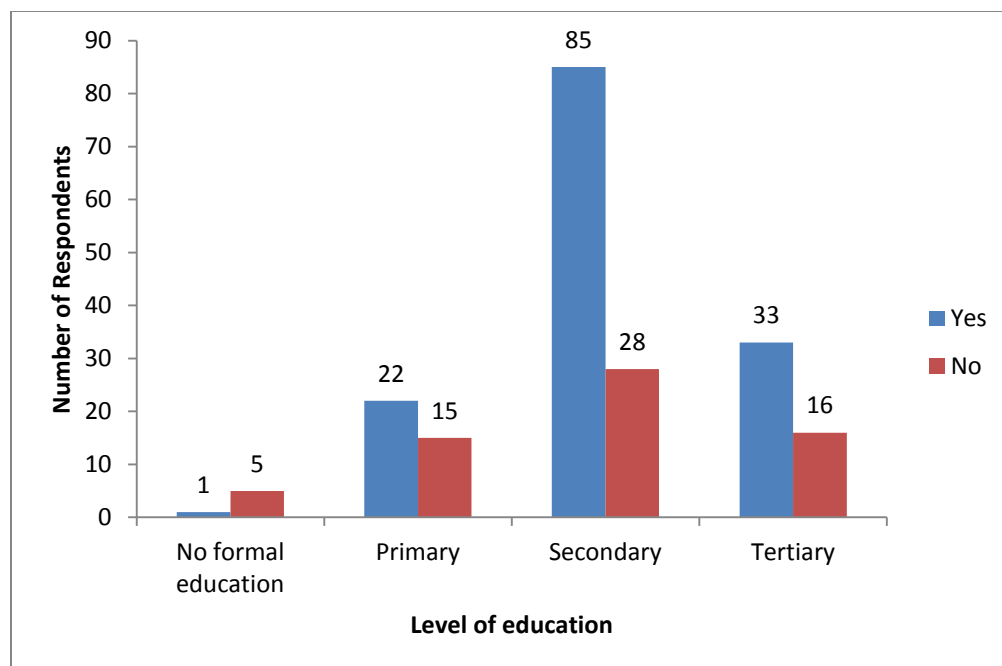
172 Most attributed it to curse from the gods (29, 45.3%) and witchcraft (15, 23.4%). Having
173 knowledge about cause of Onchocerciasis were comparatively higher in respondents who had
174 attained more than primary level of education and reverse was the case for those that attained
175 lower level of education (Figure 2) was statistically significance at 0.05 critical level ($\chi^2 =$
176 11.32; $p = 0.01$). This becomes all the more significant given that majority of the respondents
177 (55.1%) had attained at least secondary level of education (Table 1).

178
179 Twenty four of survey respondents (11.7%) acknowledged to have suffered from Onchocerciasis.
180 Those that were diagnosed at the health facility 16 (66.7%) and those diagnosed during mass
181 screening exercise 8(33.3%). Having knowledge of family members suffering from the disease;
182 only few 36 (17.6%) affirmed knowing and had one to two infected persons (51.3%) in the
183 family (Table 2).

184
185 The Onchocerciasis prevention methods suggested by respondents (Figure 3) were hinged on the
186 knowledge and perception about the cause of the disease (Table 2). Among the respondents 133
187 (64.9%) inferred that good sanitation and personal hygiene followed by 33 (16.1%) that were of
188 the view that wearing of protective clothing was the viable prevention strategies. Use of
189 mectizan by 8 (3.9%) and health education on prevention 5 (2.4%) were the key prevention
190 strategies least mentioned by the respondents.

191

192



193
194
195
196
197
198
199

FIG 2: Knowledge about the cause of Onchocerciasis varied with educational level

Table 2: Respondents' onchocerciasis knowledge and treatment profile

Variables	Frequency	Percentages
Knowledge of cause of Onchocerciasis		
Yes	141	68.8
No	64	31.2
Total	205	100
Lack of knowledge of cause of Onchocerciasis (Attributions)		
Animal	9	14.1
Curse from the gods	29	45.3
Kissing	2	3.1
Witchcraft	15	23.4
Don't know	9	14.1
Total	64	100
Has Onchocerciasis		
Yes	24	11.70
No	181	88.29
Total	205	100
How Onchocerciasis was diagnosed		
Visited health facility	16	66.67
Mass screening exercise	8	33.3
Total	24	100
How long with Oncho		
1 – 3 months	3	12.5
4 – 6 months	2	8.33
7 – 12 months	6	25.00

>12 – 36 months	5	20.83
>36 - 60 months	2	8.33
>60 months	6	25.00
Total	24	100
Treatment Status (Are you on treatment?)		
Yes	21	87.5
No	3	12.5
Total	24	100
Source of treatment		
Community Drug Distributors (CDDs)	18	85.7
Health Facility	2	9.5
Patent Medicine Store	1	4.8
Total	21	100
Family member with Onchocerciasis		
Yes	36	17.56
No	169	82.43
Total	205	100
Number of family member with Onchocerciasis		
1 – 2 persons	20	51.28
3 – 4 persons	8	22.22
5 – 6 persons	3	8.33
≥7 persons	4	11.11
Total	36	100
Oncho MDA participation		
Yes	138	67.3
No	67	32.9
Total	205	100
Duration of Oncho MDA Participation		
< 6 months	10	7.25
6 – 12 months	13	9.42
>12 – 36 months	51	36.96
>36 – 60 months	26	18.84
>60 months	38	27.54
Total	138	
Source of Oncho MDA		
Community Drug Distributors (CDDs)	100	72.5
Health Facility	35	25.4
Patent Medicine Vendor (“Chemist”)	3	2.2
Total	138	100
Payment for treatment		
Yes	8	5.8
No	130	94.2
Total	138	100

200
201
202

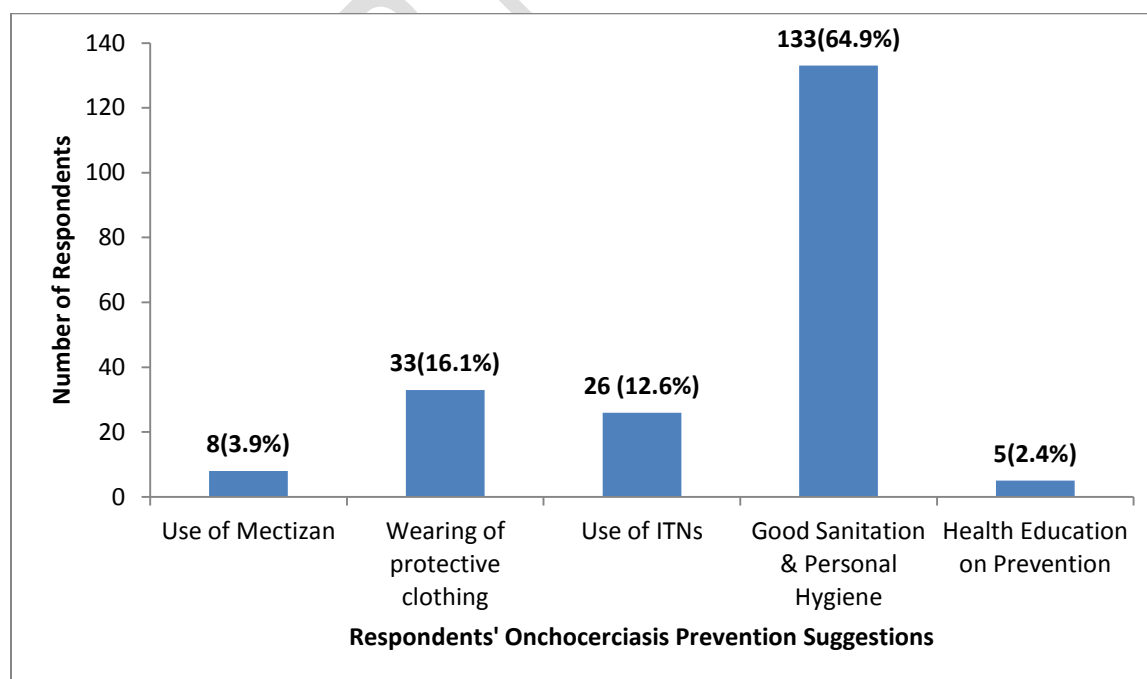
203

204

205 ***Access and uptake of ivermectin***

206 CDDs still remain the main stay of onchocerciasis treatment (72.5%). Though health facilities
207 (25.4%) and Patent Medicine Vendor, popularly known as “Chemist”(2.4%) were reported as the
208 source of treatment for the rest of the respondents. A small proportion 8 (5.8%) claimed paying
209 for the treatment (Table 2). Only very few 6(2.9%) of the respondents indicated cost of
210 ivermectin was a challenge to its uptake (Table 3).

211
212 A significant proportion of the respondents reported having difficulties in accessing
213 onchocerciasis treatment services (Table 3). Majority indicated that non-availability of drugs
214 49(23.9%) followed closely by lack of knowledge of where to get ivermectin 20 (9.8%). Other
215 access hindering factors mentioned by some respondents included far distance to health facility 9
216 (4.4%) and poor attitude of healthcare providers 9(4.4%). Possible adverse drug reaction
217 12(5.9%) and rejection of ivermectin 7(3.4%) were also mentioned as affecting the uptake of
218 ivermectin.



219

220
221
222

Fig 3: Respondents' perception about Onchocerciasis prevention strategies

223
224
225

Table 3
List of factors likely to affect to ivermectin uptake

	Variables	*Frequency (n = 205)	
		Yes (%)	No (%)
a	Drugs used for treatment not available	49 (23.9)	156 (76.1)
b	Distance to the health facility is too far	9 (4.4)	196 (95.6)
c	I don't know where to get the drugs	20 (9.8)	185 (90.2)
d	Poor attitude of the health care providers	9 (4.4)	196 (96.6)
e	Cost of drugs too high	6 (2.9)	199 (97.1)
f	I don't like taking the drug	7 (3.4)	198 (96.6)
g	I always forget to take my drugs as when due	6 (2.9)	199 (97.1)
h	The drugs make me feel uncomfortable	12 (5.9)	193 (96.6)

226
227
228
229
230
231
232
233
234
235
236
237
238

*Multiple responses
(Variables a - e speak to issues of access)

240 *Table 4: Study Qualitative results*

Major Theme	Sub-themes	Quote
Onchocerciasis is a Huge burden	Occurrence of the diseases due to the terrain, Neglected tropical diseases	<i>“Onchocerciasis is definitely a problem; it affects the larger community in the Local Government Area”</i> <i>“Yes, it a major problem as it is been called a neglected tropical disease”</i>
Myths and Misconceptions	Myths and Misconceptions Cause by witchcraft Curse from god Attack from enemy	<i>“The belief in witchcraft still stands, because every small thing that happens to them, they attribute it to witchcraft”.</i> <i>“When people fall sick which they don’t know the possible cause they will either say it an attack from their enemy or witchcraft</i> <i>“Most people in this community still belief that onchocerciasis is caused by witchcraft due to the nature of the disease”</i>
Discrimination and stigmatization	Negative attitude, financial incapacitation, blindness, high social burden	<i>“You know predominantly in Akamkpa, a larger number of them are farmers, especially those in the interior, it affect them because most of them will not be able to go to Farm”</i> <i>“Family that has somebody who is affected... the economy and everything in that family will not go on well, because as a father in the family you will not be able to go and fetch out what the family will eat and it will be shame and a mocking of family and stigmatization”</i> <i>“it affects them because when it affects the eye, the eye is the mirror for everybody, if the eye is affected, it means even the family, community or the whole Nation is affected.”</i> <i>“It doesn’t actually kill but it gives indelible marks and some of them develop eye problem that they don’t know the origin”</i> <i>“The economy and everything in that family will not go on well, because as a father in the family you will not be able to go and fetch out what the family will eat and it will be shame and a mocking family and stigmatization”</i> <i>“The disease makes people to depend on others too much”</i>
Treatment of Onchocerciasis using Mectizan and Abendazole	Faith-based treatment regimen (belief, prayers)	<i>“They are mostly treated during campaigns; we give them mectizan in combination with Abendazole mostly during campaign.”</i> <i>“I don’t belief the drugs work”</i> <i>“Due to some peoples Religious belief, they seek the face of</i>

		<i>God or look for other alternative especially if they don't know the possible causes"</i>
poor community engagement/involvement poor programme Governance and Disillusionment	Lack of incentives for volunteers, Poor political commitment, Religious belief, poor attitude, poor road network, Hard to reach area Language barrier, Lack of community cohesion	<p><i>"People who work during the first phase, during the second phase, they were not be willing saying that the money given to them is not commiserate with the job."</i></p> <p><i>"I stopped working to give the drugs because the families were hostile"</i></p> <p><i>"There are people who are living in very remote areas that the drugs cannot reach there, bike cannot get there, others includes language barrier and religion"</i></p> <p><i>"Our leaders think of themselves more. They don't care"</i></p> <p><i>"They pay them a token at the end of their services from the donor agency...There is nothing coming from the community, or PHC"</i></p> <p><i>"Their mentality here is quite difference, even when you take a good thing to them. They will still politicize it. Immediately they see you they will ask what have you brought for us talkless of saying how to support, they will not..."</i></p>
Inequity in access	increase funding, community participation, poor Availability of Drugs Increasing awareness in hard to reach community	<p><i>"It's something that Government should take control because donor at a time, they may opt out. Like in other programs that we have... if it is Government own it will be sustainable"</i></p> <p><i>"Distribution shouldn't be only during campaign."</i></p> <p><i>"People should be aware; all those remote area, we should try as much as possible to reach out to them so that the people should be aware."</i></p> <p><i>"They can step down to the community, we have to meet the opinion leaders in the community, the elders also the religious leaders especially those churches that their religion serves as a barrier."</i></p> <p><i>"People from the Cameroon as they move in they should be able to access the drugs, So I think it should be drug that should be in the facility as they come they find it."</i></p>

241
242
243
244
245
246

247

248

249 **Discussion**

250 Improving treatment access and overall coverage are critical targets that must be vigorously
251 pursued if the set goal of elimination of onchocerciasis by year 2025 is to be achieved. However,
252 achieving this lofty goal should be predicated on understanding critical factors that impact on
253 treatment access, acceptance and overall onchocerciasis control measures. This study therefore
254 sought to understand perception, awareness and treatment experiences regarding CDTI in a rural
255 setting in Nigeria.

256

257 This study showed that about 68.8% of the respondents had knowledge about the cause of
258 onchocerciasis to be from bite of infected black fly. This is in tandem with various studies of
259 69.4% in South-East Ethiopia [10] and 70% in Guatemala [15] reported knowledge levels.
260 However, **on the contrary** studies by [13] in Bioko Island, Equatorial Guinea and [16] in Ogun
261 State of Nigeria reported lower percentages of 19.3% and 9.8% respectively. **This could be due**
262 **to differences in educational level in the study communities.**

263

264 It then follows that about 31% of the respondents in this study did not know that the bite of
265 infected Blackfly can cause onchocerciasis. This is in spite of seemingly moderately high
266 educational level of the respondents for most respondents (55.1%) had attained at least secondary
267 level of education. Similarly, in a study carried out in Enugu, Nigeria, more than half of the
268 respondents (57%) had no knowledge of the cause of onchocerciasis [12]. This thus reflects that
269 myths and misconceptions on the cause of onchocerciasis still persist in the study area with most

270 attributing the cause to beo curse from the gods (45.3%) and witchcraft (23.4%). This is similar
271 to the study carried out by [10]. Hence, observed misconceptions, myths, poor attitude and
272 practices toward predisposing factors for onchocerciasis infection in the study area. Erroneous
273 beliefs about onchocerciasis could lead to abandonment of personal protective measures and
274 other preventive practices [5,8,9,10].

275
276 The pervading ignorance and poor perception on onchocerciasis is evidently reflected with most
277 (64.9%) reported that good sanitation and personal hygiene against the small proportion that
278 suggested use of Mectizan (3.9%) and health education on prevention (2.4%) as viable
279 onchocerciasis prevention strategies. These x-ray the intertwined effects of lack of knowledge in
280 reinforcing inappropriate health-seeking behaviors that invariably influence treatment
281 distribution, acceptance and coverage [8,11,13].

282
283 Lack of knowledge and poor perception of onchocerciasis may equally not only manifest in
284 discriminatory and stigmatizing attitudes and practices with the consequential drive for poor
285 health- seeking behaviors that further limit access to mass drug (ivermectin) administration
286 (MDA) [4,17], but may also affect overall efficacy of ivermectin treatment, treatment coverage
287 and communities participation in onchocerciasis control programme [11,12,16,19]. These
288 perceptions and ignorance were also re-echoed as major themes from the key-informants
289 interviewed;

290 *“Most people in this community still belief that onchocerciasis is caused by witchcraft due to the*
291 *nature of the disease” (Key informant)*

292 *“When people fall sick which they don’t know the possible cause they will either say it is an*
293 *attack from their enemy or witchcraft” (Key informant)*

294

295 It was suggested that more than formal education may be required to bring about change that can
296 positively influence onchocerciasis elimination target [7,11,13,16]. More importantly, the
297 respondents are relatively young with a mean age of 31.9 ± 12.3 years and ought to have access
298 to general information often facilitated by modern technology that should be of benefit to
299 onchocerciasis prevention and control. This therefore becomes quite pivotal in the whole scheme
300 of onchocerciasis control, if sustained efforts at its elimination is to yield great results, the youths
301 as special group and this generation's successors must be appropriately targeted with basic
302 factual knowledge about onchocerciasis.

303
304 The few respondents that affirmed having onchocerciasis symptoms (11.1%) or family members
305 with such symptoms (17.6%) indicated the public health burden of the disease in the study area.
306 When the sample size ($n = 205$) is matched against the population ($N = 203,705$) for Akamkpa
307 LGA as at 2017, then, the extrapolation of onchocerciasis prevalence may be far above the
308 prevalence estimates of 10% reported in 2012 [5]. This is despite the fact that MDA of
309 ivermectin had been on in the study area for over seven years. Thematic analysis of the
310 qualitative aspect of this study strengthens the observation that onchocerciasis is a huge problem;

311
312 *“Onchocerciasis is definitely a problem; it affects the larger community in the Local Government*
313 *Area” (Key Informant)*

314 *“Yes, it's a major problem; as it is been called a neglected tropical disease” (Key Informant).*

315 Stigmatization, financial incapacitation and blindness were major socioeconomic variables that
316 can have negative effects on the family, community and society from onchocerciasis. These thus
317 strengthen the fact that onchocerciasis entrenches the vicious cycle of poverty and increases

318 dependency. The aforementioned were listed by [4,9,12,20], that opined the association of
319 onchocerciasis with poverty, unemployment and other social and economic consequences.

320
321 *“You know predominantly in Akamkpa, a larger number of them are farmers, especially those in*
322 *the interior, it affects them because most of them will not be able to go to Farm”*

323 *“Family that has somebody who is affected... the economy and everything in that family will not*
324 *go on well, because as a father in the family you will not be able to go and fetch out what the*
325 *family will eat and it will be shame and a mocking of family and stigmatization”*

326 *“it affects them because when it affects the eye, the eye is the mirror for everybody, if the eye is*
327 *affected, it means even the family, community or the whole Nation is affected.”*

328
329 Respondents’ indicated challenges to ivermectin uptake; non-availability of drugs (23.9%)
330 followed by lack of knowledge of where to get the drugs (9.8%) demonstrated inequity in access
331 to treatment. These observations are in consonance with [2,16,17,18] that inconsistent
332 availability of ivermectin has been implicated in low Community-directed treatment with
333 ivermectin (CDTI) programme success. It is more critical in areas with increased influx of
334 displaced and refugee populations as was experienced in Cross River State, Nigeria.

335
336 Other factors reported by respondents include dislike for the drugs (3.4%) and fear of
337 ivermectin-related adverse reactions (9.3%) were in agreement with [15,16] that reported fear of
338 adverse reaction as reason for non-compliance with intake of the drugs. Adverse events in
339 ivermectin treatment have also been acknowledged to lead to rejection of treatments by
340 communities [1,3,6]. Thus this could limit treatment coverage and impact on possible reinvasion
341 and perpetuate onchocerciasis endemic status of the study community.

342
343 The issue of payment for treatment (5.8%) and that oft high cost of treatment (2.9%) should be
344 source of concern in attaining elimination targets, given that CDTI are made almost entirely free-

345 of- charge to recipients in communities at risk. Made possible by multiple source donations,
346 coordination and collaborations [1,6,9,14,18].

347

348 **Conclusion**

349 Inconsistent availability of ivermectin, myths and misconceptions about cause of onchocerciasis
350 still pervades with the dangerous consequential drive for poor health- seeking behaviours,
351 discriminatory practices and poor treatment coverage. These findings may not be typical of the
352 study area. The awareness of treatment and knowledge about onchocerciasis is a prerequisite for
353 any disease control efforts. Better knowledge is shown to have a positive effect on prevention,
354 treatment seeking and adherence to treatment, hence facilitates reductions in the socioeconomic
355 burden of the disease. Moreover, integrating contextual knowledge about onchocerciasis in the
356 design of control strategies could be considered as a vantage point in the march towards
357 achieving elimination target.

358 **Ethics approval and consent to participate**

359 Ethical clearance to conduct this study was obtained from the Health Research Ethics Committee
360 of Cross River State Ministry of Health. The participants were briefed on the purpose of the
361 study and verbal consent obtained from them to enroll into the study. Participants who did not
362 wish to be included in the research were excluded. Participants were assured of strict handling of
363 data in confidentiality and anonymity.

364 **Competing interest**

365 The authors declare that we have no conflict of interest.

367 **References**

- 368 1. Centers for Disease Control and Prevention (CDC) Onchocerciasis. 2014;
 369 https://www.cdc.gov/parasites/onchocerciasis/health_professionals/index.html
 370
- 371 2. Weldegebreal F, Medhin G, Weldegebriel Z, Legesse, M. Knowledge, attitude and
 372 practice of community drug distributors' about onchocerciasis and community directed
 373 treatment with ivermectin in Quara District, North Western Ethiopia. *BMC Research*
 374 *Notes*. 2016; 9(1), 206.
 375
- 376 3. Opara KN, Fagbemi BO, Atting IA, Oyene UE, Okenu DM. Status of forest
 377 Onchocerciasis in the lower Cross River Basin Nigeria: Change in clinical and
 378 parasitological indices after six years of Ivermectin intervention. *Public Health*;
 379 2007;121: 202 – 207
 380
- 381 4. Umoke PC, Umoke M, Ene CU, Arua CC, Ede M. Perceived Economic Effects of
 382 Onchocerciasis Disease in Ebonyi State, Nigeria: Community Health Counselling
 383 Implication. *International Journal of Applied Engineering Research*, 2018; 13(21),
 384 15136-15142.
 385
- 386 5. Eyo KD. Knowledge of preventive measures of onchocerciasis among adult residents of
 387 Aningeje, Akamkpa Local Government Area of Cross River State, Nigeria. Unpublished
 388 Research Project, Department of Public Health, University of Calabar, Nigeria; 2016
- 389 6. WHO African Programme for Onchocerciasis Control (APOC). Rapid epidemiological
 390 mapping of Onchocerciasis in Nigeria. 2005; <http://www.who.int/apoc/onchocerciasis/en/>
 391
- 392 7. Hotez PJ. Control of Onchocerciasis: The next generation. *Lancet*. 2007; 369(9575):
 393 1979- 80
 394
- 395 8. Dissak-Delon FN, Kamga GR, Humblet PC, Robert A, Souopgui, J, Kamgno J, Godin I.
 396 Adherence to ivermectin is more associated with perceptions of community directed
 397 treatment with ivermectin organization than with onchocerciasis beliefs. *PLoS neglected*
 398 *tropical diseases*, 2017; 11(8), e0005849.
- 399 9. Charles JO, Ikpeme BM, Olaniran NS, Akpan AO, Charles AO, Ikoh MO. Biomedical
 400 paradigm and cultural perception of onchodermatitis in rural communities, Cross River
 401 State, Nigeria. *African Journal of Public Health*, 2007; 1(1): 57 – 60
 402
- 403 10. Weldegebreal F, Medhin G, Weldegebriel Z, Legesse M. Assessment of community's
 404 knowledge, attitude and practice about onchocerciasis and community directed treatment
 405 with Ivermectin in Quara District, north western Ethiopia. *Parasites & Vectors*, 2014;
 406 7(1), 98.

- 407
408
409
410
411
412
413
414
415
416
417
418
419
420
421
422
423
424
425
426
427
428
429
430
431
432
433
434
435
436
437
438
439
440
441
442
443
444
445
446
447
448
449
450
451
11. Wogu MD, Okaka CE. The knowledge, attitude and perception of onchocerciasis and ivermectin treatment by the people in Okpuje, Edo State, Nigeria; *International Journal of Biomedical and Health Sciences*; 2008; 4 (3): 121 - 125
 12. Ibe O, Onwujekwe O, Uzochukwu B, Ajuba M, Okonkwo P. Exploring consumer perceptions and economic burden of onchocerciasis on households in Enugu state, south-East Nigeria. *PLoS Neglected Tropical Diseases*, 2015; 9(11), e0004231.
 13. Alonso LM, Ortiz ZH, Garcia B, Nguema R, Nguema J, Ncogo P, *et al.* Knowledge, attitudes and practices towards onchocerciasis among population in Bioko Island, Equatorial Guinea; *Annals of Tropical Medicine and Public Health*; 2017; 10(5): 1228 – 1237. DOI: 10.4103/ATMPH.ATMPH_726_16
 14. Silumbwe1 A, Zulu J.M., Halwindi H, Jacobs C, Zgambo J, Dambe R, Chola M, Chongwe G, Michelo C. A systematic review of factors that shape implementation of mass drug administration for lymphatic filariasis in sub-Saharan Africa; *BMC Public Health* 2017; 17:484 DOI 10.1186/s12889-017-4414-5
 15. Richards Jr FO, Klein RE, de León O, Mendizábal-Cabrera R, Morales AL, Cama V, Rizzo N. A knowledge, attitudes and practices survey conducted three years after halting ivermectin mass treatment for onchocerciasis in Guatemala. *PLoS Neglected Tropical Diseases*, 2016; 10(6), e0004777.
 16. Surakat OA, Sam-Wobo SO, Ademolu KO, Adekunle MF, Adekunle ON, Monsuru AA, Ososanya A. Assessment of community knowledge and participation in onchocerciasis programme, challenges in ivermectin drug delivery, distribution and non-compliance in Ogun State, southwest Nigeria. *Infection, Disease & Health*. 2018;
 17. Brieger WR, Otusanya SA, Oke GA, Oshiname FO, Adeniyi JD. Factors associated with coverage in Community-directed treatment with Ivermectin for onchocerciasis control in Oyo State, Nigeria. *Tropical Medicine and International Health*; 2002; 7(1)11-18
 18. Colatrella B. *The Mectizan Donation Program: 20 years of successful collaboration - a retrospective*. *Annals of Tropical Medicine and Parasitology*; 2008; 102 (Suppl 1): 7-11.
 19. Braide EI, Obono MO, Bassey SA. Community participation in the control of onchocerciasis in Cross River State, Nigeria. *Acta Leiden*; 1990; 59(1-2):427- 432.
 20. Bawack EA. The socio-economic effects of blindness at the community and individual levels in the South-West region of Cameroon. 2018; Retrieved from <https://www.theseus.fi/handle/10024/153526>
 21. Ejemot-Nwadiaro RI. A guide to Biostatistics and Health Research Methods. DataPro Publishers, Calabar. 2009; ISBN 978-051-089-3

452
453

UNDER PEER REVIEW