

1 Understanding onchocerciasis perception and treatment experiences 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 treatment
8 access, acceptance and overall control measures are pivotal to the march towards elimination.
9

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

14 A cross-sectional descriptive study using mixed method. Data was collected using pretested
15 questionnaire and in-depth interview guide. Quantitative data was analysed using SPSS while the
16 in-depth interviews were audio taped, transcribed verbatim and thematic analysis done. Findings
17 were presented in frequencies, charts, percentages, tables and quotes. Tests of significance were
18 determined using Chi-square (χ^2) at significance level of 5%
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20 **Results:** Ignorance, myths and negative perception about the cause of onchocerciasis still
21 persist as 31.2% of the respondents did not know that the bite of infected Blackfly is the cause.
22 Attribution to curse from the gods (45.3%) and witchcraft (23.4%) are common. This poor
23 knowledge is associated with level of education ($p = 0.01$). Non-availability of drugs (23.9%)
24 and lack of knowledge on where to access ivermectin (9.8%) were the major challenges to
25 ivermectin uptake. Inequity in access to treatment identified from the thematic analysis.
26

27 **Conclusion:** Inconsistent availability of ivermectin, myths and misconceptions about cause of
28 onchocerciasis still pervades with the dangerous consequential drive for poor health- seeking
29 behaviors, discriminatory practices and poor treatment coverage. Appropriately integrating
30 contextual knowledge about onchocerciasis into the design control strategies may present a
31 vantage march towards achieving elimination target.

32
33 **Key words:** Onchocerciasis; ivermectin treatment; Onchocerciasis perception; inequity in access

34 **Running Title:** Onchocerciasis perception and treatment experiences
35

36 37 **Introduction**

38 Onchocerciasis (river blindness) a disease of poverty continues to place huge health, economic
39 and social burden on communities at risk. The disease is a major problem among rural
40 communities living in close proximity to rivers in sub-Saharan African countries. An estimated

41 25 million people are infected with about 1.3 million people visually impaired or blind as a result
42 of the disease [1, 2]. Nigeria is estimated to bear a significantly high burden of the disease with
43 32 endemic states including Cross River State [3, 4]. In Cross River State, almost all the 18 local
44 government areas (LGAs) are endemic for the disease and the onchocerciasis prevalence was
45 estimated to be 10% in 2012 [5], which may be gross underestimation given lack of credible
46 population data in this environment.

47
48 Community Directed Treatment with Ivermectin (CDTI) is the major control strategy adopted in
49 African countries by the African Program for Onchocerciasis Control (APOC). CDTI primarily
50 involves yearly mass drug administration (MDA) of Ivermectin. Despite the successes this
51 strategy has engendered [6,7,8], meeting target goal set for elimination of onchocerciasis seems
52 far-fetched [9,10,11]. However, ignorance, myths and misconceptions about onchocerciasis have
53 been implicated in the drag to elimination. These have equally been acknowledged to lead to
54 negligence in prevention and control measures and causes acceptance of inappropriate treatment
55 regimen.

56
57 It has been recognised that knowledge of history and cause of a health condition including the
58 whole continuum of epidemiology of the disease often promotes health-seeking behaviours and
59 encourages reduction of effects or elimination of the disease [9,11,12,13,14]). Silumbwe *et al*
60 [14] opined that often programme implementation strategies do not take into account the
61 contextual factors that impact on overall programme success. Some of the key factors that have
62 been suggested by many studies include; knowledge of cause and transmission of the infection,
63 perception of disease symptoms, socioeconomic burdens of the disease, first point of call or

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

66
67 In addition, lack of knowledge of transmission of onchocerciasis can also manifest in
68 discriminatory and stigmatizing attitudes towards those affected [10,15]. This in turn may
69 negatively affect the health-seeking behaviours of those affected by onchocerciasis [8,16]. This
70 may further limit access to ivermectin, acceptance of treatment and overall treatment coverage
71 [13,17].

72
73 Another crucial factor in this could be lack of close monitoring of drug treatment and distribution
74 by Community –directed Distributors (CDD) often occasioned by technical and logistics
75 limitations in their ability to deliver interventions [1, 2, 5, 18]. It has been equally suggested that
76 poor compliance to treatment may not be unrelated to long treatment duration (10 – 15 years),
77 interval between doses (one year) that can easily be forgotten and thus missed, adverse events in
78 ivermectin treatment often leading to rejection of treatments by communities [1,3,6]. Reinvasion
79 caused by limited treatment coverage area has also been implicated in low CDTI programme
80 success [15,17,19]. Perhaps this could be attributed to the inconsistent availability of ivermectin
81 in states and government’s inability to complement the efforts of APOC leading to poor
82 distribution and follow-up in affected communities [2,5,18].

83
84 To attain community participation and design socially/locally acceptable control strategies,
85 health program planners and implementers should be familiar with people’s knowledge, attitude
86 and practice in relation to onchocerciasis and other cultural innuendos that impact onchocerciasis
87 treatment access, coverage and other control measures [8,10]. The successful use of ivermectin at
88 community level requires a broad public health program designed to address barriers to

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

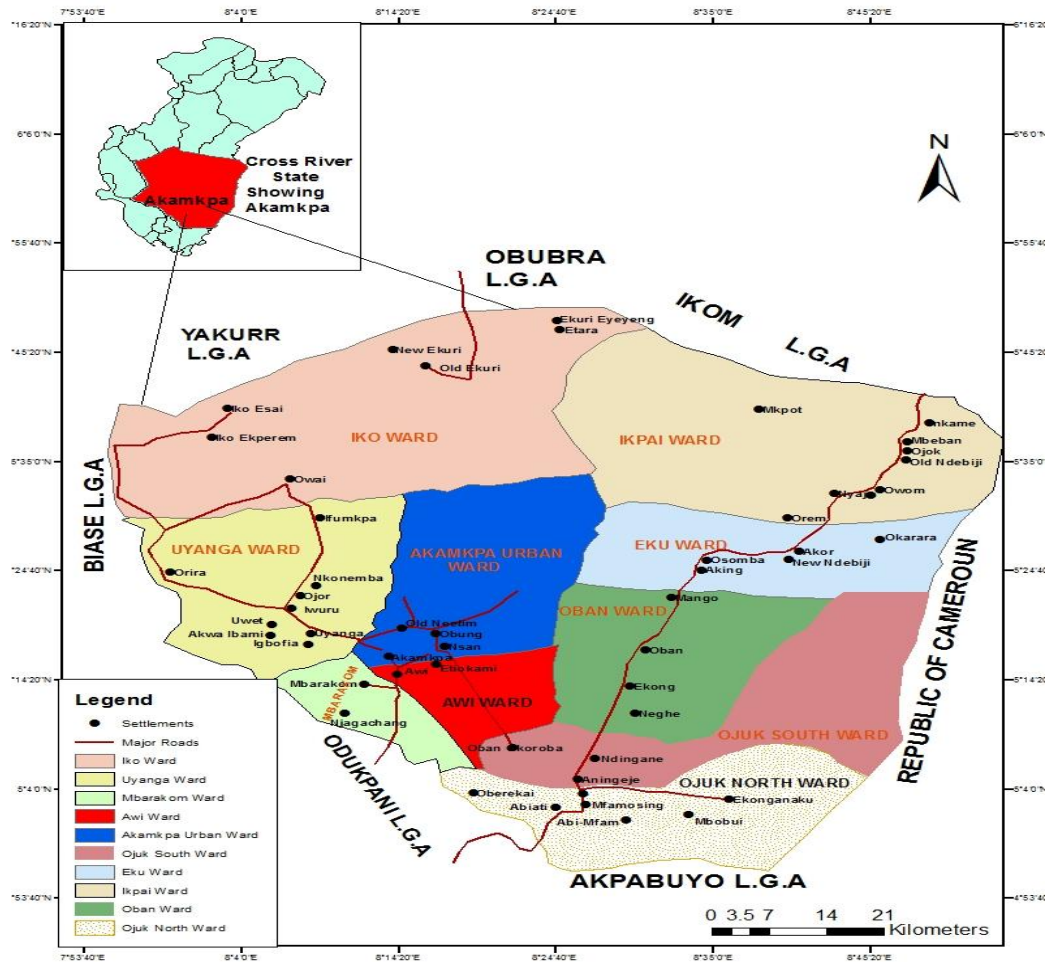
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98 **Research Methodology**

99 *Study setting*

100 The study setting was Akamkpa local government area (LGA) in Cross River State located in the
101 South-South region of Nigeria. It is one of the foci points of Onchocerciasis endemicity 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 10 political wards (Akamkpa Urban, Awi, Eku, Iko, Ikpai,
104 Mbarakom, Oban, Ojuk North, Ojuk South and Uyanya) and a projected population from the
105 2006 figures to 2017 of about 203,705 using annual growth rate of 3.0%. The study area has the
106 largest forest area in the state and a very fertile land, watered by many rivers, streams and
107 springs; veritable breeding ground for blackflies.

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

111 *Study design, sample size and sampling*

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

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

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

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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 them to enroll into the study.
146 Participants who did not wish to be included in the research were excused from the study.
147 Participants were provided all the necessary information about the research and were assured of
148 strict confidentiality and anonymity.

149

150 **RESULTS**

151 *Socio-demographic characteristics of respondents*

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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. Almost a half of the respondents were
156 married; 103 (50.7%). Respondents with a household size of 4- 6, were in the majority followed
157 distantly by respondents with 1 – 3- member household. Most of the respondents had attained
158 secondary level of education (113; 55.1%) with those with no formal education being the least
159 (6; 2.9%). The highest proportion of the respondents were self-employed (65; 31.7%), followed
160 by civil servants and farmers which were equally proportioned (40; 19.5%) amongst the
161 respondents. Most of the respondents had lived in the study area (Akamkpa LGA) for more than
162 15 years (74; 36.1%). The detailed data on socio-demographic characteristics of the respondents
163 is shown in Table 1.

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Table 1
Socio demographic characteristics of respondents, Akamkpa LGA, Cross River State

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

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169 ***Knowledge and perception on 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 attributes it to curse from the gods (29, 45.3%) and witchcraft (15, 23.4%). Cross
173 tabulation of knowledge about cause of onchocerciasis against level of education of survey

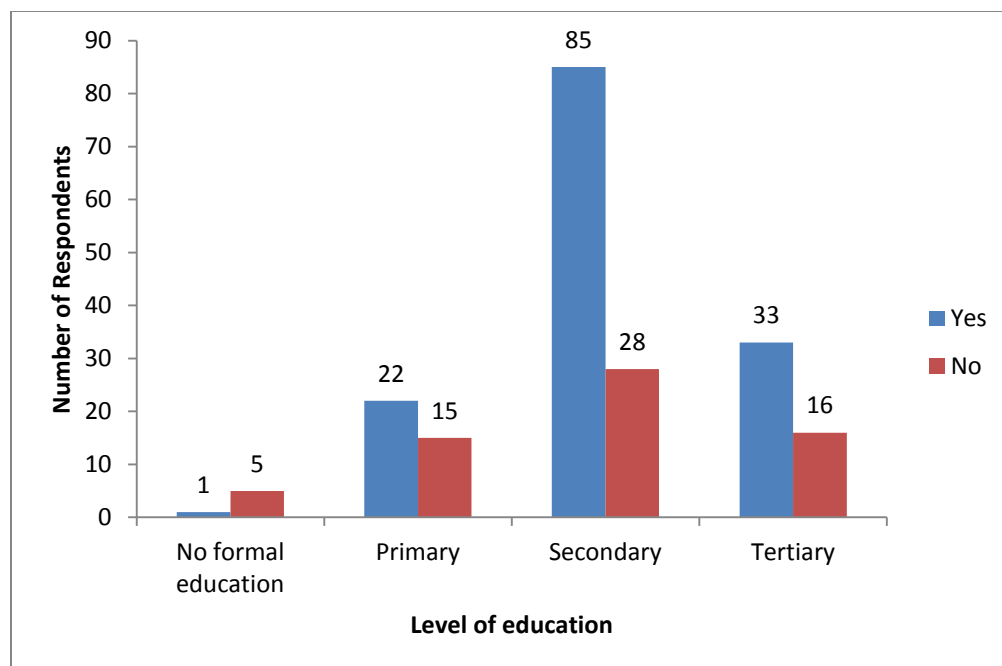
174 respondents (figure 2) indicated statistical significance ($\chi^2 = 11.32$; $p = 0.01$). This becomes all
175 the more significant given that majority of the respondents (55.1%) had attained at least
176 secondary level of education (Table 1).

177
178 Of the 205 survey respondents, 24 (11.7%) acknowledged that they suffer from onchocerciasis.
179 These were diagnosed at the health facility (66.7%); while 33.3% of those with onchocerciasis
180 were diagnose during mass screening exercise. There was also a reported knowledge of family
181 members suffering from onchocerciasis with 36 (17.6%) affirming to that. Majority of those had
182 one to two persons (51.3%) in the family with onchocerciasis (Table 2). This could be an
183 indication of how wide-spread onchocerciasis burden is in the study area.

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

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FIG 2: Knowledge of cause of Onchocerciasis by 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

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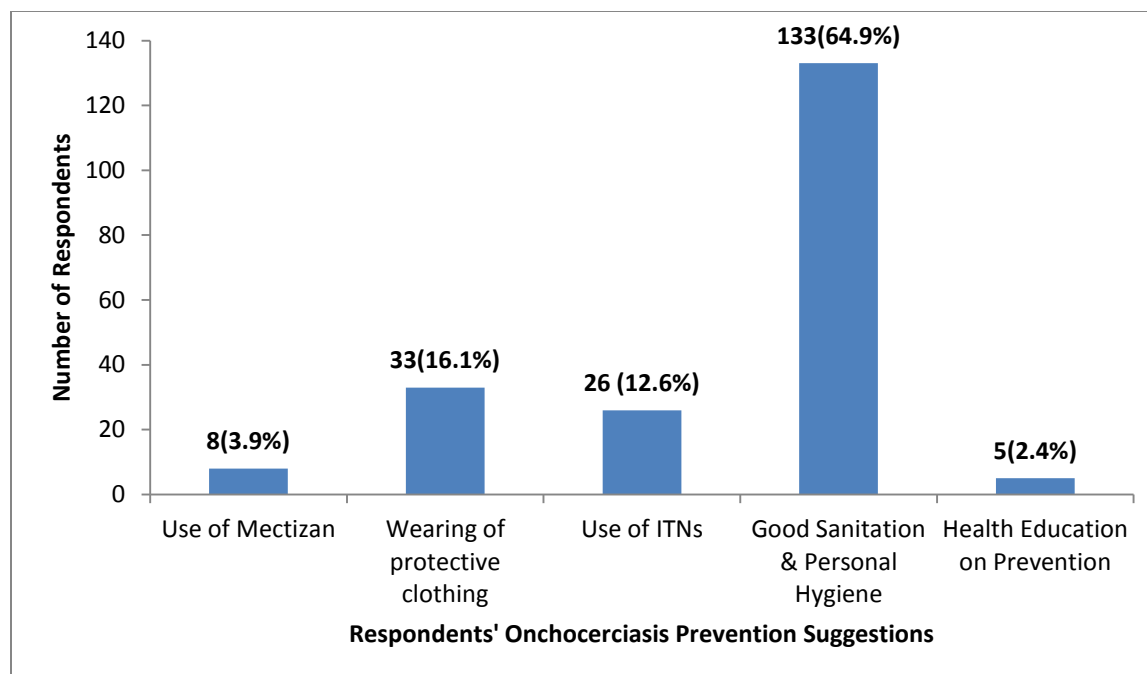
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205 *Access and uptake of ivermectin*

206 Community-directed distributors (CDDs) still remain the main stay of onchocerciasis treatment
207 (72.5%). Though health facilities (25.4%) and Patent Medicine Vendor, popularly known as
208 “Chemist”(2.4%) were reported as the source of treatment for the rest of the respondents. A
209 small proportion (5.8%) of the surveyed respondents reported paying for the treatment (Table 2).
210 This is significant as the Community-directed treatment with Ivermectin (CDTI) strategy is
211 designed as entirely free-of charge for the recipients. When this is tied to about 2.9% of the
212 respondents that indicated that cost of the ivermectin was a challenge to its uptake (Table 3), it
213 becomes noteworthy with respect to increasing treatment coverage and ultimately elimination
214 targets.

215
216 A significant proportion of the respondents reported having difficulties in accessing
217 onchocerciasis treatment services (Table 3). Majority indicated that lack of availability of drugs
218 (49; 23.9%) followed closely by lack of knowledge of where to get ivermectin (20; 9.8%). Other
219 access hindering factors reported by survey respondents included far distance to health facility
220 (9; 4.4%) and poor attitude of healthcare providers (9; 4.4%). Possible adverse drug reaction (12;
221 5.9%) and rejection of ivermectin (7; 3.4%) were also mentioned by survey respondents as
222 affecting the uptake of ivermectin.



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Fig 3: Reported Respondents' Onchocerciasis Prevention strategies

227 **Table 3**
228 **Challenges to ivermectin uptake**

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	Variables	*Frequency (n = 205)	
		Yes (%)	No (%)
a	Treatment drugs 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 is 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)

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

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 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	Treatment by faith, 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 God or look for other alternative especially if they don't know the possible causes</i>
poor community engagement/involvement	Lack of incentives for volunteers,	<i>People who work during the first phase, during the second phase, they were not be willing saying that the money given</i>

<p>poor programme Governance and Disillusionment</p>	<p>Poor political commitment, Religious belief, poor attitude, poor road network, Hard to reach area Language barrier, Lack of community cohesion</p>	<p><i>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>
<p>Inequity in access</p>	<p>increase funding, community participation, poor Availability of Drugs Increasing awareness in hard to reach community</p>	<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>

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244 **Discussion**

245 Improving treatment access and overall coverage are critical targets that must be vigorously
246 pursued if the set goal of elimination of onchocerciasis by year 2025 is to be achieved. However,
247 achieving this lofty goal should be predicated on understanding critical factors that impact on
248 treatment access, acceptance and overall onchocerciasis control measures. This study therefore
249 sought to understand perceptions and treatment experiences regarding onchocerciasis in a rural
250 setting in Nigeria.

251
252 The findings of this study show that about 68.8% of the respondents had knowledge that the
253 cause of onchocerciasis is by bite of black flies. Such knowledge varies across studies with
254 69.4% in South-East Ethiopia [10] and 70% in Guatemala [15] reporting similar knowledge
255 levels. However, studies by [13] in Bioko Island, Equatorial Guinea and [16] in Ogun state of
256 Nigeria reported even lower percentages of 19.3% and 9.8% respectively.

257
258 It then follows that about 31% of the respondents in this study did not know that the bite of
259 infected Blackfly can cause onchocerciasis. This is in spite of seemingly moderately high
260 educational level of the respondents. Most of the survey respondents (55.1%) had attained at
261 least secondary level of education. Similarly, in a study carried out in Enugu, Nigeria, more than
262 half of the respondents (57%) had no knowledge of the cause of onchocerciasis [12]. This thus
263 reflects that myths and misconceptions on the causes of onchocerciasis still persist in the study
264 area as most of the respondents in this study attributed the cause of onchocerciasis to curse from
265 the gods (29, 45.3%) and witchcraft (15, 23.4%), this is similar to the study carried out by [10].
266 Hence, among other consequences, this observation of ongoing misconceptions and myths from

267 our survey may lead to the poor attitude and practices toward predisposing factors for
268 onchocerciasis infection in the study area. Erroneous beliefs about onchocerciasis could lead to
269 abandonment of personal protective measures and other preventive practices [5,8,9,10].

270

271 The pervading ignorance and poor perception on onchocerciasis is evidently reflected in the
272 respondents suggested prevention strategies. Most (64.9%) reported that good sanitation and
273 personal hygiene were best for onchocerciasis prevention and control. This is against the small
274 proportion that suggested use of Mectizan (3.9%) and health education on prevention (2.4%)
275 viable onchocerciasis prevention strategies. These x-ray the intertwined effects of lack of
276 knowledge in reinforcing inappropriate health-seeking behaviors that invariably influence
277 treatment distribution, acceptance and coverage [8,11,13].

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

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

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

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291 In addition to the foregoing, the fact that the respondents' level of knowledge on the transmission
292 of onchocerciasis had a statistical significance ($\chi^2 = 11.32$; $p = 0.01$) with their highest attained
293 level of education suggests that more than formal education may be required to bring about
294 change that can positively influence onchocerciasis elimination target [7,11,13,16]. This also
295 significantly ties to the fact that this study's respondents are relatively young with a mean age of
296 31.9 ± 12.3 years and ought to have access to general information often facilitated by modern
297 technology that should be of benefit to onchocerciasis prevention and control. This therefore
298 becomes quite pivotal in the whole scheme of onchocerciasis control, if sustained efforts at its
299 elimination is to yield great results, the youths as special group and this generation's successors
300 must be appropriately targeted with basic factual knowledge about onchocerciasis.

301
302 The proportion of study respondents that reported experiencing onchocerciasis symptoms
303 (11.1%) or having family members with such symptoms (17.6%) provides insight to the
304 magnitude of onchocerciasis as a public health burden in the study environment. When the
305 sample size (205) used in this survey is matched against the total population (203,705) of
306 Akamkpa LGA as at 2017, then, the extrapolation of onchocerciasis prevalence may be far above
307 the prevalence estimates of 10% reported in 2012 [5]. This is despite the fact that MDA of
308 ivermectin has been on in the study area for over seven years. Findings of the qualitative aspect
309 of this study supports that onchocerciasis is a problem;

310
311 *“Onchocerciasis is definitely a problem; it affects the larger community in the Local Government*
312 *Area” (Key Informant)*

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

314 Stigmatization, financial incapacitation and blindness were major themes acknowledged from
315 qualitative analysis of this study. The negative effects of Onchocerciasis on the family,
316 community and society were also identified by the respondents. These findings not only buttress
317 the health burden posed by onchocerciasis but also strengthen the fact that Onchocerciasis
318 entrenches the vicious cycle of poverty, incapacitates and increases dependency. The
319 aforementioned are supported by [4,9,12,20], that opined the association of onchocerciasis with
320 poverty, stigmatization, discrimination, unemployment and other social and economic
321 consequences.

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

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

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

330
331 The preceding statements may thus be suggestive of ongoing challenges to ivermectin uptake
332 experienced by respondents. Significant proportion of respondents indicated that lack of
333 availability of drugs (23.9%) followed by lack of knowledge of where to get the drugs (9.8%)
334 were the chief ivermectin uptake-drag. These could be a proxy of inequity in access to treatment.
335 These findings are in consonance with [2,16,17,18] that inconsistent availability of ivermectin
336 has been implicated in low Community-directed treatment with ivermectin (CDTI) programme
337 success. This is all the more critical in areas experiencing increased influx of displaced and
338 refugee populations as its being experienced in Cross River State, Nigeria.

339

340 Other factors reported by respondents include dislike for the drugs (3.4%) and fear of
341 ivermectin-related adverse reactions (9.3%). These are in agreements with [15,16] that reported
342 fear of adverse reaction as reason for non-compliance with intake of the drugs. Adverse events in
343 ivermectin treatment have also been acknowledged to lead to rejection of treatments by
344 communities [1,3,6]. This thus limits treatment coverage and impacts on possible reinvasion and
345 perpetuation of onchocerciasis endemicity.

346
347 Another onchocerciasis treatment experience reported by respondents is the issue of payment for
348 treatment (5.8%) with small proportion but significant number of respondents indicating that
349 high cost of treatment (2.9%) was a challenge to ivermectin uptake. This becomes a concerning
350 finding as regards onchocerciasis elimination targets, given that CDTI are made almost entirely
351 free-of- charge to recipients in communities at risk. Made possible by multiple source donations,
352 coordination and collaborations [1,6,9,14,18].

354 **Conclusion**

355 Inconsistent availability of ivermectin, myths and misconceptions about cause of onchocerciasis
356 still pervades with the dangerous consequential drive for poor health- seeking behaviors,
357 discriminatory practices and poor treatment coverage. These findings may not be typical of the
358 study area. Thus these treatment experiences and knowledge level about onchocerciasis may be
359 wide spread among communities at risk. Therefore, improved consumer knowledge of disease
360 causation is considered a prerequisite for any disease control efforts. Better knowledge is shown
361 to have a positive effect on prevention, treatment seeking and adherence to treatment, hence
362 facilitates reductions in the socioeconomic burden of the disease. Moreover, appropriately

363 integrating contextual knowledge about onchocerciasis into the design control strategies may
364 present a vantage march towards achieving elimination targets.

365 **Ethics approval and consent to participate**

366 Ethical clearance for conduct of this study was obtained from the Cross River State Ministry of
367 Health, Health Research Ethics Committee. The research participants were briefed on the
368 purpose of the study and verbal consent was obtained from them to enroll into the study.
369 Participants who did not wish to be included in the research were excused from the study.
370 Participants were provided all the necessary information about the research and were assured of
371 strict confidentiality and anonymity.

372 **Competing interest**

373 The authors declare that we have no competing interest.

374

375 **References**

- 376 1. Centers for Disease Control and Prevention (CDC) Onchocerciasis. 2014;
377 https://www.cdc.gov/parasites/onchocerciasis/health_professionals/index.html
378
- 379 2. Weldegebreal F, Medhin G, Weldegebriel Z, Legesse, M. Knowledge, attitude and
380 practice of community drug distributors' about onchocerciasis and community directed
381 treatment with ivermectin in Quara district, North Western Ethiopia. *BMC Research*
382 *Notes*. 2016; 9(1), 206.
383
- 384 3. Opara KN, Fagbemi BO, Atting IA, Oyene UE, Okenu DM. Status of forest
385 Onchocerciasis in the lower Cross River Basin Nigeria: Change in clinical and
386 parasitological indices after six years of Ivermectin intervention. *Public Health*;
387 2007;121: 202 – 207
388
- 389 4. Umoke PC, Umoke M, Ene CU, Arua CC, Ede M. Perceived Economic Effects of
390 Onchocerciasis Disease in Ebonyi State, Nigeria: Community Health Counselling

- 391 Implication. *International Journal of Applied Engineering Research*, 2018; 13(21),
392 15136-15142.
393
- 394 5. Eyo KD. Knowledge of preventive measures of onchocerciasis among adult residents of
395 Aningeje, Akamkpa Local Government Area of Cross River State, Nigeria. Unpublished
396 Research Project, Department of Public Health, University of Calabar, Nigeria; 2016
- 397 6. WHO African Programme for Onchocerciasis Control (APOC). Rapid epidemiological
398 mapping of Onchocerciasis in Nigeria. 2005; <http://www.who.int/apoc/onchocerciasis/en/>
399
- 400 7. Hotez PJ. Control of Onchocerciasis: The next generation. *Lancet*. 2007; 369(9575):
401 1979- 80
402
- 403 8. Dissak-Delon FN, Kamga GR, Humblet PC, Robert A, Souopgui, J, Kamgno J, Godin I.
404 Adherence to ivermectin is more associated with perceptions of community directed
405 treatment with ivermectin organization than with onchocerciasis beliefs. *PLoS neglected*
406 *tropical diseases*, 2017; 11(8), e0005849.
- 407 9. Charles JO, Ikpeme BM, Olaniran NS, Akpan AO, Charles AO, Ikoh MO. Biomedical
408 paradigm and cultural perception of onchodermatitis in rural communities, Cross River
409 State, Nigeria. *African Journal of Public Health*, 2007; 1(1): 57 – 60
410
- 411 10. Weldegebreal F, Medhin G, Weldegebriel Z, Legesse M. Assessment of community's
412 knowledge, attitude and practice about onchocerciasis and community directed treatment
413 with Ivermectin in Quara District, north western Ethiopia. *Parasites & Vectors*, 2014;
414 7(1), 98.
415
- 416 11. Wogu MD, Okaka CE. The knowledge, attitude and perception of onchocerciasis and
417 ivermectin treatment by the people in Okpuje, Edo State, Nigeria; *International Journal*
418 *of Biomedical and Health Sciences*; 2008; 4 (3): 121 - 125
419
- 420 12. Ibe O, Onwujekwe O, Uzochukwu B, Ajuba M, Okonkwo P. Exploring consumer
421 perceptions and economic burden of onchocerciasis on households in Enugu state, south-
422 East Nigeria. *PLoS Neglected Tropical Diseases*, 2015; 9(11), e0004231.
423
- 424 13. Alonso LM, Ortiz ZH, Garcia B, Nguema R, Nguema J, Ncogo P, *et al.* Knowledge,
425 attitudes and practices towards onchocerciasis among population in Bioko Island,
426 Equatorial Guinea; *Annals of Tropical Medicine and Public Health*; 2017; 10(5): 1228 –
427 1237. DOI: 10.4103/ATMPH.ATMPH_726_16
428
- 429 14. Silumbwe1 A, Zulu J.M., Halwindi H, Jacobs C, Zgambo J, Dambe R, Chola M,
430 Chongwe G, Michelo C. A systematic review of factors that shape implementation of
431 mass drug administration for lymphatic filariasis in sub-Saharan Africa; *BMC Public*
432 *Health* 2017; 17:484 DOI 10.1186/s12889-017-4414-5
433
- 434 15. Richards Jr FO, Klein RE, de León O, Mendizábal-Cabrera R, Morales AL, Cama V,
435 Rizzo N. A knowledge, attitudes and practices survey conducted three years after halting

- 436 ivermectin mass treatment for onchocerciasis in Guatemala. *PLoS Neglected Tropical*
437 *Diseases*, 2016; 10(6), e0004777.
- 438
- 439 16. Surakat OA, Sam-Wobo SO, Ademolu KO, Adekunle MF, Adekunle ON, Monsuru AA,
440 Ososanya A. Assessment of community knowledge and participation in onchocerciasis
441 programme, challenges in ivermectin drug delivery, distribution and non-compliance in
442 Ogun State, southwest Nigeria. *Infection, Disease & Health*. 2018;
- 443 17. Brieger WR, Otusanya SA, Oke GA, Oshiname FO, Adeniyi JD. Factors associated with
444 coverage in Community-directed treatment with Ivermectin for onchocerciasis control in
445 Oyo State, Nigeria. *Tropical Medicine and International Health*; 2002; 7(1)11-18
446
- 447 18. Colatrella B. The Mectizan Donation Program: 20 years of successful collaboration - a
448 retrospective. *Annals of Tropical Medicine and Parasitology*; 2008; 102 (Suppl 1): 7-11.
449
- 450 19. Braide EI, Obono MO, Basse SA. Community participation in the control of
451 onchocerciasis in Cross River State, Nigeria. *Acta Leiden*; 1990; 59(1-2):427- 432.
452
- 453 20. Bawack EA. The socio-economic effects of blindness at the community and individual
454 levels in the South-West region of Cameroon. 2018; Retrieved from
455 <https://www.theseus.fi/handle/10024/153526>
456
- 457 21. Ejemot-Nwadiaro RI. A guide to Biostatistics and Health Research Methods. DataPro
458 Publishers, Calabar. 2009; ISBN 978-051-089-3
459
- 460