FACTORS AFFECTING COMMUNITY PARTICIPATION IN THE CDTI PROGRAM IN MOROGORO, TANZANIA

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Abstract
Background: Up to 4 million people in Tanzania are at risk for the parasitic disease onchocerciasis. A treatment program, Community-Directed Treatment with Ivermectin (CDTI), has made significant gains in prevention and treatment. Understanding factors affecting participation could help boost treatment coverage and sustain gains made in controlling onchocerciasis in endemic areas.

Purpose: To explore community-perceived factors related to participation in and sustainability of the CDTI program in southwest Tanzania.

Methods: Multilevel triangulation design using surveys, focus group discussions (FGDs), and semistructured interviews to collect data in two villages in the Morogoro Rural District of Tanzania. In total, 456 villagers participated in the survey and 42 in FGDs. Five community-directed distributors (CDDs) and three community health workers were interviewed.

Findings: High levels of awareness of onchocerciasis (90%) and methods of prevention and treatment (95%) were reported. Over 75% of participants knew how ivermectin was distributed and 74% have taken the drug. Over 90% of villagers knew that distribution of the drug was for treatment and prevention. Only 43% knew the cause of onchocerciasis. Through FGDs, villagers reported barriers to participation, including lack of comprehensive understanding of the disease, fears of medication, distrust of the method determining dose, lack of health education materials, insufficient CDD-resident communication, and inflexible drug distribution mechanisms.

Conclusions: Sustaining programs without supporting growth of CDDs and reinforcing education of communities could lead to a decrease in treatment and an increase in the public health threat. This research uncovered a need for more effective community education and sensitization.

Clinical Relevance: Understanding barriers to participation in community-based programs can assist public health and community health nurses and key stakeholders including Ministries of Health and local and regional health systems in the development of education and support materials to enhance health literacy and encourage program participation.

Up to 4 million people in Tanzania, 10% of the population, are at risk for contracting a parasitic disease known as onchocerciasis (Mweya et al., 2007; World Health Organization [WHO], 2009). Prolonged exposure to the parasite that causes onchocerciasis can lead to unrelenting itching, chronic skin changes, and visual impairment or complete blindness (Amazigo et al., 2006). Twenty countries in sub-Saharan Africa along with Yemen and...
countries in Central America have endemic areas. All told, 120 million people worldwide are at risk (WHO, n.d.b). In Tanzania, close to 6,000 villages are meso- or hyperendemic for onchocerciasis (Mweya et al., 2007; WHO, 2009). Villages close to fast-flowing waters where the parasite’s vector, the black fly, breeds are at risk. The microfilariae of the parasite *Onchocerca volvulus* are transferred from an infected person to the fly during a bite, then transferred back to a human after 1 to 3 weeks. The larva then migrates to the host’s subcutaneous tissue, where it creates a nodule in which to fully mature. Once mature, the adult female worms can produce up to 2,000 microfilariae per day (Amazigo et al., 2006). The death of the microfilariae causes an intense pruritic reaction in the host.

Control efforts in Tanzania are focused on treatment and prevention of infection using the drug ivermectin (supplied at no cost through Merck’s Mectizan Donation Program). Onchocerciasis is treatable with an annual dose of ivermectin, but as the medication kills the microfilariae and not the adult parasite, treatment for 15 or more consecutive years for those who have contracted the disease and those at risk in endemic areas is necessary. Efforts to control onchocerciasis using improved sanitation and hygiene are inadequate, and the terrain of endemic areas in Tanzania makes spraying insecticide along the waterways for vector control (a method used in West Africa) ineffective (Mweya et al., 2007).

The community-directed treatment with ivermectin (CDTI) program, developed and overseen by the African Program for Onchocerciasis Control (APOC), is an avenue for sustained treatment and is community based and operated, allowing local ownership of the program through decision making about the need for treatment, logistics and resources for distribution, and empowerment over this health issue (World Bank, 2014). Local health systems, with the involvement of interested nongovernmental organizations and nongovernmental development organizations, coordinate the program, and local people appointed by the community, known as community-directed distributors (CDDs), are responsible for the distribution of the medication and record keeping. Exploring the community-perceived factors affecting participation in the CDTI program was the purpose of this study.

At the heart of the program are the CDDs, local members of the community, chosen by the community to distribute the medication either from a central location in the village or by going house to house. Community members 5 years of age and older are encouraged to take a dose of ivermectin, calculated by measuring height with a ruler. At the initiation of the campaign in each village, CDDs receive training in order to educate about the disease, its symptoms, the medication program, potential side effects from the medication, how to measure people to establish the correct dose, and keeping a written log of the treatment status of all villagers. The initial training is held for 1 day, and yearly refresher training is recommended by APOC.

Community participation in the yearly CDTI program is the only proven approach to manage symptoms and prevent disease (APOC, 2007a). WHO’s definition of sustainability of the CDTI program requires that at least 65% of the community take the medication annually (APOC, 2004). Important factors affecting participation in the CDTI program are perceptions by the individuals and communities about the disease, treatment, and CDTI program (APOC, 2007a). Multiple factors, both facilitators and barriers, that affect the success of onchocerciasis control efforts have been identified in the literature (Akogun, Akogun, & Audu, 2000; Amazigo et al., 2007; Brieger, Otusanya, Oke, Oshiname, & Adeniyi, 2002; Katabarwa, Habomugisha, & Richards, 2002; Lakwo & Gasarasi, 2006; Nuwaha, Okware, & Ndyomugyenyi, 2004, 2005).

Program success is evident by symptom relief, decrease in onchocerciasis-related sequelae, decline in transmission rates of disease, decrease of disability-adjusted life years (DALYs) attributed to the disease, and increasing productivity (World Bank, 2014). Over time, CDTI can lead to fewer endemic areas and an overall decrease in the public health and economic threat from the disease. Coffeng et al. (2013) evaluated the impact of the program and estimated that between 1995 and 2010, mass treatment with ivermectin averted 8.2 million DALYs and will avert another 9.2 million between 2011 and 2015. External funding for this program was set to end in 2015, with communities and local and national governments required to continue the distribution of medication for those at risk. APOC’s intent was to withdraw external funding starting in 2005 after 5 years of the treatment program; however, this was too soon to ensure sustainability (WHO, n.d.a). Rakers et al. (2009) found that after 1 year of loss of external funding, treatment rates in two Nigerian states decreased by 59%, highlighting the need for continued organized funding efforts. Without sustainable programs, communities can experience a recurrence of symptoms, and the cycle of poverty and poor health outcomes will persist or exacerbate. This situation exemplifies challenges that keep Tanzania and other sub-Saharan African countries from reaching their full health and economic potential. Continuation of the control efforts generated by the CDTI program through local government-sponsored health systems and interested development partners is required. An understanding of
Factors affecting participation in the program at the village level can highlight the strengths and challenges of future sustainability without additional APOC funding.

Methods

A multilevel mixed method approach was used, which included a cross-sectional survey of the local population, focus group discussions (FGDs) with community members, and interviews with CDDs and community health workers (CHWs). This method was selected in order to capture multiple perspectives from people involved in the CDTI program in the community and to efficiently use time and resources when collecting data in the field.

Setting and Population

The settings for this research were the subvillages of Tandai (population ~1,300) and Kizinga (population ~1,700) in the Morogoro Rural District of Tanzania. Both subvillages had established CDTI programs. Tandai’s program has been in place since 2006 and has three people distributing medication in the community, while Kizinga’s program has operated since 2004 and has 16 drug distributors. The percentage of the population in Tandai taking ivermectin over 5 years of distribution has ranged from 64% to 90%, and Kizinga’s rates have ranged from 39% to 75% (D. Kabudi, personal communication, August 10, 2011).

Data Collection

Community members 15 years of age and older were recruited to participate in the survey by going house to house. The research assistants, researcher, and CDTI program team member worked in pairs, and one group went east and the other went west from a central point in each village. The following day, the pairs split again, with one group going north and the other south. All households were approached until the data collection came to an end due to lack of light. The research assistants asked if any members of the household were interested in taking part in the study by using a recruitment script and then obtained written consent. FGD participants were recruited by convenience sampling during survey gathering in Tandai and through a local leader and CDD in Kizinga. All CDDs and CHWs were invited to participate in the semistructured interviews. Interview questions were based on typical roles of CHWs, as well as questions specific to the CDTI program. All FGDs and interviews were conducted in Kiswahili and audiotaped with permission of the participants.

Ethical Clearance

Ethical clearance was obtained from the University of Cincinnati Institutional Review Board and the National Institute of Medical Research in Tanzania. Research permission was obtained from the Tanzania Commission of Science and Technology. Permission was sought from district and village leaders. Informed consent was obtained for all participants in the study.

Data Analysis

Survey, FGD, and interview data were analyzed separately and then reviewed simultaneously. Results were compared for areas of convergence (same or similar categories are found across at least two of the three methods), divergence (an opposite finding related to the same categories from the other methods), and unique findings (categories that are only found in one of the methods). This allowed for a comparison of categories developed through the data analysis of each type of data collection.

Surveys. Frequencies, percentages, and crosstabs based on gender were calculated using SPSS 18 (SPSS Inc., Chicago, IL, USA). Open-ended survey responses were translated and coded into categories. The categories were given number codes and analyzed by gender. In Tandai, 182 surveys were collected, with two excluded questions specific to understanding what people know about onchocerciasis, its treatment, and the role of CDDs and CHWs. To establish content validity, the survey was reviewed by four experts, two for content on onchocerciasis and the CDTI program and two for language after translation from English to Swahili. Research assistants from the community and members of the district CDTI program team administered the oral survey after a training session reviewing the survey questions and making slight adjustments based on local language variances. FGD data were gathered with community members through a core set of predetermined questions. These questions were developed based on prior studies using FGDs to determine knowledge about onchocerciasis and the CDTI program (Akogun et al., 2000; Brieger et al., 2002; Lakwo & Gasarasi, 2006; Nuwaha et al., 2004) and specific information related to CDDs and CHWs. Semistructured interviews were held with the CHW and both CDDs in Tandai and both CHWs and 3 of 16 CDDs in Kizinga. Interview questions were based on typical roles of CHWs, as well as questions specific to the CDTI program. All FGDs and interviews were conducted in Kiswahili and audiotaped with permission of the participants.
due to incomplete data. In Kizinga, 300 surveys were collected, with 276 used for final analysis. Despite training prior to the oral administration of surveys in Kizinga, the misinterpretation of a survey question by a research assistant required the elimination of 24 surveys, which was a limitation in this study. Three FGDs were held in Tandai (women who took the medication, men who took the medication, and men who did not take the medication), with a total of 15 participants, while four FGDs with a total of 27 people were held in Kizinga (also included a group of women who did not take the medication). A total of three CHWs and five CDDs participated in individual interviews.

FGDs and semistructured interviews. Field notes were taken and all FGDs and interviews were audiotaped, transcribed in Kiswahili, then translated into English, and back-translated into Kiswahili for accuracy of translation. Content analysis was used for FGDs and interviews. The unit of analysis was the entire transcript for each session. Open coding was used and notes taken to describe the content. Categories were created, followed by grouping of the data in order to collapse categories, followed by abstraction into main categories. Analysis was managed through the HyperResearch qualitative software program (ResearchWare Inc., Randolph, MA, USA).

Results

In Tandai, 81% of survey respondents were between the ages of 20 and 59 years and 55% were female. Participants between 20 and 59 years of age in Kizinga comprised 69% of the total, with females making up 60% of respondents. Ninety percent and 51% of participants in Tandai and Kizinga, respectively, were aware of a disease causing itching, while 92% and 89%, respectively, were aware of a disease called onchocerciasis. The majority of respondents in both villages knew there was treatment for onchocerciasis, how treatment is given, and that the drug is given yearly. However, less than half of participants knew the cause of onchocerciasis. (See Table 1 for survey results pertaining to knowledge of onchocerciasis, treatment, and participation in the CDTI program.)

Survey

An open-ended survey question asked why community members would or would not participate in the treatment program. Among those responding to this question, 85% ($n = 142$) in Tandai and 96% ($n = 237$) in Kizinga said people participate for prevention or treatment of the disease onchocerciasis. The most common responses in Tandai for not participating were: absence from the village at the time of distribution (42%), not having enough information (23%), and fear of taking the drug (12%). In Kizinga, responses included: don’t see the importance or because they aren’t sick and don’t need medication (56%), disagreement with how the dose of ivermectin is calculated (8%), and fears associated with the medication (8%).

FGDs

The FGD results with villagers in both communities found a lack of knowledge about the disease as a factor in participation. Even people who took the drug thought that education could be improved to encourage more people to take the medication. The following remark from a villager taking part in the focus groups relate to the lack of information-knowledge-education in the community: “They [CDDs] have no information, they just tell them there is this disease that you need to prevent. They don’t explain what are the symptoms, causes etc.” (woman in Kizinga who did not take the medication).

A thread of questioning during the FGDs in Kizinga centered around what types of questions the participants had about the medication or the CDTI program. The following questions from women who did not take the medication illustrate a lack of information or knowledge about the drug and the disease: “What causes the disease to the extent that we need to take the drug?” “What are the symptoms?” and “How was this place discovered to have onchocerciasis?”

Distrust of the method to calculate the dose of ivermectin and access to the medication were also found as factors in participation in the CDTI program. Other medications dispensed when ill, including antimalarials, are based on weight, and being weighed is considered part of an examination. There is distrust because measuring height is not seen as an examination: “Me, I don’t understand how the ruler can give diagnosis of a disease. . . . In other diseases you are examined by a thermometer to identify your disease” (man in Kizinga who did not take the medication). “They measure height and not weight that is why I don’t take the drug. If I were measured weight and height I would have ascertained that measurement correlate with the drug” (woman in Kizinga who did not take the medication).

In terms of access, the participants in Tandai stated that missing the distributor during the house to house campaign meant there was no way to get the dose until the following year:

I have been seeing people with the WEO [Ward Executive Officer] talking about onchocerciasis and filling
certain registers but we don’t know what the program is all about. I thought it is for few people. I have never been approached. (Man in Tandai who did not take the medication)

Finally, CDDs’ lack of knowledge and villagers not trusting the CDDs because they are not medically trained were identified by the focus group participants in Tandai. This category is seen as important by participants, particularly for community mobilization, to increase the numbers of people taking the drug: “[CDD] should get more education on how to approach, educate, and mobilize to take the drug” (man in Tandai who took the medication). “Some people don’t take the medicine because they don’t trust the CDDs . . . they are seen as people who don’t have medical qualification” (woman in Tandai who took the medication).

Interviews

Lack of understanding of the disease and treatment and misconceptions about the medication (drug causes sterility or impotency, fear of drug interactions) were found during the interviews with the CDDs and CHWs. When people refuse the drug, the CDDs state that they try to get them to participate through educating, but they lack materials to take when going house to house during distribution. This is seen as a barrier to participation. A low level of understanding in the community is seen as a contributor to people refusing to take the medication: “Usually we provide knowledge to a particular person, then he or she took the medicine and swallow before us” (CDD in Kizinga). “CDDs do not have tools for educating people” (CDD in Tandai).

In Tandai, access to medication was also identified by CDDs and CHWs as a barrier to participation. Medication is available at the central health center for those who miss the house-to-house distribution. However, there is no way to leave information at the house where they missed the distribution and can still get the medication if they go to the dispensary: “I give people drug. For those who missed, we take the drug back to the dispensary. In case someone missed and want we go to bring from the health facility and give, we cannot” (CHW in Tandai).

In Kizinga, misconceptions and suspicions were the main factors involved when community members chose not to participate as noted by the CDDs. According to the CDDs, fear of impotency and sterility are still quoted from villagers as the reason that they will not take the medication.

Table 1. Knowledge of Onchocerciasis, Treatment, and Participation in the CDTI Program

<table>
<thead>
<tr>
<th></th>
<th>Tandai men (%)</th>
<th>Tandai women (%)</th>
<th>Tandai total (%)</th>
<th>Kizinga men (%)</th>
<th>Kizinga women (%)</th>
<th>Kizinga total (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware of disease that causes itching Tandai (n = 180) Kizinga (n = 276)</td>
<td>74 (91.3)</td>
<td>88 (88.9)</td>
<td>162 (90.0)</td>
<td>61 (54.5)</td>
<td>80 (48.5)</td>
<td>141 (50.9)</td>
<td>303 (66.4)</td>
</tr>
<tr>
<td>Aware of onchocerciasis Tandai (n = 180) Kizinga (n = 276)</td>
<td>74 (91.4)</td>
<td>91 (91.9)</td>
<td>165 (91.7)</td>
<td>103 (92.8)</td>
<td>144 (86.7)</td>
<td>247 (89.2)</td>
<td>412 (90.3)</td>
</tr>
<tr>
<td>Aware of treatment/prevention Tandai (n = 165) Kizinga (n = 247)*</td>
<td>70 (94.6)</td>
<td>87 (95.6)</td>
<td>157 (95.2)</td>
<td>97 (94.2)</td>
<td>136 (94.4)</td>
<td>233 (94.3)</td>
<td>390 (94.7)</td>
</tr>
<tr>
<td>Know how treatment is given Tandai (n = 142) Kizinga (n = 142)*</td>
<td>47 (67.1)</td>
<td>63 (72.4)</td>
<td>110 (70.1)</td>
<td>44 (83.0)</td>
<td>72 (81.0)</td>
<td>116 (81.7)</td>
<td>226 (79.6)</td>
</tr>
<tr>
<td>Know drug is given once/year Tandai (n = 114) Kizinga (n = 116)*</td>
<td>43 (87.8)</td>
<td>58 (89.2)</td>
<td>101 (88.6)</td>
<td>43 (97.7)</td>
<td>70 (97.2)</td>
<td>113 (97.4)</td>
<td>214 (93.0)</td>
</tr>
<tr>
<td>Know cause of onchocerciasis Tandai (n = 109) Kizinga (n = 115)*</td>
<td>25 (53.2)</td>
<td>28 (45.2)</td>
<td>53 (48.6)</td>
<td>15 (34.1)</td>
<td>27 (38.0)</td>
<td>42 (36.5)</td>
<td>95 (42.4)</td>
</tr>
<tr>
<td>Attended a health information meeting Tandai (n = 110) Kizinga (n = 115)*</td>
<td>9 (18.8)</td>
<td>20 (32.2)</td>
<td>29 (26.4)</td>
<td>21 (47.7)</td>
<td>41 (57.7)</td>
<td>62 (53.9)</td>
<td>91 (40.4)</td>
</tr>
<tr>
<td>Health information meeting included onchocerciasis Tandai (n = 21) Kizinga (n = 57)*</td>
<td>6 (75.0)</td>
<td>12 (92.3)</td>
<td>18 (85.7)</td>
<td>18 (85.7)</td>
<td>29 (80.6)</td>
<td>47 (82.5)</td>
<td>65 (83.3)</td>
</tr>
<tr>
<td>Know drug distributed house to house Tandai (n = 118) Kizinga (n = 116)*</td>
<td>39 (76.5)</td>
<td>53 (79.1)</td>
<td>92 (78.0)</td>
<td>44 (100)</td>
<td>71 (98.6)</td>
<td>115 (99.1)</td>
<td>207 (88.5)</td>
</tr>
<tr>
<td>Took the drug in past years Tandai (n = 170) Kizinga (n = 275)*</td>
<td>45 (59.2)</td>
<td>56 (59.6)</td>
<td>101 (59.4)</td>
<td>93 (83.8)</td>
<td>149 (90.9)</td>
<td>242 (88.0)</td>
<td>343 (77.1)</td>
</tr>
<tr>
<td>Will take the drug at next distribution Tandai (n = 162) Kizinga (n = 276)*</td>
<td>66 (95.7)</td>
<td>88 (94.6)</td>
<td>154 (95.1)</td>
<td>100 (90.1)</td>
<td>150 (90.9)</td>
<td>250 (90.6)</td>
<td>404 (92.2)</td>
</tr>
<tr>
<td>Would take drug for treatment/prevention Tandai (n = 166) Kizinga (n = 246)*</td>
<td>65 (85.5)</td>
<td>77 (85.6)</td>
<td>142 (85.5)</td>
<td>92 (94.8)</td>
<td>145 (97.3)</td>
<td>237 (96.3)</td>
<td>379 (92.0)</td>
</tr>
</tbody>
</table>

*Difference in n due to conditional branching in the survey.
Factors Affecting Participation

medication. Suspicions are based around the fact that the medication is free. According to one CDD, the people want to know why this drug is free, but they have to pay for drugs to treat malaria and other diseases. There is fear about a free medicine:

The barriers are there because you go house to house and upon reaching a household someone refuses the drug. They say “I can’t take these tablets.” Some say the drug causes impotency and we still have these people. (CDD in Kizinga)

People say, “If there is a possibility of distributing medicine free of charge at home, why not for malaria instead of onchocerciasis?” (CDD in Kizinga).

Another factor perceived to influence participation in the program reported by a CDD and several FGD participants in Kizinga was relief from an enlarged scrotum. “Hanging groin” is a symptom of onchocerciasis, observed most frequently in men in hyperendemic areas, and related to the destruction of elastic fibers in the skin. Word about the relief of this symptom has spread and more men are willing to take the medication in order to gain relief.

Discussion

In both villages, the disease is known by its local name, Usubi, and the participants know that medication is used for prevention and treatment, which was overwhelmingly the reason why people in both villages reported participating in the program. Despite widespread knowledge in these areas, the data indicated that very little was understood among the villagers about the cause of onchocerciasis. The findings regarding knowledge about the disease, treatment program, and cause of onchocerciasis are well supported in the literature (Lakwo & Gasarasi, 2006; Mweya et al., 2007; Nuwaha et al., 2004, 2005). People did not participate due to lack of information about the disease or medication, fear of the medication, mistrust of the method of determining the dose of the medication, lack of symptoms, access to the medication, and misconceptions about the medication including sterility and impotence.

Access to the medication encompassed those absent from the village during distribution, people ineligible to participate (pregnant, under 5 years of age, up to 2 weeks postpartum, severely ill), and those who did not know about the distribution. Absence from the village at the time of the distribution campaign has been identified as a particular problem in the literature (Brieger et al., 2002, 2011; Okeibunor et al., 2011). Since the drug is available at the nearest health center during the month of distribution, there is a lack of information in the community. The FGD participants did not know of the option to get the drug at the health center if they missed the house-to-house distribution. Likewise, CDDs had no way of leaving information at the households where no one was home about the availability of the drug at the health center. In addition, there is no mechanism in place in the CDTI program to capture those who miss the distribution outside of the month-long distribution campaign.

Another issue identified as a factor influencing participation in the program involved the CDDs specifically. The current study found mistrust of the CDDs due to their lack of knowledge, lack of confidence, and the perception of a lack of medical training. In Uganda, a major predictor of compliance in participating in the program was the perception that the CDDs were doing their job well (Nuwaha et al., 2005). Nuwaha et al. (2004), in an earlier study, found CDDs unable to educate on all aspects of the disease. In the current study, the feeling that the CDDs lacked confidence was generated when they were unable to answer questions or lacked certainty in their answers during distribution. A study in Nigeria found that confidence in the CDD was improved if the CDDs were supervised by local health staff (Emukah et al., 2008). It is unknown if education of the CDDs by their supervisors was the reason they became more confident.

Mistrust of the method for calculating the dose of ivermectin was common in Kizinga. There was a feeling of suspicion related to measuring height instead of weight to determine treatment dose. This is related to experience with weight-based malaria treatment. Furthermore, being weighed was seen as an examination and measuring height was not. Mistrust of the method is corroborated in the literature in East Africa (Nuwaha et al., 2004, 2005), but is not seen in research on compliance issues in other parts of Africa.

Misconceptions about the medication based on erroneous rumors of sterility and impotence were reported through the CDDs in both villages as a barrier to treatment. This was not corroborated in the survey results or FGDs with the villagers. Over-reporting by the CDDs or under-reporting by the villagers is possible. Research findings from other study areas do not specifically identify the belief that the medication causes sterility and impotency as factors affecting participation in the program; however, this may be due to categorization under another factor, such as refusal to take the drug.

Another factor affecting participation in the program was the limited experience of symptoms among villagers. This may be a lack of symptom recognition, since 50% of villagers in Kizinga failed to recognize that there was a disease that caused intense itching, even though they knew the disease onchocerciasis by name. Most villagers
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in the study have not been exposed to people with symptoms of the disease and do not know anyone who has had a diagnosis of onchocerciasis. Nuwaha et al. (2005) found people’s beliefs about benefits of the drug and personal susceptibility to onchocerciasis as predictors of participation in the program. From one FGD in Kizinga, several men reported symptom relief from enlarged scrotum (hanging groin) as a benefit of the treatment, and as this information is shared, some men not participating in the program are now taking the medication.

Education at the time of distribution is a major factor in compliance. FGDs and interviews reported education as pivotal for participation. A dichotomy exists, however, in the reporting of education. Participants in FGDs reported lack of education provided by the CDDs during medication distribution. CDDs identified a lack of understanding of the disease and treatment by the villagers as a barrier to participation, but also expressed that giving education prior to dispensing the medication is part of their duties. Research from Uganda found that CDDs admitted not having enough CDTI training to teach about onchocerciasis (Nuwaha et al., 2005).

Overall, lack of education of community members and CDDs developed as a major theme of this research. This lack of education was evident in all data collection methods and across the board with types of participants. The lack of knowledge and potential for increasing education surrounding onchocerciasis are discussed in the ensuing paragraphs.

Lack of education about onchocerciasis led to a knowledge deficit for people in the CDTI program areas. Lack of knowledge about the cause of the disease exposed a deficiency in the education given to villagers either in community meetings or during house-to-house distribution. This deficit of knowledge, also observed in other studies in Tanzania and Uganda (Lakwo & Gasarasi, 2006; Mweya et al., 2007; Nuwaha et al., 2004, 2005), comes from a lack of education or ineffective education regarding the disease and its treatment.

Education from CDDs is an important factor to success of the program. One aspect of CDTI program strategy is having local people provide all services, including education, as part of the community-based approach. In Uganda, people in the community without the capacity to educate meant that outsiders provided education (Katabarwa, Habomugisha, & Richards, 2002). The inability to fully educate the community was echoed in the present study, with a CDD stating, “Because I have limited education, I can only explain until the end of my capacity.” Lakwo and Gasarasi (2006) found that participation was negatively affected by lack of knowledge about the disease and blamed low levels of knowledge on inadequate education. Lack of education was a frequently found factor in the current study, and education was often missing from the interaction with the CDDs.

Lack of point-of-service educational materials was noted by villagers and CDDs or CHWs and was seen as an important missing link in adequate education during distribution. No materials exist in either village that are carried house to house to show a visual description of the disease and its progression or to better explain the reason for the program existing in their village. In Kizinga, educational materials regarding onchocerciasis were not available to CDDs or community members in any form. Posters were displayed when the CDTI program was first initiated, but have since disappeared. In Tandai, there were reports of brochures about onchocerciasis in the dispensary, but no materials circulated in the community. The CDDs do not carry these when dispensing the medication house to house.

Development of education materials to improve sustainability was suggested by Akogun et al. (2000), and APOC and WHO (1998) mentions using pictures for education when training CDDs. The training manual for CDDs explains that pictures can be used to educate members of the community. These photos were not supplied by APOC and were available only if a local CDTI program created them. Neither village in the current study had educational materials for point of service, nor were photos available to share with the community members.

Along with lack of point-of-service education and support materials, training of CDDs affects the knowledge of community members. In Nuwaha et al.’s 2004 and 2004 studies of predictors of compliance in the program in Uganda, CDDs self-reported inadequate training as a factor in the ability to educate about onchocerciasis, while the community agreed that CDDs lacked knowledge. Tandai’s program has been operating since 2006 without additional training. Kizinga started in 2004, with new CDDs selected after attrition received training, but those who started dispensing in 2010 did not. One-day training is standard in most areas, but APOC recommends longer training for groups of 10 or more CDDs (APOC/WHO, 1998).

Opportunities for additional training are supported by the literature. A sustainability assessment of the CDTI program recommended retargeting training and retraining CDDs (Cross, 2003), and Brieger et al. (2011) suggested annual refresher training to highlight problems with community. Although there is a training manual for use with the CDDs, 15 years of field experience has been gathered since the guidelines were produced. Updating the guidelines by addressing problems encountered by the CDDs after training may be warranted. APOC
York et al. (2007b) reported retraining of 10,212 CDDs in Tanzania; however, none of the CDDs interviewed in the present study were retrained. A discrepancy exists between the reports of no annual training from CDDs and yearly training by CDTI program coordinators in the Morogoro Rural district. This could be explained by the perception of “training,” since it was not defined in this study.

Due to the lack of knowledge of community members participating in the CDTI program, development of point-of-service educational materials is warranted. Education through better understanding of the cause of disease with visual representation of signs, symptoms, and long-term effects of the disease can be a learning tool to encourage participation. Improvement of education can increase knowledge about the disease and the need for prevention or treatment. Design and pilot testing point-of-service educational materials based on the findings from the current study could be incorporated in the Ministry of Health’s development of information, education, and communication materials related to NTDs such as onchocerciasis.

Increasing the quality and frequency of training for CDDs could improve their knowledge and the degree of trust from the community. Lack of consistent education for villagers can be addressed through further training of CDDs and by providing educational materials to be carried house to house during distribution. The CDDs will be seen as experts on the disease and prevention and treatment which will increase the amount of trust the villagers have in both the education given and the knowledge of the CDD. Building trust through additional training and knowledge will enhance the efforts of the CDDs when going house to house during distribution.

Study limitations included convenience sampling to gather survey data. The accepted method of collecting data was to go house to house and ask people who were home to participate in the survey. Due to the time constraints and the logistics of traversing the entire Tandai and Kizinga areas, random sampling was not attempted. Therefore, similarities or differences in factors affecting participation in the program in the more outlying areas versus areas closer to the village center are unknown. Other limitations included the nonfeasibility of piloting the survey prior to mass data collection, the language barrier between the researcher and the community, and the reliance upon native speakers to orally administer the survey.

Conclusions

The public health threat of onchocerciasis to millions of Tanzanians and the populations of other sub-Saharan African nations can be decreased with the treatment program already in place. However, sustainability is a challenge faced by many affected communities. Discovering means to integrate the program into the existing health system at the local level requires an understanding of barriers and facilitators to sustainability. Knowledge regarding factors that influence individuals’ decisions to participate is paramount when considering the long-term efforts to sustain treatment effects at the community level. In addition, efforts to continue programs without supporting the growth of CDDs and reinforcing education of communities could lead to a decrease in treatment and an increase in the public health threat. This research uncovered a need for more effective community education and sensitization.

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Clinical Resources


References


