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Traditional kinship system enhanced classic community-directed treatment with ivermectin (CDTI) for onchocerciasis control in Uganda

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ABSTRACT

The challenges of community-directed treatment with ivermectin (CDTI) for onchocerciasis control in Africa have been: maintaining a desired treatment coverage, demand for monetary incentives, high attrition of community distributors and low involvement of women. This study assessed how challenges could be minimised and performance improved using existing traditional kinship structures.

In classic CDTI areas, community members decide upon selection criteria for community distributors, centers for health education and training, and methods of distributing ivermectin. In kinship enhanced CDTI, similar procedures were followed at the kinship level. We compared 14 randomly selected kinship enhanced CDTI communities with 25 classic CDTI communities through interviews of 447 and 750 household members and 127 and 64 community distributors respectively.

Household respondents from kinship enhanced CDTI reported better performance ($P < 0.001$) than classic CDTI on the following measures of program effectiveness: (a) treatment coverage (b) decision on treatment location and (c) mobilization for CDTI activities. There were more female distributors in kinship enhanced CDTI than in classic CDTI. Attrition was not a problem. Kinship enhanced CDTI had a higher number of community distributors per population working among relatives, and were more likely to be involved in additional health care activities. The results suggest that kinship enhanced CDTI was more effective than classic CDTI.

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1. Introduction

The African Programme for Onchocerciasis Control (APOC) was launched in 1996 to eliminate onchocerciasis as a public health problem, mainly with an annual dose of ivermectin, in mesoendemic and hyperendemic communities with nodule rates of ≥ 20 –40% and ≥ 40 % respectively.¹ Persons with complaints of onchocerciasis infection in

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hyopendemic areas (nodule rate $\leq 20\%$ and a microfilaria prevalence of $\leq 40\%$) are treated with ivermectin at their nearest health clinic.²

Community-directed treatment with ivermectin (CDTI) for onchocerciasis control was adopted as the main method for delivering ivermectin in onchocerciasis endemic communities in late 1996 after a multi-country study demonstrated that CDTI strategy performed better than programme designed ones during mass treatment with ivermectin.³ CDTI refers to an approach where the community is given adequate information to become involved in decision-making, organization, resource mobilization, selection of community distributors, carrying out or updating community household censuses, distribution of ivermectin, managing and referring side effects and submitting reports of treatment to the nearest health facility.

Although APOC succeeded in establishing CDTI projects in all 19 onchocerciasis endemic countries, it still faces challenges of: maintaining desired annual treatment coverage of at least 90% of the eligible population; responding to the demand for monetary incentives as a condition for service by the community distributors; their reported high attrition rate; and low or no involvement of women in most CDTI projects. Eligible population refers to all individuals of at least five years of age in a specific onchocerciasis endemic area targeted for mass treatment with ivermectin.

In 2000, The Carter Center assisted onchocerciasis control programme in Uganda adopted the traditional kinship system for implementation of CDTI activities in order to overcome the aforementioned challenges.⁴ The traditional African kinship system is about a central social structure that defines human relationships in terms of how people interact with one another, perceive their relationships, understand their origin and expectations that guide behaviour. Kinship refers intuitively to 'blood relationships', and the essential strands of kinship are successive relations between parents and their children.⁵ Although it refers mainly to an extended family of blood related individuals, women are included in kinships by marriage. In rural sub-Saharan Africa, this group of related persons may own and occupy land in a specific geographical area within a community. This geographical area is referred to in this paper as a kinship zone.

Kinships serve as a model for relationships to non-relatives and are a fundamental factor in social interaction. Dealing with tribal communities requires making sense of kinship in order to make sense of almost anything else. To be without kin reduces a person to a state of almost no hope of having a normal life, a valuable marriage, the ability to meet subsistence needs or being cared for in old age or when sick or injured. Kinship forms the basis of political, economic, and even religious organization;^{5,6} it is the main structure that produces and shapes patterns of behaviour and conceptual systems.

Kinship is a 'platform' where interactions produce adoptable behaviours that later become norms and values of communities in which behaviour is passed on or modified for future generations. Individuals who are likely not to comply may find themselves 'boxed in' by sanctions predetermined by the traditional kinship's social legal system. They are compelled to comply or risk being criticised and

even excommunicated.⁴ Therefore, the traditional kinship structure is vital for organising and ensuring equitable provision of services such as health education and training, as well as entrenchment of desired norms and values for disease prevention and control.

Although studies have shown that involvement of the traditional kinship system enhances CDTI, no systematic studies comparing classic versus kinship enhanced CDTI have been carried out.⁴ The objectives of this paper were to assess and compare classic CDTI with traditional kinship enhanced CDTI for measures of effectiveness on: (i) treatment coverage attained (ii) performance on community decision-making and ownership factors and (iii) performance of community distributors.

2. Materials and methods

2.1. Study areas

The study was carried out in Hoima District in western Uganda and Moyo District in northwestern Uganda in 2006; Uganda has 29 onchocerciasis endemic districts. The classic CDTI approach has been employed in Hoima District since 1997. The traditional kinship system enhanced CDTI in Moyo District was established in 2000, two years after classic CDTI began in 1998. Onchocerciasis control through ivermectin distribution was launched in Hoima District by Uganda Foundation for the Blind with support from Sight Savers International (SSI) in 1991, and in Moyo District by the River Blindness Foundation in 1993, which was taken over by The Carter Center in 1996. Hoima District received major financial support from APOC from 1997–2002 and Moyo District from 1998–2003.

After APOC funding for implementation of CDTI ended, classic CDTI continued in Hoima while enhanced CDTI with the traditional kinship system remained the approach in Moyo. Hoima District is largely inhabited by the indigenous Banyoro with Alur and Lendu immigrant communities, while Moyo is inhabited mainly by the Madi. All these tribal communities have active traditional kinship systems. The total population in onchocerciasis endemic communities of Hoima District is approximately 106 117 persons, with an eligible population for treatment of about 104 464 persons and an average of 495 persons per community. Moyo District had a total population of 191 459 persons with an eligible population of 186 772 and an average of 489 people per community.

2.2. Transition from classic CDTI to traditional kinship enhanced CDTI

Community members in Moyo District identified kinship or neighborhood zones within their respective communities during 2000. A kinship zone in Uganda is a geographic area in a community where a significant number of residents are related by blood or marriage. A large kinship may break up along family lines because of conflict or need for adequate land. The number of kinship zones in a community was provided by community members. Each kinship zone independently selected its own community

distributors, methods of treatment, health education and training centers. This resulted in more trained community distributors than in classic CDTI. Communities were also asked to identify and select community members, such as teachers or retired civil servants (commonly known as community supervisors) who could train, mentor and supervise the large number of community distributors. These supervisors were, in turn, trained and supervised by health workers from health units close to the communities. The community distributors were sensitised to provide services only within their respective kinship zones while in classic CDTI, community distributors rendered services to all community members irrespective of their kinships. The community distributors in classic CDTI were supervised by health workers as opposed to community supervisors in the kinship enhanced arm of the study. In both approaches, onchocerciasis control activities were implemented through the district health services.

2.3. Sampling

Random sampling was used to select four out of 11 sub counties in Hoima District, where classic CDTI was implemented and three out of seven sub counties in the kinship enhanced CDTI in Moyo District. Random selection of communities from the sample of sub-counties in both districts was done, and 40 communities (25 from classic CDTI and 15 from kinship enhanced CDTI) were chosen. In each community, a list of households was generated using community registers. The first household to interview was selected using the random number table, and thereafter subsequent households were selected at every fifth interval until 15 households in every community were chosen.

In the kinship enhanced CDTI arm, access to household registers in one community was not possible, and interviews were ultimately done in only 14 communities. In classic CDTI, 25 communities were selected with the intention of validating CDTI performance in Hoima District using the same questionnaires and sampling method applied in Moyo district. Although different sample sizes were selected in classic (25 communities) and kinship enhanced CDTI (15 communities), there was no statistical difference for homogeneous population at 95% confidence level.⁷ There were a total of 34 kinship zones in the 14 communities of kinship enhanced CDTI, and 107 in 25 classic CDTI communities. This was about two kinships per community in the kinship enhanced CDTI and four kinships per community in the classic CDTI.

2.4. Face to face interviews at household level

In every household, two adults (1 male and 1 female) were interviewed separately for 1197 people (Moyo, $n=447$ and Hoima, $n=750$) at 95% confidence level for homogenous populations.⁷ The questions focused on: (a) location of treatment and who participated in that decision (b) who mobilized communities (c) who selected the community distributors (d) whether the community member: (i) was health educated about CDTI activities or not (ii) was treated or not (iii) supported the community distributors or not (iv) was satisfied with CDTI services or not and (v)

would be available for treatment during the following year, and if not, why. Where relevant, probing questions were asked to gauge, for example, their knowledge about the disease and CDTI activities. Community consent at general community meetings was given, but selected individuals had a right to refuse to be interviewed without fear of any repercussions.

2.5. Face to face interviews of community distributors

All 64 community distributors in 25 communities from classic CDTI in Hoima, and 127 community distributors in 14 communities from kinship enhanced CDTI in Moyo were interviewed. The focus was on: (a) who selected the community distributors (b) from where the community distributor was selected (c) how many households the community distributor served (d) what relationship the community distributor had with the persons treated (e) how long it took to complete the distribution exercise and (f) whether community members were satisfied. Face to face interviews also considered whether the community distributor: (a) was trained or not; and if yes, who trained him or her (b) distributed ivermectin or not (c) provided health education (d) worked only in his or her kinship or not (e) was involved in other health activities and (f) if so, how many other health activities was he or she involved in (g) was supervised or not and (h) will distribute ivermectin during the following year. Individual community distributors had a right to refuse to be interviewed without fear of any repercussions.

2.6. Data analysis

The questionnaires for households and community distributors were coded, and data were entered and analysed in Epi Info statistical software (CDC, Atlanta, GA, USA). Data from yes or no questions were analysed statistically using simple χ^2 (Epi Info Version 6.04, CDC, Atlanta, GA, USA), and the level of statistical significance was $P<0.05$. Graphic illustrations were generated in Microsoft Excel (Microsoft Corp., Seattle, WA, USA).

3. Results

3.1. Mass treatment

Treatment in 2005 and 2006 for each of the three sub counties in Moyo District, the kinship enhanced CDTI, (Aliba, 95.6% and 100%; Lefori, 100% and 86.7%; Metu, 94.6% and 92.6% respectively) was better than that from each of the four sub counties in Hoima District, classic CDTI (Biseruka, 73.3% and 35.6%; Kabwoya, 81.7% and 38.3%; Kigorobya, 75% and 73.3%; Kiziranfumbi, 81.1% and 79% respectively) (Figure 1). Satisfaction with CDTI activities in each sub county under kinship enhanced CDTI was high compared to that in sub counties under classic CDTI. Improved performance in Kigorobya and Kiziranfumbi during 2006 was due to mop up operations by health workers in order to improve treatment coverage.

Overall, treatment coverage in classic CDTI was 76.4% of 750 respondents in 2005, but dropped to 62.1% in

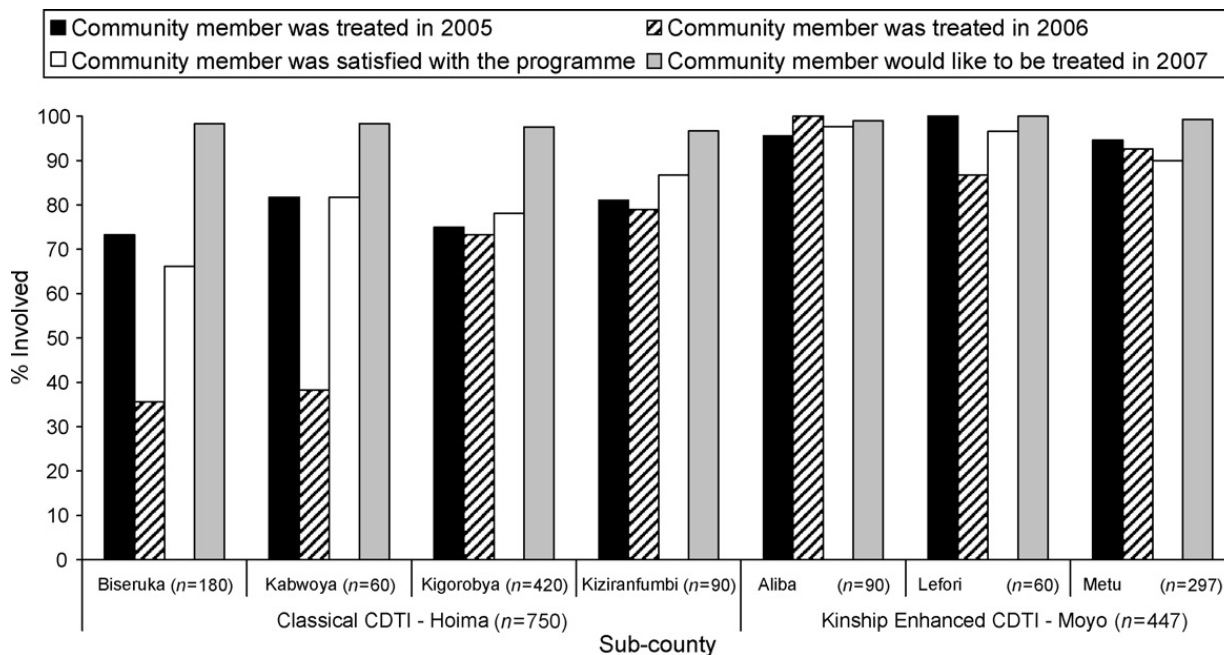


Figure 1. Household responses on treatment coverage with community-directed treatment with ivermectin (CDTI), satisfaction with the programme and willingness to be treated in 2007 by sub-counties receiving classic CDTI in Hoima District and kinship enhanced CDTI in Moyo District. Data from three respondents in Moyo was incomplete.

2006. In kinship enhanced CDTI treatment coverage, it was maintained at 93.7% of 447 respondents for both years. Overall satisfaction with CDTI activities was 78% of 750 respondents in classic and 92.5% of 447 in kinship enhanced CDTI ($P < 0.001$). The respondents in both arms of the study overwhelmingly wanted treatment during the following year (classic, 98% and kinship enhanced CDTI, 99.3%).

3.2. Community ownership policies

On community ownership policies, performance in classic CDTI was inferior to that observed in kinship enhanced CDTI (Figure 2). Results showed that in classic CDTI, 50.8%

of the community leaders decided on the location of the treatment centres without involvement of community members compared with 6.8% in kinship enhanced CDTI ($P < 0.001$). In classic CDTI, 14.7% of the respondents agreed that community members decided on the location of treatment centre compared to 62.8% in kinship enhanced CDTI ($P < 0.001$), 18.2% of respondents helped to mobilise for CDTI activities compared to 63.4% in kinship enhanced CDTI ($P < 0.001$), 17.2% selected their community distributors compared to 76.5% in the kinship enhanced CDTI ($P < 0.001$), and only 19.4% respondents were health educated about the disease and CDTI activities during health education sessions within their communities compared with 71.5% in kinship enhanced CDTI (Figure 2).

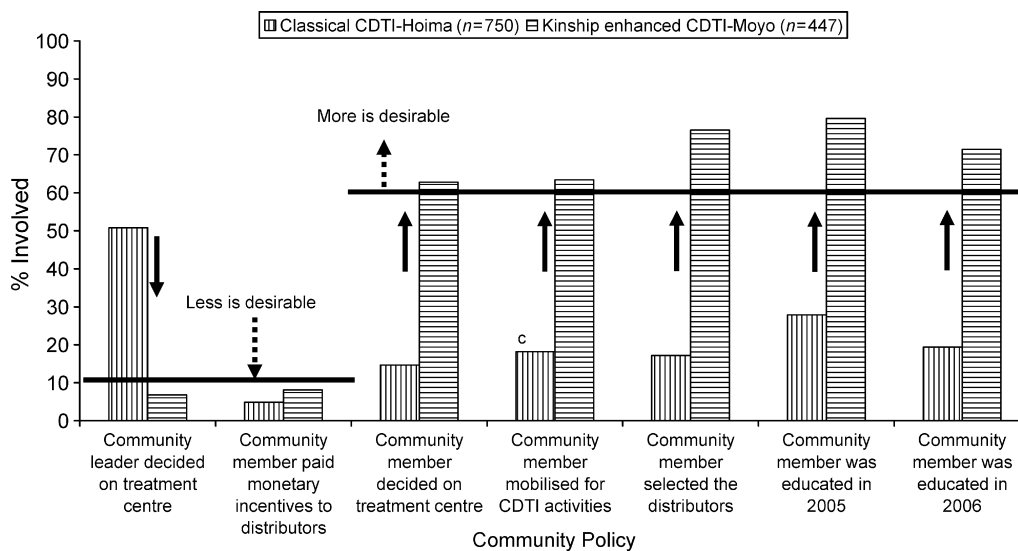


Figure 2. Household responses on community ownership factors in those receiving classic CDTI in Hoima District and kinship enhanced CDTI Moyo District. Bold arrows show significant difference ($P < 0.001$).

Table 1
Responses of community distributors from Hoima District, Classic CDTI and Moyo District, Kinship enhanced CDTI

Question	Classic CDTI			Kinship enhanced CDTI			Significance at 0.05
	Hoima District, n = 64			Moyo District, n = 127			
	YES (%)	NO (%)	TOTAL	YES (%)	NO (%)	TOTAL	
1. Were you selected by members of your community?	18 (28.1)	46 (71.9)	64	110 (86.6)	17 (13.3)	127	<0.001
2. Did you achieve treatment coverage of 90% and above?	15 (23.4)	49 (76.6)	64	96 (75.6)	31 (24.4)	127	<0.001
3. Did you distribute ivermectin in 2006?	50 (79.4)	13 (20.6)	63	105 (82.7)	22 (17.3)	127	0.579
4. Do you live in the kinship/neighborhood zone where you distributed ivermectin?	29 (58)	21 (42)	50	127 (100)	0 (0)	127	<0.001
5. Were you trained on how to distribute ivermectin?	58 (90.6)	6 (9.4)	64	124 (97.6)	3 (2.4)	127	<0.004
6. Did you distribute ivermectin to 30 households and less?	15 (30)	35 (70)	50	64 (61)	41 (39)	105	<0.003
7. The people I treated were largely my relatives	7 (14)	43 (86)	50	67 (63.8)	38 (36.2)	105	<0.001
8. Were you involved in other health and development activities besides CDTI?	47 (73.4)	17 (26.6)	64	115 (90.6)	12 (9.4)	127	<0.002
9. Did community members help to mobilise for CDTI activities?	39 (61.9)	24 (38.1)	63	103 (81.1)	24 (18.9)	127	<0.004
10. Will you distribute ivermectin the coming year in your community?	61 (95.3)	3 (4.7)	64	114 (89.8)	13 (10.2)	127	0.191

The responses do not always add up to the n as some questions were not answered.

3.3. Community distributors' responses

The differences between classic and kinship enhanced CDTI were significant when the responses of community distributors were compared (Table 1).

The responses from community distributors showed that 82.7% of community distributors in the kinship enhanced CDTI completed mass treatment within a week compared to 20% in classic CDTI ($P < 0.001$). Demand for lunch by community distributors working among relatives was 8.2% and 43.2% among non-relatives ($P < 0.001$). Also, community distributors who worked among non-relatives were more likely to demand monetary incentives than those who treated relatives ($P < 0.001$). Attrition of community distributors was not a significant problem in either classic or kinship enhanced CDTI.

3.4. Further analysis

There were 11 (17.2%) female community distributors out of 64 in classic and 59 (47.2%) female community distributors out of 127 in the kinship enhanced CDTI ($P < 0.001$). In the randomly sampled communities, the total population in classic CDTI communities was 12 380 with a ratio of 2.6 community distributors per community (1 community distributor to 193 persons or about 28 families). In kinship enhanced CDTI, a total population of 6361 people, the ratio was 9 community distributors per community (1 community distributor per 50 persons or about 7 families).

4. Discussion

4.1. Kinship enhanced CDTI

Kinship enhanced CDTI performed better than classic CDTI in treatment coverage, community members selecting their distributors and treatment methods. Also community distributors' performance, their workload reduction, involvement in other health activities and involvement of women as community distributors were better in kinship enhanced than in classic CDTI. Utilisation of the kinship system in CDTI resulted in reduced decision making by community leaders, which promoted respect for decisions made by community members, a principle at the heart of CDTI.³ With successful establishment of CDTI by APOC in 19 onchocerciasis endemic countries, the push for integration and sustainability is more likely to succeed if the kinship system is recognized and involved in enhancing classic CDTI.

The success of kinship enhanced CDTI could be attributed to the relatedness of people involved, access to health care benefits without feelings of unfair advantage, and perceived lack of harmful or selfish intentions of community distributors selected by kinsmen.⁸ Among kinsmen, perceived competition for economic advantage and political power was not likely to be a significant problem. However, in classic CDTI, such competition could heighten mistrust among community members from different kinships, ultimately resulting in poor performance.⁹ CDTI programmes at community level usually follow political or administrative boundaries, yet community loyalties

primarily divide along kinship lines.⁴ With kinships tending to cluster in specific geographical areas within a community, community members in kinship enhanced CDTI viewed CDTI work as morally binding, promoting cohesion and harmony, and regarded it highly in serving kinsmen.⁵

4.2. Community ownership policies

In classic CDTI, there was no respect or utilisation of the existing traditional kinship system. This may have impaired the ability of community members to mobilise themselves, identify appropriate kinsmen to work as community distributors, enhance the involvement of women and identify other resources necessary for implementing CDTI effectively. Where the kinship system may have been respected and utilised by some community distributors, the effect was not strong enough to improve performance in kinships beyond their own. Ultimately, the non-utilisation of the traditional kinship system inadvertently denied community members fora to discuss pertinent issues, air their grievances and affect necessary changes. Lack of ownership is likely to have affected decisions on when and where to be treated, and how to mobilise each other for health education and treatment without feeling they were being taken advantage of. Even where geographic distances were short, social distances were too cumbersome to circumvent and produce results comparable to those observed under the kinship enhanced CDTI.^{4,10}

4.3. Community distributors

Selection of community distributors by community leaders in classic CDTI may have been due to concerns that communities were indifferent, uncooperative or slow in involving themselves in CDTI, while other leaders may have viewed it as their responsibility. It is likely that the community distributors selected were unable to break through social barriers to gain the trust and support needed to implement CDTI activities beyond their own kinships.¹⁰

In classic CDTI, the community distributor to population ratio was low, and community distributors were likely to have walked from house to house, covering long distances, without community appreciation and support. Alternatively, the greater number of community distributors in the kinship enhanced system lessened the workload and created opportunities for involvement in other health activities, without competition amongst distributors, and with community appreciation and encouragement. Adaptation and utilisation of the kinship system could potentially improve effectiveness of control of other diseases such as lymphatic filariasis, schistosomiasis, malaria, tuberculosis, intestinal helminths, HIV/AIDS and delivery of Vitamin A supplements, and many programmes that incorporate elements of mass drug administration at the community level.

It was observed that community distributors who worked among non-relatives were more likely to demand lunch and monetary incentives than those who worked among relatives or their kinsmen. This is because in the

kinship system, it is an obligation to serve ones relatives without expecting payment. In traditional communities, it is blasphemous to demand payment from your spouse, parents and brothers for treatment. That is why utilisation of the kinship system may be a practical way of serving traditional communities, as community distributors may not demand incentives from their relatives.⁴ Additionally, their workload and distances to walk in relatively smaller kinship zones during health education, training and distribution of ivermectin are largely reduced thus warranting no incentives.

Although community distributors' attrition was expected to be high in classic CDTI communities as reported in many APOC supported CDTI projects, there was no evidence that this occurred.^{10–12} It is possible that in classic CDTI, a community distributor may have been active in his or her own kinship zone, but withdrew services from other kinships within the community. Such a phenomenon could explain lower treatment coverage or delays to complete the treatment exercise in classic CDTI. We recommend that future studies focus on this phenomenon.

4.4. Women's involvement in CDTI

The study showed that kinship enhanced CDTI had more female community distributors than classic CDTI, showing that the utilisation of the kinship system may be more suitable for women's involvement.¹³ As a kinship tends to occupy a specific geographic area within a community, it makes it easy for women to operate where they are known and appreciated. In this structure, the female community distributors were likely to be less burdened as they served smaller populations, walked shorter distances and completed the treatment in a shorter time compared with classic CDTI. Traditionally, the social legal systems in tribal communities have elements that restrict women from individually providing services beyond their families. For example, a female community distributor working among male community distributors who are not her relatives, or working alone in the event of a severe adverse event could easily spark off a rumour that may jeopardise her position and family in the community. Having many female community distributors within kinship zones allowed them to work in groups and stifle any rumours intended to give them or their families a bad reputation.^{14–16} In classic CDTI, a female community distributor was expected to cover a large area beyond her kinship zone. This may put her in conflict with the social legal system, and hence a sensible reason for excusing herself from serving as a community distributor. In communities where women were selected, this social barrier along with the heavy workload may have affected their effectiveness. Furthermore, a significant number of female community distributors are those married from outside their husband's kinships, and therefore thought to be a source of discord and more prone to competition and envy than males who are mainly blood relatives. If such feelings exist in a kinship where the women are known and likely to be appreciated, it can only be worse in classic CDTI where they have to interact with suspicious community members outside their indi-

vidual kinships. This phenomenon was not considered in this study and could be investigated in future studies. We also recommend studies that explore whether enhanced women involvement may have aided overall success of the kinship enhanced CDTI.

4.5. Other possible limitations to community distributors' performance

Severe adverse reactions or a coincidental sickness during ivermectin treatment could be interpreted as a set-up to harm the beneficiaries. Such incidents result in people refusing to take the medicine and could trigger reprisals against the community distributor or his or her family.¹⁷ The community distributors in classic CDTI could have instinctively been aware of this reality and therefore may have limited their services to where they are well known and appreciated. This may also explain lower treatment coverage. More importantly, classic CDTI makes the community distributors 'stand out in a crowd' more than in kinship enhanced CDTI and sets them up for targeted demand to share their scarce family resources with other people in order to elicit trust, a phenomenon termed in anthropology as the 'leveling mechanism'. A leveling mechanism is meant to keep everyone including the community distributor at the same level in terms of possessions. An example of this is when community members believe that the community distributor is better off than other members of the community as they assume that the community distributor is paid by an aid agency or government department for services to the community. In this case, community members demand that he or she buys them drinks in order to gain their friendship and confidence. That may be why the demand for incentives, especially monetary incentives, by community distributors in classic CDTI might be used as a bargaining chip to provide or withdraw services to community members. Although this phenomenon exists even within individual kinships, it is more difficult to deal with across kinships as it involves many more and less trusting community members.^{5,18}

The success observed in the kinship enhanced CDTI does not preclude social networks across kinships and communities. The present study did not consider the impact on CDTI of relationships and affiliations across kinships, and therefore we recommend such studies in future. Understanding and harnessing complexity of relationships and affiliations within and beyond the traditional kinship system could benefit CDTI programs as well as other disease control programmes, and public health initiatives that rely on well organised and confident communities.

5. Conclusion

Involvement of the kinship system increased the level of community involvement and performance of kinship enhanced CDTI. Disregarding or lack of understanding of the traditional kinship system and its social legal system reduces the impact and sustainability of health and development programmes intended for disadvantaged communities. Knowledge of the traditional kinship system presents opportunities for communities to learn, organize,

and involve themselves in their own health care. However, making CDTI more efficient and effective is a vital and dynamic process that requires constant monitoring and evaluation if the gains by disadvantaged communities are to be maintained.

Authors' Contributions: MNK was involved in study tool design, supervision of the study, selection of the study areas, sampling, data analysis and interpretation, and manuscript writing; PH was involved in study tool design, sampling, provision of logistic support, overseeing face to face interviews as well as data entry, and manuscript review; SA and ACM were involved in study tool design, sampling, training interviewers, ensured that face to face interviews were carried out effectively, helped in data entry, and manuscript review; NO, SK and FB were involved in identifying interviewers for training, participated in their training, ensured face to face interviews were carried out effectively, and manuscript review; BM was involved in ensuring face to face interviews were carried out effectively in Hoima District, and manuscript review; DM was involved in study tool design, selection of study areas, sampling, supervision of the study, and manuscript review.

Peace Habomugisha and Deborah McFarland are guarantors of the paper.

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Conflict of interest: None declared

Ethical approval: The study falls under the category of routine programme monitoring activities for the Carter Center and Uganda health services personnel and hence did

not require IRB approval. However, as two of the authors are based at Emory University's Rollins School of Public Health, the Emory IRB gave ethical approval for the study.

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