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The Eradication of Guinea Worm Disease: A Push for Community Engagement

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ABSTRACT Guinea Worm Disease (GWD) is a neglected tropical disease caused by the nematode *Dracunculus medinensis* and has been targeted for eradication since 1980. With only 14 human cases in 2021, GWD may be the first human parasitic disease to be eradicated, even without a vaccine. However, current efforts to eradicate GWD face multiple challenges, the largest of which is the lack of access to safe drinking water. Other challenges include the existence of animal hosts for *D. medinensis* and the seasonality of transmission. Interventions to address GWD have included water filtration systems, clean water initiatives, and health education programs, among others. Here, we argue that although substantial progress has been made in reducing the global burden of GWD, many studies fail to include substantive community engagement regarding the design and implementation of interventions. Past GWD eradication efforts have focused heavily on a top-down, siloed approach to health, which does not fully encapsulate the needs of affected communities. After reviewing literature on GWD control between 1985 and 2021, we conclude that a final push towards eradication should involve active community engagement. We propose specific community engagement methods that involve community members in designing and implementing interventions to eradicate GWD.

KEY WORDS COVID-19, Dracunculiasis, Guinea Worm Disease, Community Engagement, Eradication, *Dracunculus medinensis*

INTRODUCTION

Almost two Dracunculiasis, or Guinea worm disease (GWD), is a Neglected Tropical Disease (NTD) caused by the nematode *Dracunculus medinensis* and is directly linked to the lack of safe drinking water[1]. GWD is transmitted to humans by drinking water contaminated with copepods, which are intermediate hosts for *D. medinensis* larvae. After ingestion, the larvae penetrate the stomach and exit the body through blisters in the leg[2]. Affected individuals often immerse themselves in water to relieve pain, thereby releasing larvae into the water and perpetuating the cycle[2]. GWD has been targeted for eradication since 1980, largely with strategies of water filtration and the use of chemicals to kill copepods, and its prevalence has since dropped from 3.5 million cases in 1986 to 14 documented human cases in 2021[3]. If eradicated, GWD would be the first human parasitic disease to be eradicated and the first eradication campaign to succeed without a vaccine or medication[4]. We argue that while great success has been achieved thus far, some interventions are disconnected from necessary collaboration with affected communities in their design and implementation.

HISTORY OF GWD RESEARCH AND CONTROL

British parasitologist Robert Thomas Leiper pioneered research of GWD in 1905 when he was sent to present-day Ghana to study and address the impact of GWD on British financial revenue[5]. Leiper advanced the state of knowledge on safe water sources, community engagement, and the biology of GWD. However, his observations were applied directly to areas colonized by the British, thus benefiting primarily the British colonizers and their communities[6]. Leiper designed community-specific solutions for safe water supply in Ghana and India, and officials in the Soviet Union, Uzbekistan, and other countries followed his lead, demonstrating how clean water infrastructure and containment resulted in local elimination of GWD[6-8]. Former United States President Jimmy Carter's "Carter Center" spearheaded the Guinea Worm Eradication Program (GWEP) in the 1980s, which largely relies on interventions for case containment rather than medication[6, 9].

EPIDEMIOLOGY OF GWD

There are currently five endemic countries (Angola, Chad, Ethiopia, Mali, and South Sudan)[10]. Chad has been the epicenter of GWD research in recent years, as it had a 10-year absence in human cases until 2011 and now has the highest incidence, with 6 human cases reported in 2021[11, 12].

Water sources, seasonality, previous infection, and demographics impact the risk of GWD[13]. A study of the Ethiopian Dracunculiasis Eradication Program and the GWD status in other affected countries by Beyene et al. (2017) highlighted that access to safe water was scarce in many communities and that those who implemented filtration methods suitable to their needs saw greater reductions in cases[14]. Employment type and location also impact the likelihood of GWD, as farmers (and those who fetch water) are more likely to drink contaminated water during work[15]. Although its exact role is not completely understood, conflict events may also serve as a risk factor for GWD[16, 17].

There are at least six prevention methods available for GWD: proper disposal of fish entrails, proper cooking of aquatic animals, prevention of people with GWD from entering water sources, tethering of infected animals, filtration of unsafe water, and provision of safe drinking water[18]. Remaining GWD cases should be addressed through community-specific endeavors that employ these evidence-based methods.

CHALLENGES POSED BY ANIMAL CASES

Animal sources of GWD transmission are increasingly concerning for eradication, although infections in dogs remain incompletely understood[19, 20]. Identification and containment of GWD in animals are difficult because cases are confirmed only when a worm visually appears on the animal's body[18]. Reservoirs of standing water that infect dogs hinder GWD control and eradication[21]. Educating community members to provide their dogs with ample water at home can effectively address animal cases[22]. In a study in Ethiopia, this strategy resulted in dogs spending less time near standing water, thus reducing the likelihood of contracting GWD[23]. These community engagement methods should be prioritized such that communities are equipped with the tools for eradication.

THE ROLE OF COMMUNITY HEALTH WORKERS

Community health workers (CHWs) can serve as a unique resource to support GWD eradication strategies by delivering community-informed care to promote safe drinking water and health education. A review by Biswas et al. (2013) analyzed GWD control strategies, identifying health education by trained CHWs as a key strategy [4]. However, CHWs' specific roles vary by community. After evaluating programs that employed CHWs to improve child survival, Haines et al. (2007) compiled determinants of success that should be considered when utilizing CHWs to engage with communities affected by any health issue[24]. Namely, the design and implementation of their work should involve community members and consider specific contexts, including sociopolitical factors, health systems, and local leadership and infrastructures.

Many challenges hamper the effectiveness of community-based interventions that employ local CHWs to decrease GWD incidence. In Northern Ghana, Dil et al. (2012) showed that CHWs were insufficiently compensated, making it difficult to maintain their responsibilities[25]. CHWs also faced a lack of community cooperation, potentially stemming from beliefs in traditional medicine or financial constraints. CHWs were responsible for up to 200 compounds per month, which was impractical with limited compensation and modes of transport, and this overload may have caused burnout[25]. Farming seasons can be an obstacle for CHWs, as CHWs must choose between farm work or community-based surveillance programs[25].

Dil et al. (2012) found that the leading reasons individuals choose to volunteer as CHWs include altruism, a sense of pride, and respect from the community[25]. Similarly, Cairncross et al. (1996) found that a main motivator for community-selected village health workers (VHWs) is the social status that results[26]. Pride as a motivator can be extended by allowing community members to nominate volunteers[25, 27]. Additionally, national GWEP leaders should affirm CHWs in their role in successful interventions.

The burden of GWD can disproportionately fall on people of marginalized identities. Women are often responsible for water collection, and this higher exposure to potentially contaminated water sources puts them at greater risk for contracting GWD. Watts et al. (1989) explored the impact of GWD on women and described how women perceived the implementation of boreholes, wells, and filters in their communities as overwhelmingly positive developments[28]. The inclusion of their opinions makes this article uniquely informative: instead of focusing on the biological aspects of GWD, it focused on its social and economic consequences. The women championed the interventions, as their lives had improved greatly without GWD[28].

Cairncross et al. (1996) highlighted the significance of culturally relevant training to better tailor VHWs' work with marginalized individuals disproportionately affected by GWD[26]. Ciantia et al. (2013) described strategies in which GWD-endemic communities collaborated with researchers to create positive behavioral change in the Ugandan GWEP[29]. By employing CHWs who valued culturally relevant health messages and community engagement, the interventions were more accessible and feasible. Ciantia et al. (2013) asserted that successful and sustainable interventions build community capacity to maintain health[29]. They cited Uganda's struggle and success with GWD eradication as evidence that stakeholder involvement, effective partnerships, and capacity building within governments are needed to combat GWD[29]. The surveillance efforts in Uganda advanced the eradication process towards case containment, and Uganda has since succeeded in maintaining zero GWD cases[30].

UNDERSTANDING THE COMMUNITY ENGAGEMENT APPROACH TO ERADICATION

Multiple strategies, such as health education and cloth filters, are needed in conjunction with a robust community engagement approach to eradicate GWD.

Health Education

Rubenstein et al. (2021) showed that the more association a person had with Chad's GWD eradication program, the better they understood GWD symptoms and the reward systems for reporting cases, suggesting a strong need for educational interventions directed by community volunteers[18]. Out of the six GWD prevention methods available to laypeople, community volunteers could only name 2.7 on average, and villagers could only name 1.5. Villagers visited by volunteers had more knowledge of GWD than people who were not visited, demonstrating that community volunteers can improve community knowledge. However, sometimes they themselves lack information. Program fatigue, lack of compensation, or volunteers only visiting homes with previous infections can make surveillance strategies less effective. Thus, national GWEP leaders should focus on training, supporting, and supervising volunteers[18].

Cloth Filters

Cloth filters play an important role in preventing GWD by removing copepods from water, but widespread use can be difficult to achieve. A study by Tayeh et al. (1996) involved health education about GWD and encouraged people to purchase filtering cloths[31]. The authors found low purchase rates were likely due to the belief that GWD is a congenital disease. The authors recognized that their health education program was designed externally, rather than working with community members to understand how they most often engage with water sources. Tayeh et al. (1996) ultimately suggest that the entire program must be continually evaluated and adapted within communities to make their results most successful[31].

The value of community input was highlighted in a case study by Brieger et al. (1986), who worked with community members to design, produce, market, and sell monofilament nylon cloth filters in Idere, Nigeria[32]. Community members helped design the most appropriate filter, local tailors produced them, CHWs determined fair price points, and CHWs and other locals sold the filters to residents while demonstrating proper use. Villages where CHWs from those areas had obtained these filters saw the highest coverage rates, and villagers recalled an average of 7.6 of the required 10 points for proper use[32]. Aikhomu et al. (2001) addressed issues with cloth filters in Nigeria, such as the need to consistently educate communities on correct filtering habits by implementing communal filtration units[33]. The team found that these communal units had higher usage than hand-sewn

filters, even claiming that their acceptance in the community merited investing in the high costs[33]. The success of community-driven marketing efforts demonstrates how community involvement can shape GWD programs and outcomes.

EXAMINING EXISTING COMMUNITY ENGAGEMENT

We believe that community engagement will be critical for GWD eradication. We expect it to be crucial in remote areas inaccessible to regular surveillance. Strategic planning is needed to know when and how to engage with communities. While GWD research on community engagement is lacking, the literature on HIV, child and maternal health, and malaria widely support community engagement[34-36]. Community engagement can take many forms, including community mobilization, participatory research, community-based interventions, or peer education[37, 38]. The heterogeneity of community engagement speaks to the opportunity for public health authorities to tailor interventions for individual GWD hotspots, making them more appropriate and accessible.

Community engagement can occur at different levels, whether it is by improving societal cohesion through educational programming or training community members to clean and maintain water sources[9]. Cairncross et al. (1996) showed increased positive outcomes when community members executed surveillance and prevention[26]. At that time, the study showed that many people did not go to health centers because of GWD's debilitating effects, limited treatment, and long travel distances. Surveillance of cases and intervention progress must, therefore, happen within communities.

It is imperative to focus on the context of affected communities. Brieger and Kendall (1996) conducted a community-based surveillance program to monitor cases of GWD in communities in Oyo State, Nigeria[27]. CHWs met with study reporters and provided updates on GWD cases in their communities. However, many CHWs missed meetings for religious observances, which delayed updates on the status of GWD and treatment[27]. Working with the schedule of CHWs and with local cultures will be critical going forward.

FUTURE DIRECTIONS: COMMUNITY ENGAGEMENT AS THE MISSING PIECE

Lemma et al. (2020) presented a systematic review of GWD and suggested a multidisciplinary team of professionals to eradicate GWD[39]. We argue that this multidisciplinary team should include community members, as they are the main stakeholders for GWD and can provide valuable insight on the context of their affected communities. To improve GWD-related education, communities should consider strategies that allow CHWs to provide community-appropriate solutions and demonstrations for improved drinking water; programs for dog-owners to limit animal cases; and larger-scale training, supervision, and fair compensation of CHWs to ensure that they are well equipped to perform community outreach. Community-appropriate filtration units, such as cloth filters or CFUs, should be selected and produced in collaboration with community members only after understanding the most commonly used water sources in communities. Their use should be thoroughly and consistently publicly demonstrated in communities to improve acceptance. A combination of these strategies will help ensure that community members and CHWs feel agency to contribute to GWEPs in ways that are critical to achieving eradication.

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