Community-Led Approaches to the Prevention and Control of Schistosomiasis: A Sociological Analysis of the Citizen Science Model Among Selected Communities of Western Uganda

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Summary

Schistosomiasis is a public health problem and a social challenge, affecting over 240 million people globally, the majority of whom live in sub-Saharan Africa. In Uganda, despite mass drug administration (MDA) of praziquantel (PZQ) and health education and sensitization interventions, (re)infections persist, possibly due to behavioural and implementation factors. This study examined the application of citizen science, a bottom-up community-led approach to behaviour change intervention in Kagadi and Ntoroko districts. A three-phase quasi-experimental approach was employed. In the baseline phase, a cross-sectional mixed methods survey assessed knowledge, attitudes and practices, qualitative studies of lived experience and health-seeking behaviour regarding the disease. In the second phase, citizen science and participatory action research approaches were utilised to co-design and implement contextualised behaviour change interventions. Finally, a participatory evaluation of the CS approach to behaviour change intervention was conducted in phase three. Using Kish and Leslie's formula and estimation, a sample size of 613 was used for the study. Systematic random sampling and purposive sampling techniques were employed to select participants. Semi-structured survey questionnaires, in-depth and key informant interviews, focus group discussions, data party, prioritisation and ranking, world café and storytelling were used to collect data. Quantitative data underwent descriptive statistical analysis and chi-square tests for associations, while thematic analysis was applied to qualitative data. From the data, almost everyone had heard of schistosomiasis, and the majority knew its signs and symptoms, diagnosis, transmission modes and prevention. A majority recognised the disease's severity and the importance of avoiding contact with contaminated water and open defecation. Misconceptions, limited access to safe water and latrines, open defecation, inadequate drugs, health workers' negative attitudes, and poor infrastructure led some to go to witch doctors, herbalists, and prayers for treatment were barriers reported. Also, stigma, isolation, loneliness, and domestic violence were challenges mentioned by individuals suffering from schistosomiasis. Door-to-door visits by community volunteers, community radios, dialogue meetings, drama, songs, and football were preferred channels mentioned by participants. Over 9000 individuals in 18 villages were directly reached by the CSs through awareness raising about the disease in just one week. CSs reported increased respect, trust, discipline, social status, and knowledge, attitudes, and practices regarding schistosomiasis. They were also able to effectively communicate and engage with communities and stakeholders. The CS approach was appreciated by the communities for being participatory, transparent, engaging, and appropriate. High expectations from the project by the communities, differences in priorities between community needs and project priority, and a slow response to the awareness messages by the communities posed a challenge to the approach. Conclusively, there is adequate knowledge, and positive attitudes towards schistosomiasis prevention, but limited access to safe water, open defecation, myths and misconceptions, inadequate drugs, and ineffective communication which inhibit prevention and control efforts. Engaging communities in identifying schistosomiasis problems and co-designing and implementing contextualised behaviour change intervention can yield sustainable outcomes. CS as a bottom-up approach, has the potential for fostering community empowerment, ownership, transparency, inclusivity, and local leadership. For better outcomes, there is a need to address communities' real needs and high expectations of WASH infrastructures and to ensure timely and in-depth community engagement and involvement. Government and development partners should consider integrating CS and PAR as community-led approaches into preventive health programs for more impactful interventions

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