

Chapter 16

**COMMUNITY PARTICIPATION AND DISEASE CONTROL: A
CASE OF SCHISTOSOMIASIS IN NIGERIA AND OTHER
TROPICAL REGION**

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Introduction

Nigeria had the highest prevalence rate of schistosomiasis in the world (WHO, 2013). Schistosomiasis is one of the neglected tropical diseases (NTDs) and referred to as a ‘three-factor disease’ (schistosomes, snails, and humans) by Kloos (1985). The disease ranks high in priority in the light of socio-economics and public health significance in tropical and sub-tropical areas. Several million people all over the world suffer from severe morbidity due to this disease (King, 2009; Taylor, 2008). The epidemiology of schistosomiasis is more complex than expressed because of its zoonotic nature that involves more than 40 species of animal reservoirs, including cattle, dogs, pigs and rodents (Gryseels et al. 2006). The implication of this is that even after it has been controlled in human; more than 40 species of animals can help transmit the disease. The impact of schistosomiasis, therefore, is related to demographic, environmental, political, socio-economic and cultural factors (Collins et al., 2012).

Consequently, schistosomiasis poses serious public health challenges in Nigeria but is not considered a priority in health policies (Banwat, Ogbonna, Daboer, Chingle, Envuladu, Audu, & Lar, 2012). This has serious implications for policy makers and infected population on the choice of control and prevention for the disease. In this article, attempt had been made to review literature on schistosomiasis, its burden in Nigeria, gender issues, concepts of community, the Alma-Ata declaration, community participation in disease control, problems with community participation, and evaluation of community participation among others.

Schistosomiasis: Meaning and Symptoms

Schistosomiasis is NTD associated with contact with infected fresh-water (Wu, Chen, Fang, Wu, Han, Wang, Yang, Chu, Feng, Tan, Guo, Hu, Wang, Oliveira, 2014). It is endemic in areas where sanitation is poor and the snail vector is present. Locals create meaning based on the experience and symptom of schistosomiasis in their locality, they consequently give numerous name to the disease based on their information.

Various local names are christened to schistosomiasis disease in Nigeria. In Northern Nigeria some people equated the symptoms of schistosomiasis with women's menstruation and called it pseudo-gonorrhoeal (Bello and Idiong, 1982). In the Eastern part of Nigeria, especially among the Umueze-Anam people of Anambra State, Schistosomiasis is referred to as *ogbodu* known as red urine. This was seen as a sign of a venereal disease, maturity, or as a result of a curse (Amazigo, Anago-Amanze and Okeibunor, 1997). Moreover,

schistosomiasis among the Yoruba people of the Southwest Nigeria is called ‘Àtòsíjǎ’; a condition many beliefs was as the result of urinating where dogs urinated (Olorunlana, Jegede, Morenikeji, Hassan, Nwuba, Anumudu, Salawu, Odaibo, 2016).

Schistosomiasis symptom is a common knowledge among the endemic community. The commonest symptoms are painful urination with the presence of blood in the urine (Talaat, 2004). The presence of little drop of blood after urination shows schistosomiasis symptom, but this condition had been given different meaning by infected people and significant others in the community. For example among the Song people (former Gongola State, now Adamawa State) North-east Nigeria schistosomiasis is seen as a sign of manhood, while bloody urine in south-east Nigeria is a sign of a sexually transmitted infection or infertility in women (Akogun, 1991; Nwaorgu, 1998).

Schistosomiasis Burden in Nigeria

WHO report, affirmed that 90% of schistosomiasis infected people lived in the African region, as schistosomiasis infects 74 countries with the total burden of 240 million people worldwide, among whom Nigerians are the most affected (WHO, 2010). Ugbomoiko and colleagues (2010), drawing the world attention to Nigeria situating it within the sub-Saharan Africa, assert that Nigeria had the most cases of human schistosomiasis in the world. In their report, about 29 million people were infected in 2008 alone.

An earlier study by Chitsulo, Engels, Montresor and Savioli (2000) agreed with the fact that Nigeria was the most infected with schistosomiasis with 25.83%; Ugbomoiko et al (2010), reports find that urinary schistosomiasis prevalence ranged between 2% and 90% widespread in both rural and urban communities in Nigeria. For example, in rural areas of Ogun State, Ekpo and Mafiana (2004) find the prevalence rate of schistosomiasis was 25.0%. Other scholars like Hassan, Ntiaidem, Morenikeji, Nwuba, Anumudu, Adejuwon, Salawu, Jegede, and Odaibo (2012) shows 54.8% prevalence rate in the same rural areas of Ogun State. Although urban report of schistosomiasis prevalence had not been adequately reported by their study, observational evidence shows that there are likely evidence of schistosomiasis in the urban areas.

Subsequently, some scholars did a 22 years review of a retrospective histopathological review of schistosomiasis of the appendix in Zaria Nigeria (Ahmed, Mohammed, Sanda, Makama, Shehu, Ameh and Mayun, 2014). Their result shows the presence of schistosomiasis in the appendix. Schistosomiasis disease was also prevalence in some part of Anambra state (Ugochukwu, Onwuliri, Osuala, Dozie, Opara and Nwenyi 2013). Some scholars worked on the current status of schistosomiasis and found that urinary and intestinal schistosomiasis was prevalence in Sokoto State, Nigeria (Singh, Muddasiru and Singh (2016). Moreover, findings on schistosomiasis at Jos, shows that the prevalence of schistosomiasis was highest among those that obtain water from rivers/streams than in those who

used well water while there was no infection among those that obtained water from the borehole (Dawet, Benjamin and Yakubu 2012).

Continual contact with contaminated water kept schistosomiasis diseases in progression in Nigeria (Olorunlana et al, 2016). As Chitsulo et al, (2000) noted the national prevalence rate of schistosomiasis in Nigeria was 25.83%, and the schistosomiasis progress report by WHO (2013) also reveals a new national rate of 26.21% for Nigeria. The continuum trend of schistosomiasis is both local and global, as there exist a progression of 207 million people in 2010 to over 600 million people in 2014 suffering from schistosomiasis infection and about 800 million at risk in 2016 (El Ridi, Tallima, Selim, Donnelly, Cotton, Gonzales Dalton, Gobert, 2014; Olorunlana et al, 2016).

Gender, Minor, SCD and Schistosomiasis

Various views had emerged based on research and finding of the implications of schistosomiasis on gender, children and other disease like Sickle Cell Disease (SCD). Sarkinfada, Oyebanji, Sadiq and Ilyasu, (2009) affirmed that more male is infected with schistosomiasis than female in Kano state Nigeria. At Adamawa both sexes have close prevalence with males having 32.3% and female slightly higher 32.5% (Balla and Jabbo 2013).

Within Nigeria alone, infections of infants or pre-school aged children have been reported in several schistosomiasis endemic communities. For example in Adim, Cross River State, in 25 of 126 pre-school-aged children examined, 19.8% were infected (Opara, Udoidung and Ukpong, 2007). In Ilewo-Orile,

Ogun State, 97 infections were reported out of 167 pre-school-aged children (58.1%) examined (Ekpo, Akintunde, Oluwole, Sam-Wobo and Mafiana, 2010) while in Obada/Korede, Ijebu East, Ogun State, 14 infections were reported from 83 pre-school-aged children (16.9%) examined (Ekpo, Alabi, Oluwole, and Sam-Wobo, 2011). Here it is of note that the prevalence rate differs from community to community.

Ahmed, Kagu and Ibrahim, (2014), had a 7 years retrospective study in three tertiary hospitals on the Impact of urinary schistosomiasis on crisis among patients with Sickle Cell Disease (SCD) in Norther Nigeria. The results of this study suggest that urinary schistosomiasis adversely affected the severity and prognosis of SCD. SCD patients, the majority of whom live in schistosomiasis endemic countries, should have regular urine tests for early detection and treatment of schistosomiasis in order to avert its adverse interaction with SCD.

Umeh, Amali and Umeh (2004) measured, among other factors, the correlation between knowledge of urinary schistosomiasis and prevalence in rural Nigeria and suggest that health education would be a cost-effective intervention to reduce incidence. But in many of the African countries, more especially, in Nigeria there are no concerted efforts to control the disease.

Concepts of Community

The debate on what community is, is dated over a century ago, one of the most important contributors to such debate on community was Ferdinand Tonnies, who formalised much of pre-existing thought in his book

Gemeinschaft and Gesellschaft, which was first published in 1887 (Jewkes and Murcott, 1996). Tonnie's concept about community is still relevant in sociology today as we think about the rural and the urban distinction. However simplistic this may be, it is of note that authors of studies in communities were not concerned with the precise definition of community (Jewkes and Murcott, 1996). But their works inevitably require 'community' to be implicitly operationally defined.

In 1955 George Hillery reviewed published work on community and found 94 different definitions of community (Hillery, 1955). The only factor he found common to all was that they dealt with people (Jewkes and Murcott, 1996). The intercourse between Tonnie and Hillery on the community is a relevant tool in health enterprise on community participation. This is because the people in rural and urban community get involve on daily activities that can influence their health. The concept of community was employed in the Alma-Ata Declaration on community participation. The next discussion will explain this concept better.

Alma-Ata Declaration

In 1975, the Executive Board of the World Health Organization and the World Assembly called for an international conference to address the conspicuous inequalities in health and health services between countries (World Health Organization, 1988). The 1977 World Health Assembly specified that the central social goal of WHO was the level of 'acceptable'

health that would allow a ‘socially and economically productive life’ for all people by 2000-, and called on nation states to work towards this goal.

Community involvement was one of the principles – if not the core principle – of the primary health care framework formulated at the Alma-Ata conference in 1978 (WHO, 1978). Since its inception, however, there has been an inherent paradox in the concept of community involvement: it should both empower people and communities to act on their needs (an end in itself) and facilitate an improvement in health status towards health for all (an instrument for public health ‘outsiders’). This paradox has often been translated into a practice where community involvement, which ideally would be driven by communities, is often initiated and driven by external agencies, which steer by outputs rather than the quality of processes, and are not necessarily inclined to let go of their authority and influence (Espino, Koops and Manderson, 2004).

These issues were addressed at a meeting in Alma-Ata the subsequent year, and the resultant Declaration of Alma-Ata was to influence global and national strategies, policies and programme for the next two decades. It emphasized the need to provide ‘Health for All’ by collaboration between biomedical and traditional sectors and encouraged approaches to health care that incorporated community participation and community development. Subsequently, social scientist assumed an increased role in the implementation of health care programmes, as they were required to generate

relevant knowledge from which to assist the development of appropriate interventions within communities (Huang and Manderson, 1992).

The declaration called for health care to be restructured: primary health care was to be the main focus of health systems and an integral part of social and economic development. It stated that ‘Primary health care requires and promotes maximum community and individual self-reliance and participation in the planning, organizing, operation and control of primary health care, making fullest use of local national and other available resources; and to this end develops through appropriate education the ability of communities to participate’ (World Health Organization, 1978).

Community Participation

Community participation was thus presented as the principal means to ensure delivery of primary health care. Its importance, as Huang and Manderson describe, rested on two axioms: that the only way to overcome limited and unequally distributed resources and to ensure Health for All is through the involvement of local communities in the prevention of disease and the treatment of the sick, and that without community involvement and responsibility programme will fail (Huang and Manderson, 1992)

In the first half of the 20th century, a variety of public health programmes were operations with some measure of what would later be called ‘community participation’. These programmes were not unique to a particular region. In tropical countries, the majority of which were colonies, public health programmes complemented curative services. Community

involvement in some of these was successful, generally, because the intervention with which they were linked was efficiently organized. However, broad-based interventions, including those that depended upon improved or change living conditions, were somewhat less successful.

Community participation involve a spectrum of processes, including (but not restricted to) organization, planning, evaluating, cooperative, and contribution of time, labour, and/or resources by the host community (Ahmed, 1978; Woelk, 1992). Community participation is usually conceptualized as a process by which people (i.e. member of communities) individually or collectively assume increased responsibility for assessment of their own health needs, and these are agreed upon, identify potential solutions to problems, and plan strategies by which these solutions may be realized (Bermejo and Bekui, 1993). Often, during implementation, a specific organization must be created and/or sustained in order to achieve goals.

The most important justification for the Alma-Ata Declaration of Health for All and its emphasis on community participation in primary health care was its affordability compared with conventional, vertical programmes. Vertical disease control programmes were to have come to an end with the Alma Ata Declaration, following a general acknowledgement that the expenses of the vertical programme, such as facilitated by community participant, were expected to enhance the effectiveness of schistosomiasis control in endemic areas.

Community Participation in Schistosomiasis Control

A classic set of considerations regarding horizontally implemented community participation in schistosomiasis control was based on activities in the Ifakara Division of the United Republic of Tanzania (Tanner & Degrémont, 1986). Urinary schistosomiasis was recognized by the local communities, but issues related to sanitation had a higher priority among local concerns. Water supply, sanitation, environmental management and health education were planned to build on local participation, as well as to increase capacity for morbidity control at the local village health post. Village health volunteers played a central role in mediating the needs of the communities and the resources of the control programme. Continuous monitoring of water contact, snail occurrence, environmental change and infection level (prevalence, incidence and morbidity) by village health volunteers was built into the programme and reported to the district, regional and national levels, which in turn gave feedback to the community – encouraging continuous community involvement (Tanner & Degrémont, 1986).

In another project, communities were invited to elect a water and health committee in an irrigation scheme in Kenya after one month of health education. This committee made decisions and oversaw all operations in the project from initiation to completion, which included clearing of canals and construction of wells, bathing facilities and latrines. The committee decided to raise funds for water supply and sanitation facilities through household

contributions, and also received material and technical assistance from the National Irrigation Board and the Ministry of Transport free of charge. Chemotherapy for schistosomiasis was carried out after a good part of the facilities were in place. The study underlines the multi-sectoral approach and the way local and outside resources complemented each other in the implementation of the project (Katsivo, 1993a).

Committees established for a specific purpose by an intervention may not survive beyond the end of the project. Instead of setting up such committees, an alternative is to work through existing structures. The often cited study by Hewlett and Cline (1997) from northern Cameroon provides a detailed example of an intervention to control urinary schistosomiasis that built on already existing formal or informal structures in the village. These included women's groups, church groups, parents' or teachers' groups and community health workers. Individuals and communities were placed at the centre of the intervention and diversities between and within communities were acknowledged. The authors noted that the intervention entailed frequent visits to the community, approaches were adapted to both powerful and less powerful village headmen, and health personnel were motivated in various ways. The distribution channels for praziquantel were adapted to local conditions, either by including it in existing village pharmacies or providing it through local health personnel. Health education and community involvement were placed as the driving forces for all other components, such

as diagnosis and treatment, snail control and cost recovery. The cost recovery component was unique (Cline and Hewlett, 1996).

Schistosomiasis Control Strategies

Qualitative evaluation research as well as cost-benefit and cost-effectiveness analyses for decision-making regarding control strategies is needed to remedy ineffective schistosomiasis control programmes. Coura-Filho (1996) suggests an increased focus on local variations and an acknowledgement of the individuality of community members. The author suggests that previous resistance to treatment of schistosomiasis can be met by programmes based on community involvement. Such programmes should recognize that people's constructions of health and illness are fragmented and have emerged from scientific information that has been adapted to subjective, cultural imagination and magical aspects. These aspects are real to those who experience them and should be decoded by health workers in order to find a shared language and to establish contact. The federal government should provide the necessary material conditions for forming citizenship with the collective will to control schistosomiasis.

The same author reports from a control project carried out in Taquaraçu de Minas, Minas Gerais, Brazil, between 1985 and 1995, which had three phases. In the first phase, a local commission was formed by elected members of the local community, researchers and a public health supervisor as part of the newly introduced unified health system, *Sistema Único de Saúde*, in

Brazil. Volunteers were trained in registration, stool sample collection, notifying people with positive stool samples about treatment options and the establishment of small dams for raising fish and ducks for biological snail control. In the second phase, stools were examined and infected people were treated. In the third phase, prevalence and intensity of the infection were measured. Prevalence levels had been reduced sevenfold to 4.3% and intensity was also reduced significantly. The commission was pivotal in developing and implementing an alternative model for schistosomiasis control, which was appropriate to the local circumstances. It should, however, also be mentioned that a newly established commission can develop into a parallel local power structure, which may collide with other local or higher-level power structures (Coura-Filho, 1998).

Ojurongbe, Sina-Agbaje, Busari, Okorie, Ojurongbe and Akindele (2014) in their study on the ‘efficacy of praziquantel in the treatment of *schistosoma haematobium* infection among school-age children in rural communities of Abeokuta, Nigeria’, reveals that modern medication was effective against schistosomiasis. Modern medicine was here employed as control strategies. While schistosomiasis control strategies may be employed by researcher(s) or experts, the use of treatment may be more effective if it was community-directed.

Community-directed Treatment

A new approach to morbidity control has been developed in Uganda, in which community members organize and effectuate the distribution of medication

for deworming after collecting the drugs from central stocks. The approach, developed for the distribution of ivermectin for onchocerciasis, is called community-directed treatment, to underline the active participation of locals, as opposed to their often nominal involvement in the much broader category of community-based interventions (Katarawa, 2005).

A study from Uganda evaluated integrated, community-directed treatment (praziquantel for schistosomiasis, ivermectin for onchocerciasis and mebendazole for soil-transmitted helminthiasis) in comparison with routine community-directed distribution of ivermectin and school-based treatment of helminthiasis. The integrated approach, which included more people in decision-making processes, had a higher coverage than routine community-directed treatment of onchocerciasis because parents brought their children for treatment of soil-transmitted helminths and the children then also received treatment for onchocerciasis. The coverage of children was higher in the integrated, community-directed treatment scheme compared with school-based treatment, because out-of-school children were also reached. A drawback in the integrated, community-directed treatment scheme was that drug shortages occurred more often than in the two other schemes because non-targeted groups were also treated (Ndyomugenyi and Kabatereine, 2003).

A study of the roles of the drug distributors or health workers in community directed treatment schemes of ivermectin for onchocerciasis in Uganda

showed that the health workers who were involved in other health and development activities performed better in terms of coverage than those who were only involved in onchocerciasis control. The longer a person had been involved in the scheme, the more responsibilities they tended to have. Female distributors performed better inside their own communities, neighborhoods and kinship groups than male distributors, who were sometimes asked to cover other areas (Katarbarwa, 2005). Even at the point of using community-directed treatment to tackle schistosomiasis and other diseases, the concept is not without a passive problem.

Problem with Community Participation

According to Dias (1998), common problems with community participation in a health-sector perspective include the following:

1. The contradiction between the medical perspective on governments' health systems (curative, disease focused and hierarchical) and the preventive and collaborative spirit of community participation.
2. The way public health authorities regard community participation as a supplement.
3. The complexity of health programmes cannot always be solved by community participation as an approach.
4. The timing and duration of programmes are not flexible.
5. Policy priorities do not always resonate with popular concerns.
6. The way funding is distributed sets priorities instead of reflecting them and the uniting local programmes with larger-scale governmental structures are complicated.

Problem of contradiction, assumed supplement, complexity of health programme, timing, policy and funding as a summary of Dias (1998) position, calls for the evaluation of community participation.

Evaluating Community Participation

One of the very few evaluations of community involvement in control programmes was carried out at the end of a five-year control programme in a Kenyan irrigation scheme. Alternative water sources, bathing and laundry facilities, treatment and health education were introduced. The study documented how villagers appreciated the project activities, but that about half would have liked to have been even more involved in project management. Many heads of households felt that they now saved time with the new facilities and they found their children to be healthier. However, some were concerned about the future maintenance of the facilities. The study notes that discussions about the steps to be taken in the running of control projects should involve locals in a continuous fashion and not just at the beginning of the project. The mechanism for dialogue should also be flexible enough to accommodate inevitable changes in organization and management of the programme (Katsivo, 1993b).

The unplanned interaction between locals and implementers and its implications for practices is an unexplored area. Noda, (1997) observed how changes in water contact practices in a Kenyan village were much more drastic than the installation of five water standpipes and a shower unit could

account for. Health education was not included in the project, but bathing in the river decreased significantly and people began washing clothes in the river instead of in the streams (Ndamba, 1994). Chimbari, (1992) observed how people's knowledge of symptoms and causes of schistosomiasis was fairly extensive even though there was no health education intervention in a project in Zimbabwe.

Short talks on the life-cycle of schistosome parasites given before collection of urine and stool specimens as well as answers to people's questions during snail monitoring activities had given people new knowledge of the infection. Sow, (2003) observed how epidemiological research activities over the previous seven years in Senegal were the main sources of knowledge regarding schistosomiasis in a community, followed by information from friends and relatives. Similarly, it has been observed that women generally maintain a higher and more constant level of enthusiasm in surveys and control projects than men (Feldmeier, Poggensee and Krantz, 1993).

It may be worthwhile researching how men and women engage differently in non-planned aspects of control interventions in order to further increase the efficacy of control programmes one of the few more elaborate studies of the interaction between local residents and control interventions was conducted in the State of Espirito Santo, Brazil. Here, people in endemic areas regard schistosomiasis as a problem that the federal public health agency (*Superintendência de Campanhas de Saúde Pública Ministério da Saúde*,

SUCAM) brought with their different modes of testing for the infection and the free-of-charge medicine for treating it. The SUCAM control programme also carried out health education sessions in the community, but the way people were cast as passive recipients made them relate to the sessions as a kind of punishment after a hard working day. Only very few people mentioned transmission sites and sanitation as another area of intervention (Rozenberg, 1994). If treatment was the preferred response to infection over time, chemotherapy might come to be seen by the locals as the only solution to the complex of biological, environmental and social factors involved in the transmission of schistosomiasis.

Conclusion

Schistosomiasis control needs holistic trajectory of treatment of at-risk population, health education, environmental control, political will, socio-economic status and cultural modification. In order to reduce schistosomiasis disease burden in Nigeria, the Government and the community needs to employ the use of community participation, as it has been a proven strategies in the control of schistosomiasis in other endemic tropical region of the world.

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