

Consequences of hydrocele and the benefits of hydrocelectomy: a qualitative study in lymphatic filariasis endemic communities on the coast of Ghana

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Abstract

A study using focus group discussions and in-depth interviews was conducted to determine the consequences of hydrocele and the benefits of hydrocelectomy on physical activity and social life in three lymphatic filariasis endemic villages where males had recently been offered surgical operations to repair their hydroceles. Respondents were of the view that hydrocele, especially large ones, severely reduced the patients' work capacity and impaired sexual function, and that overall it had a considerable negative effect on the quality of living for the patients, their families and the community. The main reasons for refusing hydrocelectomy in the past were the high cost of surgery, and to some extent fear of death, impotence and/or sterility that might result from the operation. The recently offered hydrocele operations, which included 40 males, were financially supported and preceded by appropriate counselling, and from the patients' point of view were highly successful. Patients spent between 4 and 12 days in the hospital and there were no post-operative complications. Patients observed that, between 3 and 6 months after surgery, there were remarkable improvements in their work capacity and sexual function, and restoration of self-esteem, thus enabling them to participate more actively in community activities. The need for hydrocelectomy to be incorporated as an important morbidity control measure in lymphatic filariasis control programmes is discussed. © 2001 Elsevier Science B.V. All rights reserved.

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1. Introduction

Lymphatic filariasis, resulting from infection with the mosquito borne nematode parasite *Wuchereria bancrofti*, is an important public

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health problem in many developing countries, affecting over 50 million people in Africa alone (McMahon and Simonsen, 1996; Michael and Bundy, 1997). The common clinical manifestations of lymphatic filariasis are acute attacks of adenolymphangitis (ADL), and disfiguring chronic conditions such as hydrocele and lymphoedema/elephantiasis. Because of the debilitating nature of these manifestations and the large numbers of individuals affected, lymphatic filariasis has been identified as one of the leading causes of permanent and long-term disability in the world (WHO, 1995).

Hydrocele, a condition that results from the accumulation of fluid in the tunica vaginalis of the scrotum, is the most commonly observed chronic presentation of lymphatic filariasis in *W. bancrofti* endemic regions of the world. Hydrocele is rarely fatal, and patients are usually not in pain, but it may carry grave social and economic consequences for those affected (Evans et al., 1993; Dreyer et al., 1997; Coreil et al., 1998; Ahorlu et al., 1999; Gyapong et al., 2000). Studies in lymphatic filariasis endemic communities in coastal villages in southwestern Ghana have revealed a negative impact of hydrocele in terms of work performance, sexual functioning and everyday social interaction and relationships (Ahorlu et al., 1999). The only definitive treatment of hydrocele is surgery (hydrocelectomy).

Recently, a non-governmental organization sponsored surgical operations on hydrocele in some lymphatic filariasis endemic coastal villages in southwestern Ghana as part of its community health programme. By using qualitative research methods, the present study examined the implications of hydrocele and the benefits of hydrocelectomy to the individual patients, their households and the community at large in three of the beneficiary village communities.

2. Materials and methods

The study was conducted in three lymphatic filariasis endemic villages (Butre, Achowa and Miamia) located in the Ahanta West District of the Western Region of Ghana. Detailed descrip-

tions of the study area and its population, and of the endemicity of lymphatic filariasis in the villages have been presented previously (Dunyo et al., 1996; Ahorlu et al., 1999). Briefly, each study village had 500–800 inhabitants composed mainly of Ahanta speaking people. Overall prevalences of *W. bancrofti* microfilaraemia were in the range of 18–20%, while hydrocele affected approximately 20% of adult (≥ 20 years) males and 6–7% of adult individuals had limb lymphoedema/elephantiasis. Hydrocele was defined as fluid accumulation in the tunica vaginalis of the scrotum, and hydrocele patients did not have scrotal or penile lymphoedema (very rare in these communities).

As a follow-up to the reported high prevalence of hydrocele in the villages the District Health Management Team (DHMT) of the Ahanta West District in conjunction with chiefs and elders made an appeal to a Christian non-governmental organization (NGO), for financial assistance to perform hydrocelectomy on those affected. The NGO agreed to meet the request. Hydrocele patients who wanted the surgery were registered by the chiefs in the communities, with the assistance of the DHMT and the assemblymen (elected political representatives to the District Assembly). The DHMT thereafter arranged clinical examination and counselling of the patients in the villages, and gave them an appointment for surgery in the district hospital (Dixcove Hospital). The patients provided their own transport to the hospital and feeding while on admission, while the NGO paid the cost of hydrocele operation and transport after discharge. A total of 40 males benefited from hydrocelectomy in the three study villages (17 in Butre, 10 in Achowa and 13 in Miamia). A few males with hydrocele did not register for the surgery mainly because they felt their conditions were not serious and, therefore, they did not warrant 'self-exposure' to public ridicule.

The study was carried out from March to April 1999, approximately one and a half years after the surgery. Focus group discussions (FGDs) and in-depth interviews (Rubin and Rubin, 1995; Smith and Morrow, 1996) were held with patients, their wives/caretakers, other community members, and opinion leaders to explore the perceptions, and the impact on physical activity and social life,

of hydrocele and hydrocelectomy. The FGDs were conducted using a FGD question guide administered by a research assistant who spoke the local language fluently. The same research assistant conducted the in-depth interviews. The senior author (Collins K. Ahorlu, a sociologist), who also understood the local language, was present as observer during FDG and in-depth interview sessions.

Four FGDs were conducted in each community with 6–10 participants in each group. Two of the FGDs involved residents randomly selected from the village population register on the basis of age (≥ 30 years) and sex since these variables are considered to influence free and natural discussion in rural Ghana. Two other FGDs were held with individuals randomly selected from the list of those who had had hydrocelectomy and their wives, respectively. Eleven in-depth interviews were held in each community. These involved the chief, the queenmother (traditional women's leader), the assemblyman, two hydrocelectomy patients, two wives of hydrocelectomy patients and four adults aged ≥ 30 years (two for each sex). None of those requested to participate in FDGs or in-depth interviews declined. In each community, in-depth interviews with two key informants (the chief and a hydrocelectomy patient) were repeated with the same individuals (i.e. the research assistant and the senior author) to determine the reliability of responses. There were no major differences between first and second rounds of responses.

Proceedings from both FGDs and in-depth interviews were tape recorded and notes were taken. The dialogues were transcribed to English and entered into a computer. After using Textbase Alpha software for coding and categorization of statements, the senior author performed content analysis and selected representative and relevant responses for presentation. There were no obvious differences in response of FDGs and in-depth interviews. The study was carried out as part of a larger research programme on the epidemiology and control of lymphatic filariasis on the coast of

Ghana, which was approved and ethically cleared by the Ministry of Health, Ghana.

3. Results

3.1. Perceptions about hydrocele

The local perceptions about hydrocele agreed well with those reported earlier from this area (Ahorlu et al., 1999). Thus, hydrocele and hernia were considered the same disease condition presenting in two different ways. It was generally believed to be inherited, and to some extent to be enhanced by hard work, excessive drinking of palm-wine and excessive sexual activity. Some respondents believed that sugarcane consumption could also cause hydrocele while others attributed the condition to 'dirty blood' and the eating of 'poor foods'. Phlegm (mucus accumulation) was also reported as one of the perceived causes of hydrocele. The main treatment options were consultation of spiritualists and/or herbalists, the use of analgesics and/or antibiotics bought from peddlers and chemical shops, and in some cases surgical operation at the hospital. Notable among local preparations for treatment of hydrocele were bitter herbs such as *Rauwolfia vomitoria* and *Picralima nitida* (locally known as kakapempem and ekwamba, respectively).

3.2. Effect of hydrocele on physical activity and social life

Hydroceles were reported to result in impairment of productive capacity, and especially large ones could have a disastrous effect on the work performance of the patients. Respondents revealed that as a result of the size and weight of the hydrocele, some patients were unable to go about their activities of daily living. This affected themselves, their families and the whole community. Patients and their families were furthermore teased and called names and some could not get marriage partners. Patients were permitted to attend public gatherings and were free to contribute to discussions at such meet-

ings but due to the ridicule and teasing they usually suffered at the hands of the youth, most of them did not attend such gatherings.

A more serious and perhaps more worrisome effect of hydrocele for patients and their spouses was the inability to have satisfactory sexual intercourse. As in the case of teasing, this also prevented some patients from getting marriage partners. Due to strong community sanction against divorce, the majority of patients who were married before developing hydrocele or before their disease reached an advanced stage were still married. However, there had been a few cases of divorce due to hydrocele, but this occurred only when the patient could no longer have sexual intercourse with the wife. Respondents generally agreed that the negative effects depended upon the size of the hydrocele. They maintained that with small hydroceles males were able to work and have effective sexual intercourse, but that these activities were severely hampered when the hydroceles enlarged.

These views were presented in the following responses. “As for hydrocele, it is heavy, so you cannot do any serious work with it. This has affected my work output such that even my uncle who should have named me to inherit him had refused and instead named my younger cousin (mother’s sister’s son), saying that I cannot take care of his property and children with my hydrocele when he dies. Unfortunately, he died before I had the hydrocoele operation so the decision could not be changed”. Another respondent said, “my penis was buried into the scrotum leaving only a small opening for urinating, so how could I have sex with my wife? However, because I am the Oman panyin of this village (the one on whose lap the community rests), my wife could not simply divorce me. That is why she stayed with me up to this time but we had to contend with a lot of problems in our bed room”. Another respondent in his early forties said, “this males’ disease is a disgraceful one. In fact, before the operation I could not do enough farming activity. I could also not go fishing, because my colleagues without the disease teased me at sea. Even though

my penis was functioning well, I could not get a woman to marry because the ladies teased me so I could not even converse with them”.

3.3. Perception about hydrocelectomy

It came to light that in the past many hydrocele patients were not willing to go for surgical operation because they were afraid that the operation could render them impotent and/or sterile, thus making them lose the ability to have sexual intercourse and/or children. Those with big hydroceles said they had desired to have theirs removed, but the cost of surgery and the fear of death had prevented them from doing so. The respondents maintained that in the 1970s the cost of hydrocele operations were affordable but nowadays most patients could not afford it. The current cost of hydrocelectomy was estimated by the villagers to range between 75 and 125\$ (US dollars), based on reports from those who went for the operation on their own before commencement of the present programme. An additional amount of 20–30\$ was estimated for feeding and other expenses during hospitalisation. This amount was beyond the reach of most patients. In fact, the actual cost for operating a patient in the present organised programme was somewhat cheaper, in the order of 30–60\$ per case, but even this amount would be beyond the capacity for most of them to pay.

At the time of the study 40 patients (mostly those with big hydroceles) had benefited from the surgery. According to the respondents there were no complications during and after the surgery, and everybody recovered well. In fact, a few patients chose to go back for hernia operation after the hydrocelectomy. On the whole the respondents who had surgery spent between 4 and 12 days at the hospital. At the initial stage of the programme, those with smaller hydroceles concealed their condition because of the local perception about hydrocelectomy. One and a half years later, those who had concealed their condition from the beginning felt the need to also have their hydrocele removed. This was be-

cause they had observed that there were no complications from the surgery and because their hydrocele had increased in size.

3.4. *Effect of hydrocelectomy on physical activity and social life*

Patients reported major improvements in their health, work capacity and sexual performance after hydrocelectomy. They maintained that these became evident after a 'resting' period of 3–6 months after the surgery. Family members and other respondents corroborated these sentiments. One patient said, "there is a change after the operation. When the disease was there I was not active at all, but now I am happy with my wife and we have expanded our farm." The wife of a patient who had surgery said, "oh! things have improved and my husband is now able to do his farming activities better than before and his sexual performance has improved very much."

Community members were appreciative of the external support for the hydrocelectomy programme. They maintained that the support could not have come at a better time since most of the patients and their families were so much bothered by the disease, but could not afford to pay for the operation. Furthermore, the exercise allayed their fears about hydrocelectomy. One Chief said, "I and my people are grateful to the NGO for assisting us to remove hydroceles. In fact, formerly at communal labour I realised that some of the young men were not coming because of their disease, but now everybody comes out freely to work and you see them wearing short knickers, something they could not have put on without the operation". A female respondent put it this way "The operation was good for us all. Before the operation my husband was an 'old man' and one of the wives left him because he was not performing well sexually. Furthermore, we the women did most of the farming work, but now, after the operation, he is a real man and looking very handsome and hardworking. The wife who left him wanted to come back but I warned my husband against it very seriously because I cannot suffer for her to come and enjoy".

4. Discussion

In many lymphatic filariasis endemic communities of Africa, 20–30% or more of adult males have hydrocele (Gyapong et al., 1994; Meyrowitsch et al., 1995; Simonsen et al., 1995; Dunyo et al., 1996). Despite the huge public health burden, the physical and social wellbeing of those affected has received little attention in the past.

Hydrocele was found to be a well-known condition and a major health problem in the study communities. However, as seen in other studies (Gyapong et al., 1996; Coreil et al., 1998; Ahorlu et al., 1999), there was no realisation of its biomedical aetiology. Hydrocele was recognised to result in impairment of the productive capacity and sexual performance of the patients, especially in those with large ones. Patients and their families were teased, and some patients could not get marriage partners. Women married to hydrocele patients were 'silent sufferers' of the disease of their husbands by being imposed to extra work and by living a marriage without sexual satisfaction. The impairment of physical activity and sexual performance and the social stigmatisation associated with hydrocele and other manifestations of lymphatic filariasis have previously been documented from Ghana (Gyapong et al., 1996, 2000; Ahorlu et al., 1999) and elsewhere (Dreyer et al., 1997; Coreil et al., 1998).

Surgical operation was known by the community members to be the definitive treatment for hydrocele, but factors such as fear of impotence and/or sterility, death and financial cost prevented the majority of patients from taking advantage of the facility. The absence of post-operative complications in the initial round of surgery allayed the fear about surgical operation to repair the hydrocele. After the operation, patients regained their self-esteem and respect from wives, children and the entire community. Although an NGO paid for the cost of surgery, patients had to provide for their own feeding and other expenses while on admission, but they were willing and able to pay for that. However, the total cost of operation per patient was considered by the respondents to be too high for most villagers to cater for by themselves. The financial assistance provided by the

NGO had, therefore, been essential for the programme to gain a high coverage.

The key lymphatic filariasis intervention measure recommended at present is regularly repeated community-wide drug treatment to control transmission (Ottesen et al., 1997). Since drug treatment does not have obvious short-term effects on already developed chronic clinical manifestations, additional measures of morbidity management are essential to provide immediate benefits to the patients. In this respect, management of leg lymphoedema/elephantiasis by simple hygiene measures, which has been shown to halt or even reverse this condition, has been recommended (Ottesen et al., 1997; Dreyer and Piessens, 2000). Even though hydrocele is the most common clinical manifestation of lymphatic filariasis, active programmes for its management are usually not included in lymphatic filariasis control activities. Several reasons may be responsible for this. Thus, since the definitive intervention for hydrocele is surgery, the cost will be relatively high and available health institutions may not be able to cope with the large number of sufferers. Furthermore, as a result of inadequate knowledge of the plight of hydrocele patients, and the lack of information on the social and economic benefits of hydrocelectomy, policy makers are not stimulated to consider hydrocele as a priority health problem.

This study suggested that hydrocelectomy not only corrected the hydrocele but also improved the physical and social status of the patient, his household (in terms of increased capacity to work and improved sexual function) and the community (in terms of active participation in communal activities). Promoting and supporting improved access to facilities for hydrocelectomy in endemic communities could be an important adjunct to the repeated drug treatments, which would furthermore help to increase and sustain local interest in lymphatic filariasis control activities. It could also be an important entry point for health education to improve local understanding about the biological aetiology and consequences of lymphatic filariasis. Since patients often cannot afford it, policy-makers and other public-spirited organisations, especially NGOs, should be encouraged to assist by subsidising the cost of hydrocelectomy.

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