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The burden of hydrocele on men in Northern Ghana

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Abstract

The social and economic impact of lymphatic filariasis was studied in Northern Ghana. Qualitative methods of gathering information revealed that even though the disease was a problem to both men and women, men with hydrocele suffered a greater psychosocial burden. Particular attention was paid to them, distinguishing men with small hydroceles and men with large ones. Out of frustration men with small hydroceles sought health care from a wider range of places than men with larger ones. The pain associated with adenolymphangitis (ADL) renders them inactive for up to 5 days. Complications of lymph scrotum and ridicule from community members were a problem. Unmarried men in particular found it difficult to find a spouse with their condition, and various degrees of sexual dysfunction were reported amongst married men. The clinical significance and the value of time and attention for counseling to mitigate the effects of the disease on damaged male identity and the need for gender studies to address male issues and the need for including psychosocial issues in the calculating of disability adjusted life years (DALY's) is also discussed. © 2000 Elsevier Science B.V. All rights reserved.

Keywords: Gender; Hydrocele; Disease burden; Ghana

1. Introduction

The 1993 World Bank Development Report uses disability adjusted life years (DALYs) as a standard measure for comparing the public health impact of different diseases. In this report, the global burden for lymphatic filariasis was estimated at 850 000 DALYs lost, which represents only 0.23% of the global burden of parasitic and infectious diseases (World Bank, 1993). Even though the disease does not kill, it is ranked as the

second leading known cause of disability worldwide (Ottessen et al., 1997). In Africa alone, it is estimated that there are some 4.6 million cases of lymphoedema and over ten million cases of hydrocele (Michael et al., 1996). These figures represent about 40% of the global burden of the disease. These estimates were largely based on extrapolations from only gross chronic clinical manifestations due to lack of data on the acute phase and other stages of the disease. Based on more recent knowledge of the epidemiology of the disease, the figure of the DALYs lost is seen as a gross underestimate, especially in the light of new findings relating to incidence, duration, and sever-

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ity of acute adenolymphangitis (Gyapong et al., 1996a). Such a definition ignoring adenolymphangitis (ADL) significantly underestimates the burden of disease not only because the acute disease occurs more frequently, but also because it occurs among younger age groups, which are positively weighted in the calculation of DALYs. The younger age groups also constitute the majority of the population in endemic areas. More importantly, since the psychosocial burden of the disease is difficult to quantify and has not been taken into much consideration in these calculations, one can still say that the DALY figures are underestimates.

In recent years, efforts have been made to document the burden of the disease on affected individuals (Amuyunzu, 1997; Ramu et al., 1996; Bandyopadhyay, 1996; Gyapong et al., 1996b) but, little attention has focused on the important but hidden disability associated with genital manifestations of the disease. In women, chronic manifestations affecting the genitals are rare. When they occur, the effect is hidden. Women also experience manifestations of the breast but this is also very rare. Hydrocele, which is the accumulation of fluid in the tunica vaginalis in the scrotum, has been reported in several countries to be a very common manifestation of the disease (Amuyunzu, 1997; Lu et al., 1989; Muhondwa, 1983). In Ghana, Gyapong et al. (1998) used it as a rapid diagnostic index for lymphatic filariasis. Whether in a man or woman, a genital manifestation would go a long way to affect the roles each of the sexes play in society.

Gender refers to women's and men's roles and responsibilities that are socially determined. It is related to how both men and women are perceived and expected to think and act as male or female because of their biological differences (WHO, 1998). Gender roles according to Tanner and Vlassoff (1998) change over time and over an individual's life stages but in practically all cultures, women have a lower status than men. They are for example denied the right to manage their own property, and have little control over their own sexuality. This is shown in the variables of the gender framework for tropical

disease research proposed by Rathgeber and Vlassoff (1993). The three tiered gender variables which link to disease prevention and treatment include issues related to economic/productive activities, social/reproductive activities and personal factors. Over the years, studies of gender and tropical diseases have focused almost exclusively on women (Wijayarante et al., 1992). This is due to the fact up to the late 1980's the male model was used as the standard for most health measures, development of therapy and so on. It is in the light of the above problems of women that the WHO proposes the adoption of the gender approach to policy and planning.

This paper is written from a study whose aim was to look at the social and economic impact of filariasis. It attempts to address the important but neglected aspect of the effects of having a hydrocele on men in Ghana. It also highlights the fact that, when a disease impairs male sexuality, its significance may be socially amplified, inasmuch as sexual functioning may be culturally defined as the essential feature that defines an acceptable male self-image. It shows how gender stereotyping may damage men. We also look at the whole issue of disability and the need to include psychosocial aspects in the calculation of DALYs.

2. Materials and methods

The study was conducted in the Kassena-Nankana district of Northern Ghana and was part of a multi centre study coordinated by WHO. The objectives were to document the community's definition of filariasis and their knowledge on the cause and transmission of the disease. The attitude of the community towards individuals with the disease, treatment seeking practices and the role of the community in the management of the disease. We were also interested in the effect of the disease on social and economic activities. Ethnographic data was collected throughout the period of the study. The study begun with informal discussions with community leaders and key informants. Issues ad-

dressed included general health seeking practices, terminologies for filariasis and the community's perception of filariasis. Information gathered from these semi-structured interviews formed a basis for drawing up guidelines for focus group discussions and in depth interviews involving affected and unaffected individuals in the community. Specific attention was paid to the objectives listed above. The principal author lived in the study communities and observed the community's attitude towards people with disease (particularly chronic disease), their involvement in the care of the patients and the assessment of the degree of impairment of patients. All the information gathered from the ethnographic work was collated and used to design a questionnaire administered to a cross section of the community in a bid to assess the social and economic impact of lymphatic filariasis.

Every individual in the community was given a full clinical examination by clinicians and medical assistants at easily accessible locations, to define disease rates at baseline, particularly chronic filarial disease. At baseline out of a population of about 5097, 404 individuals with various degrees of chronic filarial diseases were identified in the community. They were categorised into those with infections of the upper limb (UL), lower limb at early stage (LL12), advanced lower limb infection (LL3), hydrocele of tennis ball size (HT), and large hydrocele (HL). For the cross-sectional survey, 20 affected individuals in each of the categories mentioned above were randomly selected to be administered with a questionnaire designed from information gathered during the ethnographic phase. A similar number of unaffected individuals were interviewed using a similar questionnaire but with the aid of vignettes depicting the various categories mentioned above. The results of questionnaires from men with hydroceles are presented in this paper.

The information generated from the ethnographic phase was recorded on cassette, transcribed and analyzed using Textbase Alpha, a database management system for qualitative textual data Tesch (1989).

3. Results

3.1. Living with a hydrocele

After the survey we had HL = 19, and HT = 22. The youngest patient was a 15-year old school boy and the oldest a 95-year-old man. They have had the condition for between 6 months and 32 years.

Of the 41 cases of patients with hydrocele interviewed, 11 experienced at least one episode of ADL. Headache, fever, swelling, pain and tenderness of the scrotum are characteristic of this condition. In addition, the scrotal area becomes very hot. This ADL episode could have been as a result of bacterial etiology of the scrotal wall. During focus group discussions and key informant interviews, another experience was mentioned, which had not been reported in the sample survey, namely, leakage of lymphatic fluid through the scrotal skin and cellulitis. One elderly man discussed his illness experience in a focus group discussion, as follows:

I don't get acute attacks, however from time to time slimy water passes out of my scrotum, and my waist becomes stiff for about 2–4 days. This happens at least twice a year.

What the man described above could have been lymph scrotum, which is one of the complications of hydrocele repair. However lymph scrotum could occur without hydrocele repair. It is also not uncommon for patients with lymphedema of the scrotal wall and lymph scrotum to also have a hydrocele creating an even greater burden for men than just pure hydrocele. It must be noted that these are possible explanations since the pathophysiology of lymph scrotum is not yet well understood.

During the study period, 54% of men with hydrocele of tennis ball size (HT) and 26% of men with a larger hydrocele (HL) had sought relief of some sort for their condition. Table 1 indicates that 15% of men with HL and 23% of men with HT had visited the hospital. Ten percent of men with HL and 36% of men with HT had gone to

the drug peddler for analgesics to relieve the pain during acute attacks. The same number (10% of HL and 39% of HT) resorted to self-medication in the form of a mentholated balm, which was massaged on the swollen scrotum to relieve the pain of acute attacks. Almost 50% of people with HL said they sought no help and did nothing; they said they would just wait and see what would happen to them. This could be explained as the result of their having experienced the condition for a longer period of time, and disappointment in the past with all the treatment options the HT patients were currently trying, which had not given the HL men much relief. The greatest desire of both groups of patients was to have surgery.

Their fear of 'temporary death' while under anesthesia and the cost of the surgery prevented them from going to the hospital. A 55-year-old man who has two wives and six children offered this account of his fear:

I know I have to go in for an operation but what if I die? Who will take care of my children and my family? Since the disease has not killed me, I will stay like that 'till you people do something about it.

One man who had undergone a successful surgery had to borrow money to pay for it, and his brother in the city had to come and help to help pay the cost. The man with the hydrocele explained:

Table 1
Treatment seeking practice for hydroceles in northern Ghana

Source of help	Small hydroceles N = 22 (%)	Large hydroceles N = 19 (%)
Soothsayer	5(22.7)	0
Traditional healer	2(9.1)	0
Self medication	8(36.4)	2(10.5)
Relatives/friends	1(4.5)	0
Drug peddler	8(36.4)	2(10.5)
Health center/hospital	5(22.7)	3(15.8)
Other	5(22.7)	9(47.4)

I paid it myself and I had a brother in Kumasi who also helped in paying for the debt. I paid 35 000 cedis.

(about 35 US dollars in 1995). For a man who cannot earn a regular income because of his incapacitation, this is a considerable sum of money, not readily available if at all.

3.2. On being a 'man' and having a hydrocele

The concept of manliness combines sexual functioning and social responsibilities. In the study area, a real man 'Baro' (Kassim) 'Boda' (Nankani) is someone who can satisfy a woman sexually, has many wives and children, large farms, and the ability to provide for the total needs of the family. One who does not fulfill such criteria for manliness is said to be a woman 'Oyi kaamo' (Kassim) or 'Adela Poka' (Nankani). Men whose hydrocele interfered with this concept of male identity were deeply frustrated. An elderly man who had to retire from regular employment prematurely expressed his frustration in the following way:

Who wants a disease, if I wanted it or if I felt it was something good, would I have been wanting to remove it and throw it away. I wish I did not have this disease, so that I could also do my normal work to my satisfaction. I worked with Ghana Railways for 7 good years and later joined the survey department; but for the disease which brought me home, I think I would have been better by now.

In addition they feel like a burden to their family because they have less income and cannot work as they could before they had the disease. One man said:

A hydrocele patient is a problem during the farming season. After 2–3 h of weeding it becomes difficult to walk. You have to take a rest for a brief period. You cannot even bend down and get up at once. You can only employ labor to weed if you can afford the capital. When you are a peasant farmer and cannot

afford the labor costs, then you must die on the field with your hoe. When you even ask for help, you need money to buy them drink and food. Otherwise, they will not work. Unless you have children to work for you, or your in-laws/daughter or sisters husband may sympathize with you and work for you.

In addition to their economic physical handicap, the issue of marriage for young unmarried men and sexual problems for men with large hydroceles was raised. In a group discussion with unaffected men, the following discussion arose.

Q. What are the marriage prospects of a man who has a hydrocele?

R1: 'They find it difficult to get married because in our area we consider such people as sick people. Nobody who is normal would like to marry a sick boy or girl. They often find it difficult to marry, but in a case where you get married before the disease occurs, you are forced to keep your spouse. This is because you can not sack your wife because she has 'naa pimpim' (elephantiasis) neither would your wife leave you because you have now developed 'paa manchale' (hydrocele).

R2: 'If you marry my daughter and develop a hydrocele afterwards, I can't take her back. But if I get to know you have it, and you come in for my daughter, I will drive you away.'

R3: 'If I get to know my daughters fiancé has such a load in the scrotum, I will never endorse any proposal of marriage, even if she is in dying need.'

This statement proved to be controversial, however, and a young man argued:

R4: 'No that will be crude, you will have to allow them to get married'.

R3: 'No I will not (dismissing the idea)'.

R4: 'After the marriage he can contact a doctor to help him remove it'.

R3: 'Ay, but what if he cannot produce children again?'

This discussion between the more elderly man and the young man indicates the loathing men in the community have for the disease and the dilemma it presents to unmarried men. Once married, a hydrocele is less likely to end a marriage than it is to obstruct one but, it continues to exert its effects; 10.5% of HT told us it affected their sex life, and 35% of men of HL reported a wide range of adverse effects, including pain during acute attacks and reduced desire for sex. As a matter of great concern, 29% of HL men reported that their penis was too far embedded in the scrotum to achieve an erection for a satisfying sexual relationship.

Men with the condition reported they were sad and had all kinds of negative feelings about the condition, but they did not say they avoided social functions, hid their condition or had been teased. Perhaps minimizing the social liability helped to cope with their self-stigma and stigmatization from others as a result of their condition. Unaffected people, on the other hand, readily explained what they understood to be the social impact of the disease, especially for men with large hydroceles. Among patients with hydroceles, 7.2% admitted they avoided social functions, compared with 25.4% of unaffected individuals who said such men avoided social functions. Only 7.5% of affected men admitted to concealing their condition, but 66.1% of unaffected persons said men with hydroceles tried to conceal their condition by wearing especially large pants. About 50% of men with HL admitted that they were teased whilst 80.5% of the unaffected population said such men were teased.

4. Discussion

The peak incidence of noticeable hydrocele seems to occur in early adulthood between the ages of 19–34 when men are physically robust and actively formulating social and sexual identities. This is also a time when they are pursuing career and family goals. The disease not only interrupts these pursuits but, its very location threatens the integrity of the body and an organ that is associated with self esteem, sexuality, fertil-

ity and masculinity issues of importance to ill and healthy men alike. In this study, younger men who have seen what elderly men have gone through because of their condition are extremely concerned and therefore spend time and money seeking care for their condition because of what they know it could progress to. The results also indicate that the qualities that make a man are hampered when he has a hydrocele. He gets regular acute attacks and therefore cannot farm. He has to hire labour, which has financial implications. If he has a large hydrocele, the penis is embedded in the scrotum and so he cannot have a proper erection for sexual intercourse.

Although our study considered only hydrocele arising from lymphatic filariasis, other tropical diseases may also have specific effects on men but this is not known since (as mentioned in the introduction,) the male model has been used over the years as a standard for most health measures. Vlassoff (1997) expressed this concern when the Gender Task Force of WHO/TDR came to the final year of its 3-year work-plan. It had achieved most of its goals but a particular area which had not been addressed was gender difference in the impact of filariasis including the social stigma attached to hydrocele in men and gender sensitive interventions for female and male patients. This concern about mens health has also been shown in political circles. Speaking at a conference on young men's health at Aston University in Birmingham, the British Minister for public health Yvette Cooper is quoted by Yamey (2000) of the British Medical Journal as saying 'promoting mens health has failed so far'. Because it may be painful to disclose and discuss the kind of problems reported from this study, such research as we conducted requires a substantial commitment to time spent with the people involved. According to Vlassoff (1992), information of a sensitive nature including the fear and suffering experienced from stigmatising diseases may be difficult to capture by survey techniques and qualitative methods are essential to unveil the complex dimensions of a problem. This was not the case in our study since the first author spent 2 years in the community observing, listening, interacting, and employing a variety of qualitative methods, which put these men sufficiently at ease

to discuss personal aspects of this sensitive, stigmatising condition. Dreyer et al., (1997) reported a similar experience in a clinical setting in Brazil.

The greatest desire for a man with a hydrocele in the study area was to have surgery on the other hand, the fear of death and cost of the operation was a problem to the men studied. We therefore raise a number of issues. Is it possible to provide hydrocelectomies in a setting where the fear of temporary death will not be felt? Can something be done about the cost of this surgery such that more people can benefit? If treated as day cases, can patients handle their post operative wounds properly?

In the Ahanta West district in Ghana, the district medical officer with assistance from World Vision has started a program where men with hydroceles are operated on free of charge at a health centre as day cases with local anesthesia (In this regard, it is important to note that, hydrocelectomies depending on the size and extent of damage can be performed under local anesthesia). Taking this course of action even without support from a non governmental organisation (NGO) like World Vision could reduce the cost involved in having this kind of operation and take away the fear of temporary death under general anaesthesia.

A few weeks before the day of the operation, people in the surrounding communities are informed by health workers of the date on which the operations will be performed. All men with hydroceles are encouraged to register. Any one who did not register during the 1 week given period would have to pay for the operation. Two weeks before the operation the men are brought together for pre- and post-operation counselling. These men are taught how to wash and keep the scrotal area clean before the surgery and how to take care of the post operative wound. After the operation, all patients are observed for a day and allowed to go home.

The approach described above begun during the latter part of 1999 and has not been evaluated but, since surgical intervention for men with hydrocele is one of the concerns of the Global Program for the Elimination of Lymphatic Filariasis as a public health problem, we think that in addition to disseminating as broadly as possible the most practical surgical techniques appropriate for the care of patients with hydrocele, it would

be worth looking into the feasibility of adopting the Ahanta West approach.

The results have also shown that apart from issues related to inability to work when experiencing acute attacks, and the cost of surgery, the emotional and psychosocial burden on patients with the hydrocele in rural communities is enormous. Murray (1994) mentions four key social preferences or values that must be incorporated into an indicator of the burden of disease. These are: the duration of time lost due to a death at each age, the value of time lived at different ages, non-fatal health outcomes and time preference. The fact is that, psychological resilience and personal values, the stresses perceived by the patient and those close to him, and his available strategies for coping with the physiological challenges imposed on him by the disease form the core of the problem. These psychological consequences of disease for both men and women have been under researched and under valued in the DALYs calculation and needs to be considered.

In conclusion, this paper has attempted to address the critically important but frequently overlooked topic of male urogenital disease in lymphatic filariasis. It has also given some insight into the psychological or social burden of hydrocele in filariasis endemic areas particularly in Africa. Addressing the burden of persons already suffering from chronic filarial disease is an important component of the current global program to eliminate filariasis and we have raised issues with regards to some barriers to and more widespread availability of hydrocele surgery.

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