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Living with AIDS: perceptions, attitudes and post-diagnosis behaviour of HIV/AIDS patients in Ghana*

Kofi Awusabo-Asare

Department of Geography, University of Cape Coast, Cape Coast, Ghana

Abstract

AIDS infection has created a fear of stigmatization, isolation and panic among infected persons. There are, however, few studies that explore the perceptions and attitudes of HIV/AIDS patients in sub-Saharan Africa, partly because of the isolation and withdrawal of patients. Using data from a study on the social dimensions of AIDS infection in Ghana, this paper explores the attitudes and behaviour of patients and their perception of the attitudes of their relations and neighbours towards them. The traditional forms of support for sick persons in Ghana are under strain either due to or independent of HIV infection. In spite of changes, infected persons perceive their female relatives to be more sympathetic than their male relatves. Some patients continue to deny to themselves their HIV status. These findings have implications for programming as the disease enters its second decade.

Evidence from AIDS research in the last decade has reinforced the view that the state of health of any group of people is related to its living conditions, the socio-cultural context in which people are socialized and operate, and the respect for basic rights of the individual. In most parts of the world, the vulnerable in society have been the hardest hit by the AIDS epidemic (Mann 1992; Mann et al. 1994).

With the initial misconceptions and negative reactions to the disease, AIDS patients throughout the world have been blamed, stigmatized, marginalized and isolated (Sabatier 1988). In developing countries, the conditions of HIV/AIDS patients have been further exacerbated by poverty, poor infrastructure and inadequate medical services. There is also a big gap in African countries between public statements about the disease and the reality of programs in place and the living conditions of infected persons. For many of these countries intervention programs are basically concerned with education and information and the targeting of 'high-risk groups'. As the disease diffuses into the general population, the categories of infected people become more diverse and the effect of the disease becomes more complex (WHO 1992, 1994).

While there have been various attempts to measure the economic costs (see for instance, Ainsworth and Over 1992, 1994) and the social implications of the epidemic (Brokensha

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1988; Schoepf 1988; National Research Council 1993; Preston-Whyte 1994), the emotional and other costs of the disease can only be guessed (Shilts 1987; Panos 1992). Quantifying emotional stress from stigma, isolation, blame and self-pity in the individual and the family is difficult since AIDS infection involves some of the most intimate of personal relations. The World Bank in its World Development Report of 1993 introduced the concept of 'Disability-Adjusted Life Years (DALY)' as a measure of the burden of ill-health. Although an interesting concept, it will be difficult to apply to aspects of some diseases. As pointed out by Klauda (1994) '...how many DALYs would be allocated to a person who is stigmatised ... because (s)he has AIDS' (p. 104). And as the disease enters its second decade and more people get infected, there is the need to understand the psycho-social coping mechanisms adopted by HIV seropositive patients. This is important in Ghana where counselling is not well developed or incorporated into the modern health care system (Ego and Moran 1993).

This paper examines the perceptions, attitudes and behaviour of some HIV/AIDS patients interviewed in a study on Social Dimensions of AIDS infection in Ghana. The focus is on the reactions of patients to their situation, their assessment of the care they are receiving, their perception of the attitudes of their relations, neighbours and the community towards them and some of their post-diagnosed sexual behaviour. In general, there are gaps in our knowledge about the perception and post-diagnosed behaviour of patients in West Africa. This is partly due to the fact that it has not been easy for patients to openly discuss their disease. However, we need to understand the strategies adopted by patients as an input into the design of intervention programs for infected persons.

Context

In Ghanaian cosmology health and illness are social as well as medical issues that are of concern to kin members and the community. The physical health of an individual, considered to be a manifestation of spiritual health, is perceived to be linked with the health of the corporate clan. Illness separates an individual from the group while a cure restores a person to physical health and his or her relationship with the group (Appiah-Kubi 1981). As a result of the social meaning of health, it becomes the responsibility of both the immediate family members and the kin group to ensure that an adult member suffering from a life-threatening disease is healed. The family and the corporate clan then function as a social support system for the individual in need. It is important for the welfare of the infected persons to know how well this social support system will continue to function in the face of the changes taking place in Ghana from modernization and other factors and because of AIDS.

The outbreak of a disease whose cause is not immediately known and which has no known cure is given a supernatural explanation.[1] Such diseases may be attributed to an offence against one's own spirit, the gods or ancestral spirits or a spell cast on an individual by an envious relative, neighbour or competitor, for property or in a polygynous marriage (Twumasi 1975; Appiah-Kubi 1981; Schoepf 1988). This view does not exclude biological explanations of ill-health: biological causes are accepted and often herbs or tablets are used to cure a disease. Most often, it is the factors that bring about the biological changes that are given supernatural explanation.

Historically, a number of diseases have been given such an explanation: for instance, towards the end of 1874, the outbreak of smallpox in the Gold Coast (now Ghana) was attributed to the cracking of palm nuts; outbreaks of diseases such as guinea worm, tuberculosis and measles have been similarly explained (Dickson 1969; Twumasi 1975). In

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[1] This is not unique to Ghana. It is true of a number of societies in Africa and was also the case in ancient Israel as recorded in the Bible (e.g. Leviticus, 13 and 14).

Ghana at the moment, traditional views coexist with modern ones and people resort to one or the other to explain events, depending upon the circumstances (Kirby 1994).

If a disease is perceived to result from a sin of omission or commission against the gods, ancestral spirits or one's own spirit, the offender when exposed is expected to confess and appease the gods or spirits in order to be restored to good health. The offence if committed in secret may manifest itself in the form of disease in the individual or the community. An act done in secret when exposed through a disease or in any other form, carries with it a sense of shame (Bleek 1981). One of the reactions of relatives when this occurs is to distance themselves from the shame and ridicule brought about by a member of the family or corporate clan. It is within this context that the reaction of some people to HIV infection should be viewed. Such interpretation of disease causation obviously influences perceptions of a particular disease, patients suffering from it and the behaviour of infected persons.

Interviewing AIDS patients

In 1992, a study was conducted in Ghana on the social dimensions of HIV/AIDS infection (Awusabo-Asare and Anarfi 1995). Among the objectives were to study the demographic and social-economic background of HIV/AIDS patients and their relatives, to assess the attitudes of diagnosed persons to their situation and to examine some of the coping mechanisms adopted by the patients.

AIDS patients and their relatives in eight out of the ten administrative regions in the country were interviewed over a period of four weeks by trained interviewers. Two of the regions, Upper East and Upper West, were left out partly because there were few officially reported AIDS cases and partly because of problems of cost and supervision. These are the two regions in the extreme north of Ghana and are poorly linked with the rest of the country. There was one interviewer per region except in the Eastern region where two interviewers were used: one for the Manya Krobo district and the other for the rest of the region. Each interviewer was allocated a minimum number of patients and their relatives on the basis of officially reported cases from the regions and from a reconnaissance survey.

Researching AIDS infection is not like any ordinary phenomenon in demography. Even at the best of times demographic data are affected by distortions and misinformation (Bleek 1981, 1987); AIDS is a disease whose sufferers have been stigmatized and blamed for the outbreak and spread of the disease (Sabatier 1988; Safo 1993). Therefore, patients who agree to be interviewed could be considered as those motivated enough to share their experiences with others. A related issue in AIDS research is ensuring confidentiality. The medical history of any patient is between the patient and the medical officer; if a patient decides to share that with another person, what transpires is expected to be only between the persons involved. This is important under the circumstances where people are stigmatized and isolated. It has an ethical dimension as well, especially if respondents confide in the researcher that they are putting other people at risk through their activities (see Gray, Lyons and Merton 1995). Thus, in dealing with AIDS patients it is not possible to obtain a 'representative sample' as used in population studies. The sample is self-selective and biased.

Locating patients was a further consideration since it was not easy identifying and approaching individuals for interview. Through consultations with regional AIDS counsellors and medical officers of health in the selected regions and the district medical officers of health of some districts it became clear that some patients were willing to discuss their conditions with other people, provided confidentiality could be assured. Thus, appointments for interviews were made through the counsellors and those who accepted our request to be interviewed were listed and contacted. In the case of some AIDS patients permission was also sought from their families.

Table 1
Socio-demographic background of patients

Demographic characteristics	Males	Females	Both sexes
Age (%)			
15-19	2.5	5.9	5.0
20-24	2.5	16.8	12.8
25-29	17.5	30.7	26.9
30-34	40.0	16.8	23.4
35-39	7.5	15.8	13.5
40+	30.0	13.9	18.4
Place of residence (%)			
Rural	7.5	4.0	5.0
Urban	50.0	50.5	50.4
Large urban	42.5	45.5	44.6
Place of birth (%)			
Rural	55.0	40.6	44.7
Urban	35.0	30.7	31.9
Large urban	10.0	28.7	23.4
Education (highest attained) (%)			
None	15.0	30.7	26.2
Primary	12.5	21.8	19.1
Middle/JSS	57.5	40.6	45.4
Secondary or higher	15.0	7.0	9.2
Current main occupation (%)			
Sub-professional	7.5	2.0	3.5
Clerical	20.0	33.7	29.8
Farmers/fishermen	22.5	5.0	9.9
Transport	5.0	0.0	1.4
Crafts and production	12.5	5.9	7.8
Service	2.5	7.9	6.4
No response	30.0	45.5	41.1

Table Continued

Patients and relatives were interviewed at a health facility, at an appointed place or in their homes in the areas where there was home-based counselling. During the fieldwork, some regional counsellors were given a crash course on the interviewing schedule when it was realized that some of the patients and their relations were prepared to talk to the counsellors instead of our interviewers. In some cases people who initially agreed to be interviewed cancelled the appointment. The respondents were, therefore, patients and relations who accepting being interviewed. These constraints need to be borne in mind; see also Anarfi and Awusabo-Asare (1993); Awusabo-Asare and Agyeman (1993); Caldwell, Orubuloye and Caldwell (1994). This paper is about the AIDS/HIV seropositive patients who were interviewed.

Socio-demographic background of seropositive patients

In all 141 seropositive patients were interviewed (Table 1) with a sex ratio of 40 males to 100 females, similar to the ratio of officially reported cases in Ghana. Over 75 per cent of the respondents were aged between 20 and 39 years, a pattern also similar to that found among diagnosed persons (Ghana Ministry of Health 1992). The median age for the

Table 1 Continued
Socio-demographic background of patients

Demographic characteristics	Males	Females	Both sexes
Ethnic group (%)			
Twi	10.0	10.9	10.6
Fante	12.5	11.9	12.1
Other Akan	37.5	17.8	23.4
Ga-Adangbe	20.0	36.6	31.9
Ewe	12.5	6.9	8.5
Mole-Dagbani	2.5	6.9	5.7
Other Ghanaians	5.0	7.9	7.1
Non-Ghanaians	0.0	1.0	0.7
Religion (%)			
No religion	7.5	16.8	14.2
Catholic	22.5	13.9	16.3
Protestant	27.5	21.8	23.4
Other Christian	42.5	34.7	36.9
Muslim	0.0	11.9	8.5
Traditional	0.0	1.0	0.7
Marital status (%)			
Single	40.0	38.6	39.0
Married	32.5	23.8	26.2
Separated	12.5	10.9	11.3
Divorced	7.5	21.8	17.7
Widowed	7.5	5.0	5.7
TOTAL (%)	100.0	100.0	100.0
NUMBER	40	101	141
Number of times married (%)			
1	44.0	58.6	54.0
2	44.0	35.5	37.9
3	8.0	6.4	6.9
4 or more	4.0	0.0	1.2
TOTAL (%)	100.0	100.0	100.0
NUMBER	25	62	87

respondents was 29.8 years, but 31.1 years for the males and 25.1 years for the females. As observed among diagnosed persons in Ghana, infected females are on average younger than the males, indicating earlier sexual experience for females than males.

Ninety-five per cent of those interviewed lived in urban and large urban areas although 45 per cent reported being born in rural areas. This may be due to the fact that most of the patients were interviewed at health facilities located in towns. The majority of the respondents were Akan (44 per cent) and Ga-Adangbe (32 per cent). The Ga-Adangbe, the ethnic group with Ghana's highest reported incidence of AIDS at that time, was deliberately over-sampled; the Akan as the largest single ethnic group in the country are found in five of the eight regions surveyed.

Nearly half of the respondents had completed ten years of basic education (middle/JSS); 19 per cent had primary school education, and 26 per cent had no formal education. In general the few males had higher formal education than the females. Over 40 per cent reported being unemployed at the time of the survey; some of the respondents were not physically capable of undertaking any economic activity at this time. Among those economically active, the majority were in low-level professional and clerical occupations; however, there were more males in the sub-professional category than females. The pattern of previous occupation was not markedly different from that of current occupation (not indicated). Over three-fourths of the respondents gave their religion as Christianity, eight per cent reported Islam and only one person reported traditional religion. It is possible that those who reported ‘no religion’ are adherents of traditional religion.

Only a quarter of the respondents were married (Table 1). The rest were either never married, divorced, separated or widowed. One woman gave her AIDS infection as the reason for her divorce. The same number of men were in their first and second marriages, while there were more women in their first than in second marriages. One man had married four times and eight of the women were in polygynous marriages.

The background variables indicate that the disease now affects people in all socio-demographic and economic backgrounds in Ghana. Unfortunately, such detailed data on the background of HIV seropositive patients are not routinely collected in Ghana for inferences to be made about infected persons, but this type of information is useful for planning and the design of intervention programs.

Responses of diagnosed persons

The hysteria surrounding AIDS infection and its associated stigmatization has created a sense of panic and fear of discrimination, resulting in some infected persons denying their HIV seropositive status or refusing to inform other people. For a number of reasons, including denial, some patients do not seek expert medical advice until they are already very sick. In Ghana, most of the diagnosed cases are symptomatic ones in which the medical officers confirm their worst fears, although there are a few who become aware of their HIV status under different circumstances.

All the respondents found out about their seropositive status at a health facility when they were diagnosed or counselled, donated blood, or deduced it from the nature of questions they were asked at the centre. However, all the females reported learning their status from counsellors or medical officers. Three of the males were informed when they donated blood (Table 2). Because of the publicity given to AIDS in the mass media, it seems that people have a fairly good idea about the disease (McCombie and Anarfi 1992), hence their ability to infer their status from the questions asked.

Table 2
Source of information about serostatus

Source	Males %	Females %	Both sexes %
Told at hospital	67.5	83.2	78.7
Counsellor	22.5	16.8	18.4
When donated blood	7.5	0.0	2.1
Questioning at hospital	2.5	0.0	0.7
Total	100.0	100.0	100.0
No.	40	101	141

Another aspect of AIDS infection is the negative reactions that have built up about the disease, partly because of scapegoating and witch hunting (Schoepf et al. 1988). Although the fear of disease and death is not unique to AIDS (Kubler-Ross 1970), the reactions to it seem to manifest themselves particularly strongly. Of the 137 respondents who reported their reaction to their serostatus, 86 per cent (118) said they were shocked, afraid, angry and sad; 12 per cent reported being indifferent (Table 3). In terms of proportions more females were shocked and sad than males. These reactions may be related to some of the popular views about the disease, such as it is a disease which affects 'immoral' people, and to the fact that it has no cure (Awusabo-Asare and Anarfi 1995). As one patient said, 'If you are informed that you have AIDS it means you have been given your death warrant'. Such negative views about the disease were repeated by a number of patients.

A feature of the disease which was observed was the attempt by some of the patients to keep their HIV-seropositive status to themselves. Schoepf (1988) reported on a physician in Zaire who kept his HIV status from his wife and continued to have sexual relations with her; she learnt about his HIV infection only after his death. At the time of the survey, 26 per cent of the respondents had not informed anybody about their HIV seropositive status. Those who had informed somebody were more likely to inform their mother first (49 per cent), followed by brother (15.4 per cent), sister (12.5 per cent) and spouse (9.6 per cent). The spouse was the first to be informed by only 27 per cent of those who were married. The observed situation among married persons is consistent with other observations on couple interaction and communication in Ghana on social issues such as family planning (Ghana 1989; Oheneba-Sakyi et al. forthcoming). Members of the natal lineage and corporate clan are expected to support the individual in times of illness: a spouse is not a member of the natal lineage and therefore may not necessarily be the person who will be informed first. That a quarter had not informed anybody is an aspect of the disease in Ghana which needs to be addressed with proper counselling (Ego and Moran 1993). Such people are likely to put others at risk either deliberately or unintentionally.

Table 3
Reaction to information about serostatus

Reaction	Males %	Females %	Both sexes %
Shocked	32.5	44.6	41.1
Sad	22.5	25.7	24.8
Indifferent	17.5	8.9	11.3
Sorry	7.5	7.9	7.8
Afraid	10.0	6.9	7.8
Angry	0.0	2.0	1.4
Did not believe	2.5	0.0	0.7
Other	2.5	2.0	2.1
Not reported	5.0	2.0	2.8
Total	100.0	100.0	100.0
No.	40	101	141

Respondent's perception of the reaction of relatives

The choice of a person to confide in with such delicate information as HIV infection is likely to be influenced by the patient's perception of the reaction of the recipient to the information. All things being equal, people are more likely to inform those they think will be sympathetic but may also keep the information to themselves. Table 4 shows the reactions of various relations, friends, neighbours and the community as reported by the patient, when they first heard of the serostatus of the patient and at the time of the survey. They show some of the familial and community dynamics which influence the decision to inform another person and the choice of that person.

In general, the respondents perceived their female relations – mothers and sisters – to be more sympathetic than fathers and brothers. Fewer males were perceived to be sympathetic at the initial stages. The few married persons among them did not consider their partners to be sympathetic towards them at the initial period. However, at the time of the survey the reported attitudes of relatives had improved, as indicated by increases in the proportion of family members reportedly sympathetic. It is possible that with time some relatives were prepared to accept the situation and assist the patient, or the respondents did not want to appear ungrateful, or owing to their condition some of them could not assess the reactions of people around them. It appears some of the patients and their relations had gone through what Lloyd (1988, quoted in Anarfi 1994) describes as the post-diagnosis process of shock, blow, recoil and recovery. Those patients who had been confined could not have assessed the reactions of some of their relatives towards them. Some of the issues are indicated in four case studies reported opposite (Ahensa 1993).

Case 1 A young woman aged 23 years was being cared for by her mother and her six-year old daughter at home. She had been abandoned by her husband and her father did not want to have anything to do with her. She lived in a small room and had her own household items such as plates and drinking cups which she used alone. Her daughter was responsible for her hygiene.

Case 2 A young woman in her early 30s returned to her village from C™te d'Ivoire very sick. At the district hospital she was diagnosed HIV seropositive. She lives in her village with other family members. Only her mother knew what she was suffering from. Although aware of her HIV seropositive status, she wanted to get married.

Case 3 A young man who had returned from studies in Europe was diagnosed HIV seropositive. When he was informed of it he worked out an arrangement with the hospital authorities to allow him to stay at the hospital, as he puts it, 'till he dies'.

Case 4 At one of the district hospitals, a female patient brought by her relatives for an AIDS-related disease, was still there two weeks after she had been treated and discharged. In spite of repeated messages to her relations nobody had come to pick her up.

These case studies illustrate some of the problems HIV patients in Ghana are going through. From some, their HIV serostatus has had to be kept secret from the rest of the family for a variety of reasons. Afraid of stigmatization and isolation, some have kept away from family members (Case 3). The social 'safety net' once offered by the corporate clan to its members appears to be undergoing changes; it does not seem to provide the individual with the protection and support it once gave. This may be because AIDS, as a disease with no known cure, is interpreted as a curse or punishment for disobedience: such a situation brought shame not only to the individual, but also to the corporate clan (Bleek 1981). Thus, some kin members may withdraw physically or emotionally from the patient because they do not want to be associated with the shame brought by a relative. There may also be a general decline in the traditional social support system arising from the unintended effects of improvement in education, industrialization, migration and urbanization which the AIDS infection has only exposed and exacerbated (WHO 1992). These factors need to be disentangled.

The patients' perception of their condition was explored further by asking them to evaluate the care they were receiving (Table 5). About 80 per cent of the respondents (higher proportion of females than males) were satisfied with the care being provided. However, a quarter of the males, compared to only six per cent of the females, were dissatisfied with the care. The expectations of the respondents reveal a range of negative feelings and frustrations. Thirty-nine per cent indicated that they did not want anything, while about 25 per cent had given up hope (up to God/don't know and wishing to die). We observed that some of the patients were in desperate conditions: poor and isolated. Emotionally, some had given up hope and were, as they themselves put it, 'waiting to die'. Others, abandoned and with no regular source of income, depended on charity and on the health facilities they were visiting for treatment for support in such diverse areas as drugs, food and money for transport (Ahensa 1993).

Table 4
First reactions of others when they became aware of patients' serostatus (%)

	Sympathetic	Unsympathetic	Outraged	Indifferent	No idea	Total	Number
Spouse	38.5	7.7	15.4	7.7	30.8	100.0	26
Father	38.9	5.6	14.8	14.8	25.9	100.0	54
Brother	47.5	4.9	9.8	23.0	14.8	100.0	61
Mother	73.6	1.1	19.5	0.0	5.7	100.0	87
Sister	61.5	4.6	15.4	6.2	12.3	100.0	65
Children	26.3	0.0	5.3	10.5	57.9	100.0	38
Friends (S.sex)	31.7	4.9	0.0	7.3	56.1	100.0	41
Friends (O.sex)	15.4	5.1	5.1	10.3	64.1	100.0	39
Other Relative	4.8	2.4	2.4	11.9	78.5	100.0	42
Neighbours	2.5	2.5	0.0	0.0	90.0	100.0	40
Community	10.0	0.0	3.3	0.0	86.7	100.0	30

Reaction at time of interview (%)

	Sympathetic	Unsympathetic	Outraged	Indifferent	No idea	Total	Number
Spouse	50.0	10.0	3.3	10.0	26.7	100.0	30
Father	53.6	7.1	3.6	14.3	21.4	100.0	56
Brother	66.7	3.3	3.3	13.3	13.3	100.0	60
Mother	89.3	1.2	1.2	1.2	7.1	100.0	84
Sister	79.7	6.3	0.0	3.1	10.9	100.0	64
Children	27.0	0.0	0.0	13.1	59.5	100.0	37
Friends (S.sex)	31.7	4.9	0.0	7.3	56.1	100.0	41
Friends (O.sex)	21.4	4.8	4.8	11.9	57.1	100.0	42
Other relative	4.8	4.8	2.4	7.1	80.9	100.0	42
Neighbours	5.0	2.5	0.0	5.0	87.5	100.0	40
Community	6.4	0.0	0.0	6.4	87.2	100.0	31

Note: S. Sex = Same sex; O.Sex = Opposite sex

Table 5
Level of satisfaction with and expectation of care (%)

	Males	Females	Both sexes
Satisfaction with care			
Yes	62.5	87.1	80.1
No	25.0	5.9	11.3
Not reported	12.5	6.9	8.5
Expectation of care			
Nothing	25.0	44.6	39.0
Proper medical care	22.5	17.8	19.1
Balanced diet	0.0	2.0	1.4
Death	7.5	7.9	7.8
Up to God/don't know	17.5	17.8	17.7
Other	15.0	7.9	9.9
Not stated	12.5	2.0	5.0
Total	100.0	100.0	100.0

Sexual behaviour of patients

Of considerable importance for limiting the spread of the disease is the nature of post-diagnosed sexual behaviour of seropositive patients. This is the period when infected persons need counselling, not only to keep themselves fit but also to avoid further transmission of the disease through sex or other means. In a country where counselling of patients is not well developed (Ego and Moran 1993), knowing the attitudes and behaviour of diagnosed patients towards their condition and to others is important for the development of intervention programs and to assist the patients to lead healthier lives.

The sexual behaviour of HIV-seropositive patients was explored, beginning with issues on sexual behaviour in couples when a partner is infected and patients' sexual behaviour after infection. To the question whether a person had the right to refuse sex with his or her partner who was known to be HIV-seropositive, 82 per cent reported that the person had the right to refuse. Seventeen respondents (12 females and 5 males) felt that the partner did not have the right to refuse, and their reasons were that the two people involved were married or partners, or the partner could have been infected already anyway, or they could use condoms (Table 6).When asked about their own behaviour, 15 (10 males and 5 females) of the respondents said that they had had sexual relations with their partners since they were diagnosed HIV-positive. Of the number ever having sex with partners, nine (4 males and 5 females) reported protecting themselves and their partners by either using condoms (8) or avoiding penetration (1), but six, all males, did not protect themselves or their partners. Three out of the six reported that they did not protect themselves because they did not believe that they had contracted HIV.

Ten of the respondents had sexual relations with people other than their regular partners, four of them with only one person, three with two people each, and three with three, four and eight persons respectively. The people involved were casual partners (3), stranger (1), prostitute (1) and girl or boy friend (5). The reasons for doing so were desire for sex (6), need for money (2) and disbelief of being infected (1).

Denial, as depicted in the behaviour of those who reported that they did not believe that they were HIV-seropositive, is part of the syndrome associated with the disease. Mensa-

Bonsu (1993) has defined denial syndrome to be among other things, 'a firm refusal to accept a certain state of affairs as real' (p.13). Their denial and unprotected sex had put some people at risk of infection, with some of them reportedly involved in sex for money. Thus, some of the infected persons had knowingly been involved in sex for financial reasons in a situation where condoms are rarely used. Some of the infected persons are people who were involved in the sex trade in the first place for financial reasons (Adomako 1991; Anarfi 1993). As the epidemic gains ground, the public health establishment and the government will have to face these realities and assess some of the economic, social and emotional consequences of the disease.

Table 6
Sexual rights of infected person and actual sexual behaviour since diagnosis (%)

	Male	Female	Total
Has one the right to refuse sex with infected partner?			
Responding ‘No’	8.9	15.0	8.4
Should one refuse sex with infected partner?			
Responding ‘No’	12.5	11.9	12.1
Ever had sex with partner since knowing seropositive status?			
Responding ‘Yes’	9.9	12.5	10.6
Ever had sex with regular partner and another person?			
Responding ‘Yes’	7.5	3.0	4.2

Discussion and conclusion

AIDS is not the leading cause of ill-health or of death in Ghana at the moment (Ghana, Ministry of Health 1992). However, the nature of the disease is such that it has ramifications beyond mere infection. For instance, as a disease transmitted through heterosexual contact, there is potential conflict between reproductive interests of individuals or groups and public health concerns. In areas where there is a demand for high fertility and the level of HIV infection is high, some individuals are likely to be put at risk in an effort to achieve their reproductive goals. AIDS as a disease affecting young adults has the potential of creating an orphan generation. Furthermore, in the last two decades individuals and groups in a number of sub-Saharan African countries have become vulnerable to infection because of poor health services and facilities, and deteriorating environmental and social-economic conditions. These and other factors have contributed to give AIDS a high profile in international circles (WHO 1994).

Research on AIDS touches on some of the intimate issues in human life such as people's sexual behaviour, an area difficult to research (Schoepf 1988; Caldwell et al. 1994). Responses on such issues can rarely be cross-checked since they do not lend themselves to observation or some other forms of research strategy. However, the results from this research indicate that it is possible to obtain some information on sexual behaviour as it relates to the transmission of diseases. The respondents appeared to be open about some of their sexual experiences; perhaps the interviewers served as sympathetic ears to some of the patients.

However, ascertaining the reliability and validity of information obtained goes beyond a single cross-sectional study (Dare and Cleland 1994); this is an issue which has to be considered in any research on sexual behaviour. Experience from the survey suggests that a number of approaches will have to be adopted to collect information on individuals and groups, particularly data from patients and their relations who face stigmatization and discrimination. For instance, our knowledge on the coping strategies adopted by patients and their relatives, particularly those directly responsible for the physical care, is at best scanty;

understanding this aspect calls for long-term data collection on patients and their relations. Among the strategies that can be adopted to collect data are counselling sessions and intensive observation: counselling will help to catalogue some of the inner feelings of patients and their relatives, issues which are not well documented and are difficult to obtain in interviewing sessions; and through intensive observation detailed information can be collected about the daily activities of patients.

African societies have been portrayed as community-based and providing support for their members: as indicated by Goody (1969), 'Family responsibility (in Africa) has not diminished to the point that national welfare agencies have constantly to step in' (p.85). One of the areas known to have strong familial support is health. However, the available evidence suggests that this 'idealized past' is under strain, either independent of or as a result of HIV/AIDS infection. That sick family members are ostracized is contrary to expectation, creating conditions of despair and hopelessness. In a country where there is no intensive care for AIDS patients at hospitals and home care is provided by family members, the few patients who are abandoned face problems. Currently, only a few mission-run hospitals and clinics provide support services for families caring for their relations at home; some were even under strain from underfunding (Awusabo-Asare 1994). Although counselling is available in government hospitals for patients, there is not enough and some patients do not attend these sessions for a number of reasons, including the inability of some of them to afford the cost, that they do not want people to know they are suffering from AIDS for fear of stigmatization, or they are too weak to move on their own. At some of these fixed locations the staff were few, over-stretched and without adequate logistic support (Ghana, Ministry of Health 1992). The evidence suggests that there should be a well-thought out program of support for HIV/AIDS patients in their homes: this is important because in the event of case overload the present facilities at our hospitals and clinics will not be able to cope with inpatient care. While the numbers are small, structures should be put in place to promote and support home-based care. More importantly, given the nature of the disease, home-based care is going to be the norm and so we should start planning for it now. Ghana can learn from the alternative approaches adopted in Uganda and Zambia (Masheija et al. 1993; Foster 1993, both quoted in Ainsworth and Over 1994).

There are also hidden costs of AIDS which are not immediately apparent. An example is the plight of the six-year old girl in case 1 described above. Given the situation, it is likely that she will not be sent to school. Her mother needs her services since there is no adequate support for her, but this is also the time when she should be in school to prepare for her future. Some of these issues will have to be brought out into the open for resolution.

At a wider level, however, the search for solutions will have to be more than targeting individuals or high-risk groups for intervention programs. The fight to reduce the spread of HIV infection is likely to be successful if there is a general policy of reducing both individual and collective vulnerability. Some of the people suffering from AIDS in Ghana now are people who took risks during the period when the economy of the country had virtually collapsed (Alderman 1994). For instance, the economic hardships led to large-scale migration of Ghanaians to neighbouring countries where some of them, especially the females, entered the sex trade: some of these people returned as AIDS sufferers in the mid-1980s (Adomako 1991; Anarfi 1993). This is a challenge not only for the governments of sub-Saharan African countries but also for the international community. AIDS has implications beyond the borders of one country.

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