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HIV/AIDS in fishing communities: Challenges to delivering antiretroviral therapy to vulnerable groups

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Abstract

Fishing communities have been identified as among the highest-risk groups for HIV infection in countries with high overall rates of HIV/AIDS prevalence. Vulnerability to HIV/AIDS stems from the time fishers and fish traders spend away from home, their access to cash income, their demographic profile, the ready availability of commercial sex in fishing ports and the sub-cultures of risk taking and hyper-masculinity in fishermen. The subordinate economic and social position of women in many fishing communities makes them even more vulnerable to infection. In this paper we review the available literature to assess the social, economic and cultural factors that shape many fisherfolks’ lifestyles and that make them both vulnerable to infection and difficult to reach with anti-retroviral therapy and continued prevention efforts. We conclude from the available evidence that fisherfolk will be among those untouched by planned initiatives to increase access to anti-retroviral therapies in the coming years; a conclusion that might apply to other groups with similar socio-economic and sub-cultural attributes, such as other seafarers, and migrant-workers including small-scale miners, and construction workers.

Introduction

The 3 by 5 initiative, launched at the end of 2003, aims to provide life-long antiretroviral therapy to three million people living with HIV/AIDS in poor countries by the end of 2005 (WHO & UNAIDS, 2003). Recent successes in supplying antiretroviral therapy (ART) in resource poor settings (Farmer et al., 2001; Kasper, Coetzee, Louis, Boulle, & Hilderbrand, 2003; Attawell & Mundy, 2003) as well as the considerable progress made in facilitating access to affordable treatment in Sub-Saharan Africa (MSF, December 2003) have raised hopes that many lives can be saved. Yet, many obstacles stand in the way of this initiative. Access to reliable supplies of drugs and adherence to the treatment regime are essential for success. Even if the 3 by 5 initiative is successful, several hundreds of thousands of people will die of HIV/AIDS related illnesses in the next few years.

The authors of the World Health Report 2004 highlight the difficult choices that must be made as treatment is rolled out: ‘Special attention must be paid to questions of fairness as programmes get under way, since more people need treatment than will receive it. Yet the risk that programmes will not be perfectly fair should not delay action’ (WHO, 2004a, p.35). So what factors might be used to define ‘fairness’, and who are those most likely not to be reached by ART? It is obvious that those people who have not been tested for HIV infection, or are already too sick to be able to access therapy, will not be reached, but it is
less obvious how factors such as where people live, what they do and how they live their lives (or how their lifestyles are perceived) will affect their access to ART. This paper considers the people working in the small-scale fisheries sector to explore these issues.

Criteria to determine eligibility for treatment, particularly in resource poor settings where supplies are limited, continue to be devised and refined (Attawell & Mundy, 2003, p. 44; Ciccio, 2004, p. 53; WHO, 2004a, pp. 35–37). The WHO guidelines (2004b) recommend treatment for people diagnosed with AIDS and people with HIV who have a CD4 cell count below 200. While the WHO criteria have been criticized as too restrictive in poor countries (Reynolds, Bartlett, Quinn, Beyrer, & Bollinger, 2003, p. 1807), the need for a CD4 cell count or clinical assessment is a vital step in accessing treatment. Because of concerns about the ability of health services to meet demand as well as ensure adherence, further criteria such as ‘geographical catchment areas’ to define the population served (Kasper et al., 2003, p. 21) and assessments of a person’s ability to keep in regular contact with the ART provider have been introduced in some places. The ‘Implementation Guidelines for ART in Uganda’ (WHO, 2003a), for example, mentions monitoring a patient’s ‘adherence to booked appointments’ (p. 20) and the criteria: ‘patients must have regularly attended the clinics for at least three months’ is included in MSF’s programme in Khayelitsha (South Africa).

Even if supplies of free ART can be provided clinical selection criteria will remain, and as Beauchamp and Childress (2001, p. 264) remind us, all health services operate in a world of competing health demands where health care professionals and policymakers often have to decide who will receive a medical service that cannot be provided to all. Such decisions often rest on ‘medical utility, social utility, and impersonal mechanisms, such as lotteries and queuing’ (ibid, p. 267). The ‘social utility’ criteria is particularly likely to be influenced by moral judgement. To explore these decisions, we now turn to an overview of HIV and AIDS in fishing communities before assessing how fisherfolk and other groups with similar socio-cultural characteristics might be expected to fare in the ART lottery.

**HIV and AIDS in fishing communities**

From the time that HIV/AIDS was first described in a Ugandan fishing village on the shores of Lake Victoria in 1982 (Serwadda et al., 1985), it has repeatedly been stated that fishing communities are among the occupational groups most vulnerable to HIV infection, particularly in the SE Asian and African countries where the epidemic has hit hardest (Bain, 1998; Hemrich & Topouzis, 2000). It is also in these areas that the vast majority of the world’s 100 million fisheries-dependent people live and work (Garcia & de Leiva Moreno, 2003). Fisherfolk are now increasingly identified among those labelled as high risk groups (e.g. Entz, Ruffolo, Chinveschakitvanich, Soskolne, & Van Griensven, 2000 and Huang, 2002) although the available data on seroprevalence is limited, but persuasive (reviewed in Allison & Seeley, 2004). The most reliable data on seroprevalence comes from recent studies in Thailand and Cambodia (Entz et al., 2000, Kim et al., 2000), prevalence rates of 15–20% among migrant deep-sea fishermen in the region mark them out as a very high-risk group, comparable to other ‘sentinel’ groups such as commercial sex-workers, military recruits and long-distance truck drivers (Perrin, 2001).

In East Africa, anecdotal evidence puts seroprevalence as high as 70% in important centres of the fish trade like Homa Bay, Kenya, on the shores of Lake Victoria (Seemungal, 2003). HIV/AIDS is identified as the leading cause of death in adults aged between 15 and 50 in lakeshore areas in Uganda (MAAIF, 2002), while in Kagera region, Tanzania, fisherfolk are said to be five times more likely to die of AIDS-related illnesses than farmers
National seroprevalence rates in the countries bordering Lake Victoria region are already high, being between 10–15% of the 15–50 age group through the 1990s (Sahn & Stifel, 2003). In this context, the relative estimates for fishing communities are devastating.

According to Hemrich and Topouzis (2000, p. 90):

Vulnerability of fisheries livelihood systems to HIV/AIDS ... stems from the socio-economic dynamics of the fisheries trade and lifestyle, and in particular the fishermen's high mobility, their long absences from home and their cash incomes which are then often spent in the trading centres on casual sex and alcohol. Vulnerability extends to their (fishermen's) casual or semi-casual sexual partners and to their wives at home.

These lifestyle characteristics stem from the physical risks and economic uncertainties of making a living from fishing, the social and political marginalization of many fishing communities, existence of strongly gendered social and economic roles (in which women are often found in highly competitive and less profitable trading activities, where 'sex for fish' transactions are common) and the existence of a sub-culture of 'hypermasculinity' among some fishermen that encourages or condones having multiple sexual partners (Allison & Seeley, 2004).

In terms of relative prevalence rates, the fishing communities around the Gulf of Thailand and Lake Victoria might therefore be considered as priority groups for impact mitigation and ART. But factors that seem to increase risk of infection in these and other fishing communities in developing countries might also be obstacles to effective and reliable long-term treatment for these groups. We discuss these factors in the subsequent sections of this paper.

**Mobility and irregular working hours**

Many fisherfolk are geographically mobile, seasonal or long-term migrants or even, in some cases, nomadic (Acheson, 1981; Overå, 2001; Allison & Ellis, 2001). Migrants are frequently characterized as vulnerable to HIV/AIDS infection (papers in International Migration, 36, 1998; UNAIDS, 2001; IOM, 2003). Mobile traders, for example, are viewed as one of the key risk groups in studies of HIV/AIDS transmission in Uganda (Seeley et al., 1994; Nunn et al., 1996); these are mainly young men travelling to sell produce in trading centres, where they accessed sexual services (Pickering, Okongo, Ojwiya, Yirrell, & Whitworth, 1997b; Gysels, Pool, & Nnalusiba, 2002).

Mobility may not only encourage behaviour that increases the risk of infection, it also poses problems for treatment. Access to testing and treatment facilities is difficult for mobile populations, while mobility coupled with irregular working hours may hinder adherence to the treatment regime and keeping to a regular schedule with medications (CARE, 2001; McGreevey, Alkenbrack, & Stover, 2003). Eligibility for ART based on catchment area thus poses problems for migrants, as in Khayelitsha where criteria based on length of residence were instituted despite the highly mobile nature of Khayelitsha’s population (Kasper et al., 2003, p. 21). In addition, the WHO guidelines (2004b, p.44) suggest ‘continuous involvement of relatives, friends and treatment supporters’. People who are mobile do not always have ‘family and community members’ on hand to provide such support.
Treatment adherence, dangerous occupations and risk cultures

Life-long adherence to ART is essential for individual and programmatic treatment success (WHO, 2004a, p. 44). The development of regimes that are easy to take (for example two pills twice a day used in Khayelitsha [Kasper et al., 2003, p. 21]) have been aimed at improving compliance. Nevertheless, to be effective even the simplified regimes need 90–95% compliance with the prescribed dosage (Chesney, Morin, & Sherr, 2000).

Some authors (Chapman, 1997; Rosen, Tsai, & Downs, 2003) suggest that risk attitude plays an important role in health care utilization. Given the risky nature of marine and deep-water fishing (Ben-Yami, 2000), attitudes to and ways of coping with risk may also influence access and adherence to ART. Social and cultural attitudes, beliefs and values play an important role in the perception of, and response to, risks and dangers. The denial of danger, an emphasis on independence and fatalism are common themes among many fishermen around the world (Poggie, Pollnac, & Jones, 1995). It has been suggested that these attitudes may apply as much to attitudes about safe sex as to safe seafaring (SPC, 1999). Certainly, fatalism with regards to dying of AIDS was evident in Ugandan fishing communities in the Pickering, Okongo, Bwanika, Nnalusiba, & Whitworth’s, 1997a study and is encapsulated by the young man from Kasensero village, on the Ugandan shores of Lake Victoria, saying in 1989 ‘I cannot think about this AIDS business. I could drown tomorrow. There are too many girls here’ (Barnett & Whiteside, 2002, p. 19).

The risks involved in putting to sea (or large lake) to make a livelihood have similarities with risks faced by other occupational groups like miners and long-distance truck drivers who may risk injury or death because of rock falls or road accidents. People devise different strategies to cope with risk and uncertainty in their work. Gratz (2003, p. 204) describes how miners develop ways to cope with risk ‘according to their experience, but also according to the examples of others, and a permanent process of risk communication takes place’. Perception of self and one’s tolerance of danger may also play a part. Lupton (1999, p. 157) suggests that testing one’s ability to cope with fear and endurance may be a way of ‘proving one’s adulthood or masculinity’. It may be something that a man takes pride in. Alcohol and drugs can also provide a way of coping with risky, dangerous or unpleasant work (Gratz, 2003). The occupational sub-culture of fishermen, with respect to taking risks, which plays a part in their increased vulnerability to HIV infection may thus also affect their adherence to therapy.

Food, alcohol and risk

Fishing may require being out at sea or on a lake for long periods of time, which means meals may be scanty and irregular and keeping to any form of medication schedule is hard. The women in fishing communities may be living in poverty and lacking adequate nutrition. While ART medications like Combivir and Nevirapine do not need to be taken with food it is recognized that without good nutrition people living with HIV and AIDS do not respond so well to drug treatment and may be prone to diseases like tuberculosis. So it is not only a matter of maintaining compliance in taking medications; a lifestyle that involves irregular meals and poor diet may impair the effectiveness of treatment (FAO/WHO, 2003; Hudspeth, 2003). Consumption of alcohol, as a part of that diet may also be problematic.

The literature on fisherfolk includes many references to the place of alcohol in their lives, Appleton (2000, p. 23), for example writes ‘In Kerebe harbour, the “boom-town” of Nile perch-fishing, the beach was crowded with energetic fishermen. Their usual behaviour was to leap out of their boats, grab their pay, and make straight for the pombe (banana home-
brew) bars until the next day. Alcohol may help relaxation, but it may also be a part of coping with dangerous work. Gratz (2003, p. 195) describes how miners in Benin make use of soft drugs and alcohol to ‘endure the hardships of this work’, and in the description of Summertown, a community of gold miners and commercial sex workers in South Africa, Campbell (2003, p. 112–113) talks of the value of alcohol ‘as a psychological coping mechanism, a form of medication for dealing with the violence, poverty and stress of daily life’.

Alcohol not only fosters risk taking in sexual behaviour, reducing the likelihood of condom use (Mbulaiyeye et al., 2000; Gibney, Saquib, & Metzger, 2003) but may also affect adherence to antiretroviral therapy. Adherence appears to be highest where simplified and affordable treatment coupled with patient education and support are available (Attawell & Mundy, 2003, p. 70). Murphy, Marelich, Hoffman, & Steers (2004) found that age and social support measures as well as alcohol use are important factors in determining adherence with younger people, with those who lack good support and those who consume alcohol being less compliant.

Alcohol may interact with prescribed medications lessening the effectiveness of the treatment. Of course, this impact depends on the amount of alcohol consumed, the specific drugs prescribed and the health status of the person taking the ART. The limited number of existing studies (in the USA) on the effects of drug and alcohol abuse on HIV treatment have found an association between alcohol use and a worsening of antiretroviral utilization or adherence (Lucas, Gebo, Chaisson, & Moore, 2002). Such life style factors can thus affect the efficacy of the ART.

Some of the challenges of providing ART for fishing communities

A major theme of the 2002 14th International Conference on AIDS, in Barcelona, was optimistic recognition that ARTs work and there was now a need to ‘export medication, expertise and technology to treat patients in resource-poor areas of the world’ (Valenti, 2002, p. 228; who went on to say that ‘we will be accountable’ if progress has not been made by the next AIDS conference in Bangkok in 2004). While the fall in price of ART has been dramatic (WHO, 2004a) even a nominal cost for drugs, plus transport costs to access treatment, is prohibitive for many poor people (Whyte, Whyte, Meinert, & Kyaddondo, 2004). Green (2003, pp. 129–130) catalogues the obstacles in the way of effective delivery of ART in many parts of Africa: lack of effective delivery systems, trained staff, health facilities as well as clean water and electricity. To that list one could add the problems of addressing the needs of people who may develop drug resistance. Popp and Fisher (2002, p. 676) talk of Africa becoming a ‘veritable “petri dish” for new, treatment-resistant HIV strains’. IRIN-SA (United Nations, 2004a) tells the story of a woman from Zambia who had developed a drug-resistant strain: ‘No one told her treatment was life long, or that she could develop a resistant strain if she stopped’. Such stories temper the optimism displayed at the 2002 AIDS Conference about the medical treatment solutions to HIV and AIDS. How can ART reach groups like many fisherfolk?

There are few examples of effective chronic care delivery in resource-poor countries on which to develop ART services because it is life-long treatment, not a six-month course as it is for TB (Gilks, 2001, p. 11). The DOTS (Directly Observed Treatment, Short course) strategy for TB treatment aims for six months of therapy but it is difficult to get patients to adhere to and complete even this time-limited treatment (Volmink & Garner, 1997; Liechty & Bangsberg, 2003). While some initiatives are building on existing mobile home-based
care for the delivery of ART (Byakika, 2002) huge obstacles remain in scaling up ART in urban centres, let alone remote rural areas (Martinez-Jones & Anyama, 2002, p. 17).

Not only must people on ART take their pills regularly, the supply of drugs must be reliable. Given the lack of effective delivery systems for drugs in parts of the developing world, providing drugs to people away from main urban hubs is problematic. Lange (2002, p. 2) observes ‘In most developing countries there is an enormous lack of facilities and manpower to deliver comprehensive HIV care and of laboratory facilities to support and monitor the therapy treatments’. Even for those in main urban centres the supply may not be guaranteed:8 The Guardian reported in February 2004 that the ‘Nigerian government plan to provide cheap AIDS drugs had failed, threatening the lives of people with HIV who began taking the drugs two years ago, only to be told now that the supply had run out’.9

Some, who have treatment supplied by employers, may face problems with access and supply of treatment if they leave or lose their job.10 IRIN-SA (United Nations, 2004b) reported that ‘the shortfall in extending antiretroviral therapy (ART) to HIV positive people in Southern Africa is “enormous”, with mostly educated, urban males benefiting from existing programmes’.

As the above accounts illustrate the problem is that in many high prevalence countries, even if ART is free, attempts to widen access are likely to be thwarted by the lack of capacity. So programmes can cover no more than a small percentage of potential patients. As Gilks (2001, p. 14) comments ‘The risk is that specific elites or favoured groups will get preferential access and thus inequity is widened; and hidden subsidies are given’.

So where does this leave fisherfolk? Lifestyle factors like high mobility, irregular working hours as well as place of residence, often remote from infrastructure, would seem to put them among those least likely to access ART, and most likely to be judged as inappropriate for therapy, even if programmes are massively scaled up. Add to this some of the factors like high consumption of alcohol, evidenced among some fishing communities, and fisherfolk11 seem unlikely to be ranked among those ‘viable’ for ART even if they are among the vulnerable. This not only raises the moral issue of whether poor people can win the ‘ART lottery’ in the competition for resources, which the 3 by 5 initiative seeks to address, but it is also an ethical question. Do occupational or social groups that pursue a high-risk lifestyle ‘deserve’ equal access to treatment? Triage decisions based on medical/social utility may suggest not (Beauchamp & Childress, 2001, pp. 270–271). That some may be deemed more deserving of support than others (because of what they do, for example), is known to lead to double-standards in care (Farmer et al., 2001) and carries the same fundamentally moral judgement that underpinned the English Poor Laws.12 Clearly if access to ART is limited, criteria for selection are necessary (Kasper et al., 2003, p. 21) but these criteria should not depend on living in a stable household setting with people around to provide support during therapy. If, as one would hope and expect through the use of ART, those who are sick experience rapid improvements in their health, the return to pre-sickness work and life-style patterns may jeopardise adherence to therapy.

**Conclusion**

Reaching three million people with antiretroviral therapy by next year, 2005, is a big challenge. But even if that goal is achieved, many people will not be reached and, as we have argued in this paper, many fisherfolk and groups with similar lifestyles, are likely to be among those not reached. This has consequences for the wider population if it results in the existence of high prevalence ‘enclave groups’ that act as a reservoir of untreated infections.
There is a need for approaches to delivery of ART that are not dependent upon a population being stable and urban (or at least close to a clinic or health post). The challenge for HIV and AIDS mitigation as well as ART delivery is to be able to respond to gender and cultural diversity. The very life-style characteristics of many fisherfolk, which help them to face the risky nature of their work, may make them among the hardest people to reach with long-term therapy and support. Thus, we conclude that fisherfolk are likely to be untouched by planned initiatives to increase access to anti-retroviral therapies in the coming years; a conclusion that might apply to other groups with similar sub-cultural attributes such as miners, construction workers, and those in other seafaring professions.

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Notes

1 In this paper the term ‘fishing communities’ is used to mean all those who live in communities where the main livelihood activity is fishing, ‘fisherfolk’ – men and women engaged in fishing, fish processing and trading and ‘fishermen’ – men who take to the water to catch fish.

2 It must be stressed that not all fishermen conform to the image of hard-drinking, sexually promiscuous risk-takers suggested by Hiemrich & Topouzis (2000) and others. Thompson’s (1985), Tunstall’s (1963), Tietze, Groenewold, & Marcoux (2000) and our own work in East Africa provide an alternative image (which can of course coexist with ‘hypermasculine’ one) of fisherfolk as hardworking, adaptable, innovative and forward-thinking, using fishing as a means to ensure security and a better standard of living for themselves and their families. Nevertheless, the scattered data on HIV seroprevalence rates (Allison & Seeley, 2004, p. 219) suggest a high-risk subculture exists among some of the world’s fishing communities and the consequences of this behaviour may be far reaching, not only for the fisherfolk themselves, but the communities they interact with, the economies they contribute to, the consumers they supply and the conservation of the fish resources they harvest.

3 Patients must live in Khayelitsha and patients must have regularly attended the clinics for at least three months.

4 Acheson (1981) reviews a cultural theory literature that identifies a ‘macho complex’ and displays of ‘supermasculinity’ in North Atlantic fishermen.


7 In March 2003 the National Institute on Alcohol Abuse and Alcoholism of the US Government issued a call for research on ‘Alcohol and HIV/AIDS in Resource-Poor Societies’, in the call they observe that ‘In addition to being a risk factor in the contraction and progression of HIV disease [sic], alcohol misuse affects adherence to complex HIV medication regimens and to physician advice. […] carrying out research on the effects of alcohol consumption and drinking behaviors on HIV-related health outcomes is challenging. […] many questions about the relationship between alcohol consumption, increased susceptibility to HIV infection and accelerated progression to AIDS remain unanswered’. www.grants.nih.gov/grants/guide/rfa-files/RFA-AA-03-009.html (2003, p. 2).


9 ‘Lives at risk as HIV drug runs out’. http://www.guardian.co.uk/international/story/0,3604,1140306,00.html

10 For example, problems with supply to former bank employees who have been retrenched are reported in www.procaare.org/archive/procaare-art/200401/msg00005.php accessed 11th April 2004.
This not only applies to fishermen, their wives and other sexual partners may be even less likely to gain access given existing gender disparities in access to treatment (Fleischman, 2004).

The Poor Law Act of 1601 in England categorized paupers into three categories: the able-bodied poor for whom work would be provided, the old, children, the handicapped or sick and those who were thought able but unwilling to earn a living for themselves.

References


Challenges to delivering ART to vulnerable groups


