AIDS Exceptionalism: The View From Below[1]

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Introduction

The AIDS epidemic has stimulated an outpouring of foreign aid, particularly aid that is intended to help governments and individuals in sub-Saharan Africa respond to the epidemic. AIDS has been treated as "exceptional" among other health and development problems. AIDS exceptionalism is perhaps best defined by former executive director of UNAIDS, Peter Piot:

> This pandemic is exceptional because there is no plateau in sight, exceptional because of the severity and longevity of its impact, and exceptional because of the special challenges it poses to effective public action (Piot 2005: 2).

When the potential scale of the epidemic in sub-Saharan Africa became evident to experts and when the media made the epidemic visible to western publics, it indeed seemed so alarming that it justified exceptional efforts and exceptional funding. Eventually governments in affected countries agreed to also privilege AIDS over other health and development priorities. Initially the privileging of AIDS met only minor resistance. More recently, and especially as huge sums have been allocated to scale-up the provision of HIV Counseling and Testing (HCT), prevention of mother-to-child transmission (PMTCT), and antiretroviral treatment (ART), an intense debate is occurring among policy makers and groups or individuals who are attempting to influence international policy. This debate occurs in a rarefied atmosphere: the corridors of international agencies and the pages of major journals. But what are the views of those living in countries where HIV prevalence is high, and where many know, or at least assume, that they are HIV-positive? This paper examines the view from below, those who we would expect to welcome funding for AIDS.

We begin with a brief background to AIDS exceptionalism, featuring the supply of aid for AIDS, followed by the outlines of the current critiques of AIDS exceptionalism. We then turn to evidence of the demand for aid for AIDS in sub-Saharan Africa. We use multiple sources of data: 1) the multi-country Afrobarometer surveys, which asked respondents whether their government should devote more resources to AIDS or focus on other problems; 2) survey, qualitative and biomarker data collected by a longitudinal research project in rural Malawi, a country that, like many other countries in the region, has

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a high prevalence of HIV and great poverty.

2. Disease control and development priorities:

At the 2001 UN General Assembly Special Session on AIDS, "189 nations agreed that AIDS was a national and international development issue of the highest priority…." (UNAIDS 2006:2), a priority that the UN Secretary General, Kofi Annan, repeated in 2004, when he said that "AIDS is a new type of global emergency—an unprecedented threat to human development…." (UNAIDS 2004). In the 2004 Copenhagen Consensus, a panel of eight prominent economists, including four Nobel Prize winners, was asked to rank problems in health and nutrition in terms of a cost-benefit analysis: AIDS was at the top of their list: (1) Control of HIV/AIDS, (2) Providing micro nutrients, (4) Control of malaria, (5) development of new agricultural technologies that would increase nutritional value of foods and income of poor, malnourished farmers and farm workers, (7) Community-managed water supply and sanitation, (11) Improving infant and child nutrition, (12) Reducing the prevalence of low birth weight, (13) Scaled-up basic health services (Behrman, Berhman and Perez 2008).

Some, however, have been skeptical, calling the attention of the international health and development policy community to the implications of AIDS exceptionalism for funding other priorities, such as food insecurity and illiteracy (Bayer 1991; MacKellar 2005). This debate has been nicely summarized by Shiffman (2008). Shiffman (2008) points out that if influential donors, such as the United Nations, prioritize AIDS, there may be bandwagon effects on other donors that lead to the neglect of other issues; for example, special funds for AIDS provide incentives for health personnel to focus on well-paid positions in the AIDS industry rather than prevalent causes of illness and death (Shiffman 2008, citing Brugha et al. 2004; Caines and Lush 2004; Caines et al. 2004, and Garrett 2007). Another critique comes from an analysis of attention given to AIDS by social science researchers compared to other categories of communicable and chronic conditions. It concludes that "by the two criteria of current shares in DALYS [disability-adjusted-life-years] or estimated future shares in DALYS… the recent social science research on health in developing countries has overfocused substantially relatively on HIV/AIDS and injuries and underfocused substantially on non-communicable diseases and the CMPNC [communicable, maternal, perinatal and nutritional conditions] category other than HIV/AIDS" (Behrman, Behrman and Perez 2008). Large fractions of the respondents in the Gallup World Poll report the mortality of an immediate family member in the last twelve months, with malaria typically more important than AIDS, and deaths of women in childbirth more important than deaths from AIDS in many countries (Deaton, Forsten and Tortora 2008). Sridhar and Batniji (2008) compare international funding disbursements across disease by share of mortality; though HIV/AIDS accounts for only 5% of the deaths, the US spends nearly 49% of its international health aid budget on HIV/AIDS. Countering these arguments have been claims that foreign aid is fungible, such that foreign aid for AIDS makes it possible for governments to focus their limited resources on other health and development issues; moreover, funding for AIDS may build national health infrastructure that can be used for other health issues (Shiffman 2008 citing Devarajan and Swaroop 1998; Waddington 2004).

In a controversial 2008 piece, "The Writing is on the Wall for UNAIDS", health services expert Roger England presents a particularly aggressive critique, arguing not only that funding for AIDS has been disproportionate, but that much of it has been wasted. Notably, this was published in the *British Medical Journal*, giving it a wide audience, including elite policy-makers. Because England's critique summarizes many of the earlier arguments against AIDS exceptionalism, we quote from it extensively:

> HIV is a major disease in southern Africa, but it is not a global catastrophe, and language from a

top UNAIDS official that describes it as "one of the make-or-break forces of this century" and a "potential threat to the survival and well-being of people worldwide" is sensationalist. Worldwide the number of deaths from HIV each year is about the same as that among children aged under 5 years in India.

Similarly, multisectoral programmes were misguided and have got nowhere slowly and expensively. Some small projects of non-governmental organisations (NGOs) have successfully integrated sectoral efforts, but government ministries such as agriculture and education have not succeeded in the HIV roles imposed on them. Vast sums have been wasted through national commissions and in funding esoteric disciplines and projects instead of beefing up public health capacity that could have controlled transmission. Only 10% of the $9 billion (Ł4.5 billion; €5.8 billion) a year dedicated to fighting HIV is needed for the free treatment programme for the two million people taking those treatments. Much of the rest funds ineffective activities outside the health sector.

It is no longer heresy to point out that far too much is spent on HIV relative to other needs and that this is damaging health systems. Although HIV causes 3.7% of mortality, it receives 25% of international healthcare aid and a big chunk of domestic expenditure. HIV aid often exceeds total domestic health budgets themselves, including their HIV spending. It has created parallel financing, employment, and organisational structures, weakening national health systems at a crucial time and sidelining needed structural reform. Massive off-budget funding dedicated to HIV provides no incentives for countries to create sustainable systems, entrenches bad planning and budgeting practices, undermines sensible reforms such as sector-wide approaches and basket funding (where different donors contribute funds to a central "basket," from which a separate body distributes money to various projects), achieves poor value for money, and increases dependency on aid. Yet UNAIDS is calling for huge increases: from $9 billion today to $42 billion by 2010 and $54 billion by 2015. UNAIDS is out of touch with reality, and its single issue advocacy is harming health systems and diverting resources from more effective interventions against other diseases (England 2008).

England ends with a call to abolish UNAIDS, the international agency charged with stimulating international action against AIDS and for advocating increased funding for HIV prevention and AIDS treatment. Not surprisingly, his critique provoked an outpouring of responses, some supportive but most not.[5]

These debates over AIDS policy have occurred at a high level in the international community. But what are the policy preferences of the people who are themselves navigating AIDS in their daily lives, trying to avoid infection and to care for orphans and the sick?

3. Cross-national analysis of local demand for aid for AIDS

Data from the Afrobarometer study show that there is, in effect, a debate on AIDS exceptionalism even among individuals living in the hard-hit countries of southern Africa, who might be expected to call most vociferously for more resources to be devoted to AIDS. Figure 1 below shows that fewer countries

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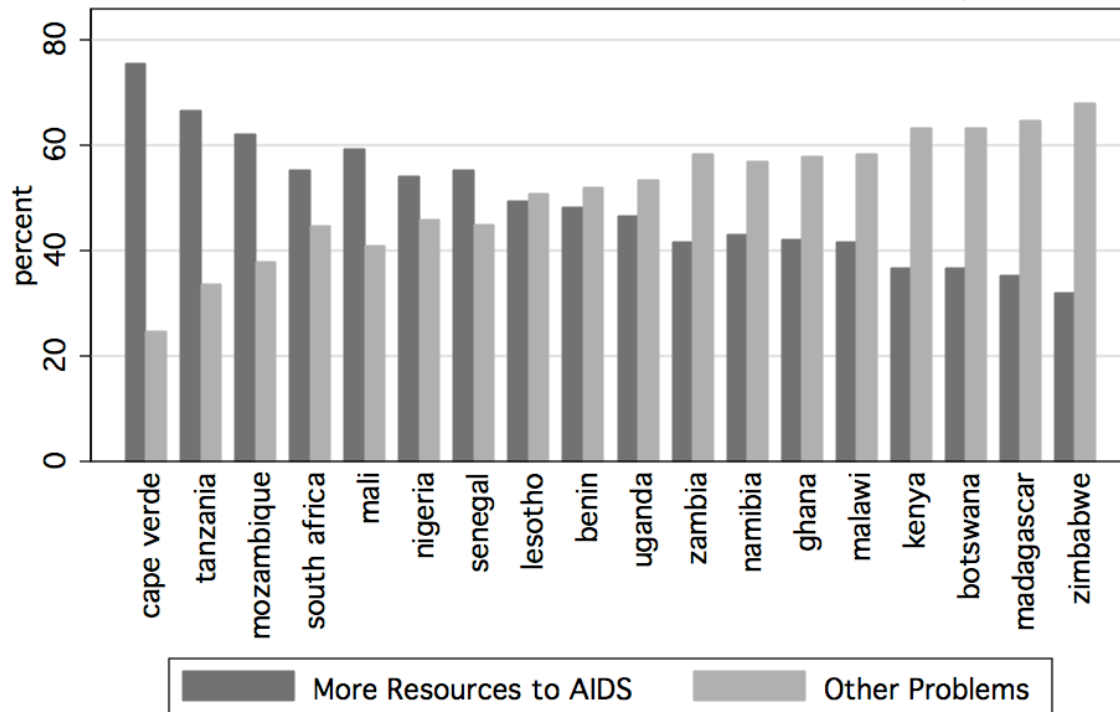
5 See DeLay (2008) and the long list of critical "Rapid Responses" to England's article published to the BMJ online: http://www.bmj.com/cgi/eletters/336/7652/1072.

had higher proportions of respondents who demanded more resources be devoted to combating AIDS vs. other problems, as depicted by the tall dark columns, notably Cape Verde, Tanzania, Mozambique, South Africa, Mali, Nigeria, and Senegal. However, in Botswana, Malawi, Zambia and Zimbabwe, all with exceptionally high HIV prevalence rates, more than 50% of respondents preferred that resources be devoted to problems other than AIDS.

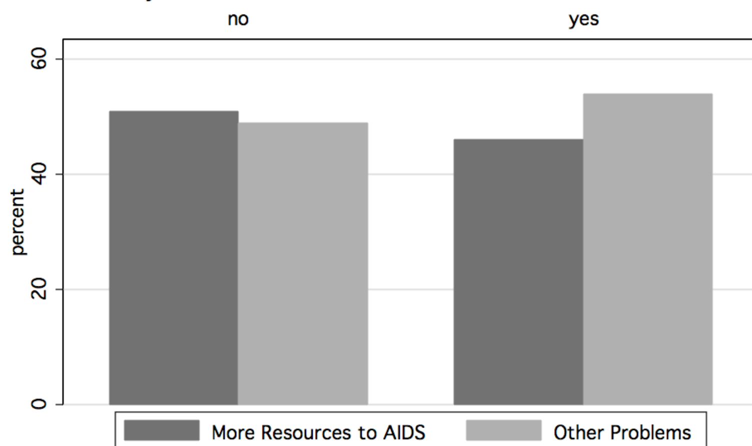
Figure 1: Should Government Devote More Resources to AIDS?



Perhaps, however, the debate over more resources for AIDS is a function of the respondents' own serostatus or, since few are tested, their subjective estimate of their serostatus.[6] Although Afrobarometer does not collect data on HIV serostatus, respondents did report on whether they knew someone who died of AIDS. We expect those who reported losing a close friend or relative to AIDS to have a stronger demand for resources to be devoted to AIDS (Dionne 2009). We separated the data by whether the respondent knew someone who died of AIDS (see Figure 2).

Figure 2: Should Government Devote More Resources to AIDS?

6 In sub-Saharan Africa, only 10% of the HIV-positive population is aware of their status (UNAIDS 2008). For the importance of subjectively estimated serostatus, see Anglewicz and Kohler (2009).



Those who reported not knowing a close friend or relative who died of AIDS were split on whether to devote more or fewer resources for AIDS. However, contrary to our expectations, those who would seem to be more affected by the disease (people who knew someone who died of AIDS) were actually *less* likely to demand additional resources be devoted to combat AIDS, and were more likely to demand resources be devoted to other problems. The pattern persists even when disaggregating the data by country (see figures of high-prevalence countries in Appendix A).

One limitation of Afrobarometer data is the inability to determine if there is an undersampling of the HIV-infected, given the lack of data on the serostatus of respondents; another is that the survey does not require respondents to choose among their needs for resources to address other problems, nor between general health services and AIDS-specific health services. Thus, to learn more about the view from below, we use data from an ongoing study in rural Malawi, the Malawi Longitudinal Study of Families and Households.

4. Local Demand for aid for AIDS in Rural Malawi

With more than 80 percent of the population living in rural areas, and with a national HIV prevalence among adults of 11.8% in 2007 (UNAIDS 2008), AIDS in Malawi is problem not just for urban areas (17%) but also for rural areas (11%) (National Statistical Office [Malawi] and ORC Macro 2005: 230-232).

Malawi has been a favored recipient of international funds supporting HIV prevention and AIDS mitigation and treatment. Much of the funding to implement AIDS-related programs is channeled through non-governmental organizations (NGOs); thus, a measure of AIDS exceptionalism is the proportion of newspaper advertisements that feature AIDS work. Opportunities for employment in AIDS-related work increased substantially between 1985 and 2005: indeed, there were no advertisements for agriculture-related positions between 2001 and 2005, even though agriculture accounts for approximately one-third of Malawi's GDP (Morfit 2008). Interviews with people employed within and outside the AIDS arena show that in addition to AIDS providing financial resources, it also provides social legitimacy: one staff member of an NGO said "if you do not engage in AIDS you're looked upon as if you're not doing anything by communities and other NGOs," another that "well, education is working on something, but you don't score the higher points that you score when working

on HIV" (Morfit 2008).

Per capita income in Malawi was estimated to be US$168 per year in 2008 (World Bank 2008), but is much less in the rural areas, where families depend primarily on subsistence agriculture supplemented by piece-work agricultural labor on the fields of their neighbors and small scale retail (e.g. selling tomatoes in a local market). Rural residents, however, know that unimaginable sums of foreign aid for AIDS have been given to Malawi. A review of newspaper articles provides some examples (US$1 is approximately equivalent to 140K (kwacha)): "Canada grants K700 million for HIV/Aids" (Nyoni 2002), "UNFPA, BLM Launch K437.5m Youth Project" (Times Reporter 2006); "MSF assists orphans with items worth K130,000" (Phalula 2000), "Bush pledges $500m ... to help fight HIV/Aids" (Reuters 2002). Many rural villagers have some access to these announcements through newspapers and radio, but they can also see signs of donor wealth in the 4x4 vehicles with NGO logos zipping along the roads, or stories of a friend of a friend who got about US$8 per diem at a three-day NGO workshop. Little of the AIDS money, however, comes to the villages (Swidler and Watkins 2009). Rural Malawians suspect government interference; for example, a field journalist chronicling conversations about AIDS in rural Malawi[7] writes about an older man talking about AIDS while riding a minibus, "And he said... the rich people especially those in Government and the Malawi leaders like the Presidents becomes richer and richer from the money they hide sent from donor countries to be used in caring the patient suffering AIDS" (Simon 040318).

Below we use datasets collected in conjunction with the Malawi Longitudinal Study of Families and Households (MLSFH). The project's overarching goal is to investigate the role of social processes in responses to modern family planning and AIDS and the consequences of high morbidity and mortality. The MLSFH has gathered individual-level data on HIV/AIDS, sexual behavior, religion, health, and economics, including the collection of biomarkers for HIV and other sexually-transmitted infections, village-level data, data on faith-based organizations and on sexual networks.[8] Though the original sampling strategy in 1998 was not designed to be representative of the rural population in Malawi, the sample's characteristics is not any different from those of the rural population interviewed by the Malawi Demographic and Health Surveys that covered nationally representative samples (Anglewicz et al. 2006).

We queried the MLSFH study population about their three biggest worries in 2004, and in 2008 we asked respondents to rank their preferences for HIV/AIDS services compared to the provision of other public goods and services. Supplementing the individual-level data, we conducted a survey of village headmen in the study sites in 2008 that asked them the same question about their policy preferences. Finally, we analyzed existing ethnographic data on informal conversations about AIDS in local social networks.

The first data analysis studies a question in the 2004 round of the MLSFH panel survey: approximately 4000 respondents were asked their three biggest worries over the last year (answers were unprompted, and ranked by interviewers in the order mentioned by the respondent). The following precoded sources of worry were used by interviewers: (a) AIDS-related health problems, (b) non AIDS-related health

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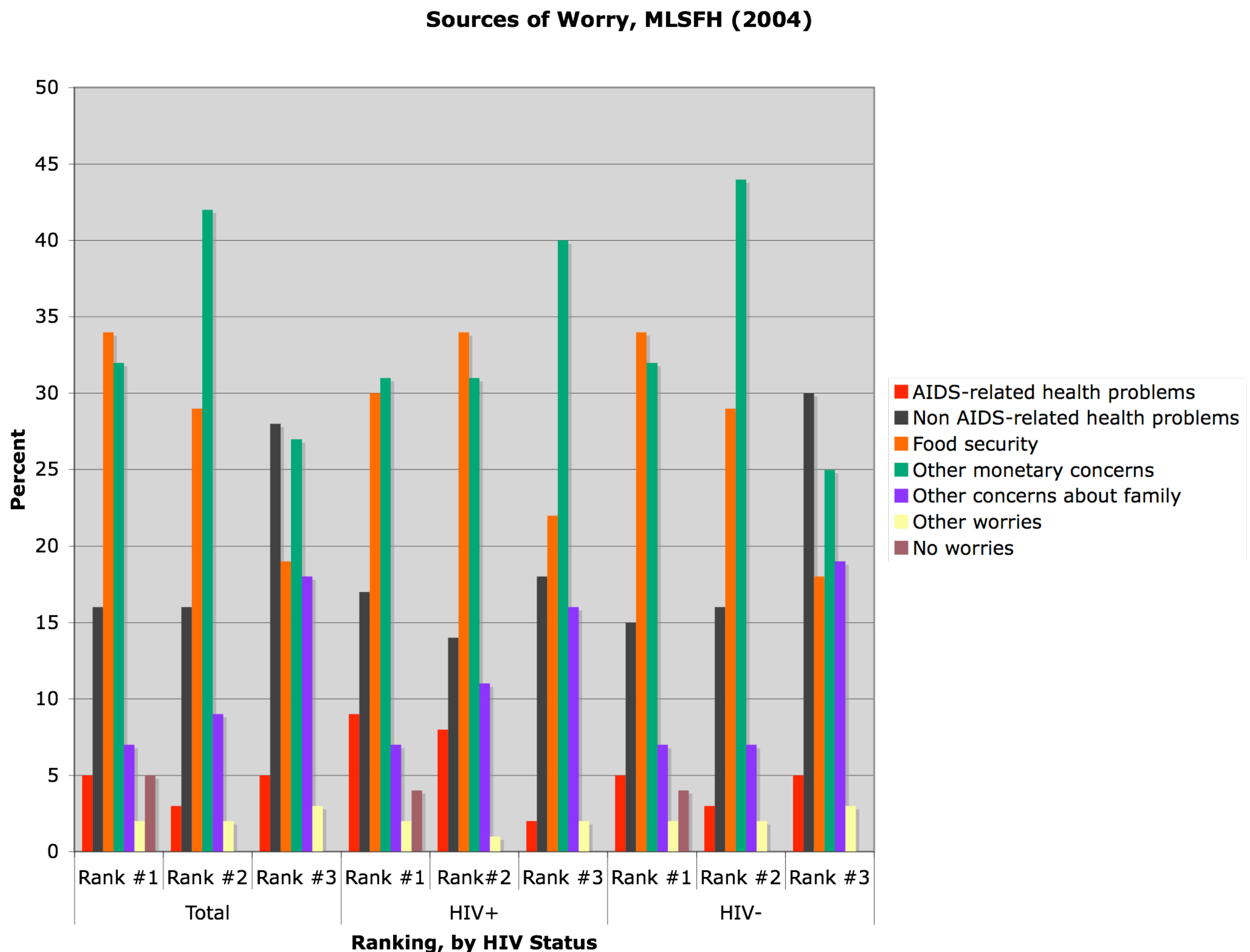
7 The journals are described in detail in Watkins and Swidler (2008), and an anonymized copy of the diary from which the quote is extracted is posted online in its entirety at www.malawi.pop.upenn.edu.

8 More about the MLSFH can be found online at: www.malawi.pop.upenn.edu.

problems, (c) food security, (d) other monetary concerns, (e) other concerns about family, (f) other issues, and (g) no worries. Table 2 shows that AIDS ranks low on respondents' priorities, even among those whom the survey subsequently found to be HIV+ (the survey preceded the testing) (see Figure 3). Food security, money and health issues not related to AIDS are the top three concerns mentioned by more than 80% of respondents.[9]

Figure 3: Top three sources of worries in 2004 for MLSFH respondents by HIV status



By the most recent round of the survey, in 2008, virtually all respondents had been tested at least once and knew their results (Onyango et al 2009). Moreover, between the two survey rounds antiretroviral treatment became increasingly available in rural Malawi (Ministry of Health 2005, Harries et al 2006), permitting some respondents to see that a spouse or a child who had been suffering from AIDS had, through the drugs provided with AIDS money, become healthy again. Thus, it is reasonable to expect

9 We do not want the reader to confuse our respondents' low priority ranking for AIDS as a demonstration of denial of AIDS as a problem. In 2004, more than 90% of our sample report to have known someone to have died of AIDS and the plurality of adults surveyed were "worried a lot" about catching AIDS (44% of women, 37% of men).

that the 2008 data will demonstrate stronger preferences for AIDS programs and services.

In 2008, MLSFH respondents were asked to rank the importance of five public policy priorities: clean water, health services, agricultural development, education, and HIV/AIDS programs. Villagers fail to rank HIV/AIDS services high on the list of public policy priorities. In fact, HIV/AIDS services ranked last among the five options. In Figure 4, we present boxplots of villagers' priorities. Most important was Clean Water (average score of 2.0) Second most important was Agricultural Development (average score of 2.6). Health Services was third most important (average score of 2.9). Education was fourth most important (average score of 3.6) and HIV/AIDS Programs were the least important (average score of 3.8).

Figure 4: Ranking of policy priorities by villagers in rural Malawi (MLSFH 2008)

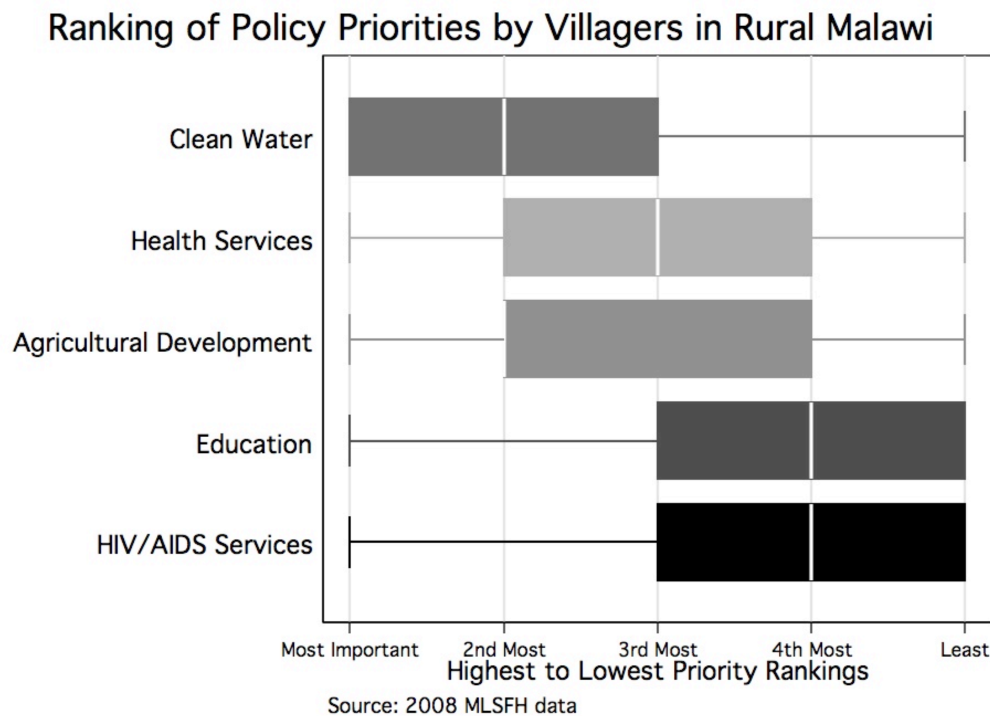


Table 1 presents the average scores for each policy preference, separated between those who tested HIV-positive and those that tested HIV-negative. When disaggregating the study population by HIV serostatus, the average score for HIV/AIDS Services moves from least important to fourth most important among the HIV-positive population, but all other rankings remain the same. Plainly, even among the HIV-positive respondents in our sample, Clean Water is most important, followed by Agricultural Development.

Table 1: Average scores of policy rankings, lower scores meaning more important (MLSFH 2008)

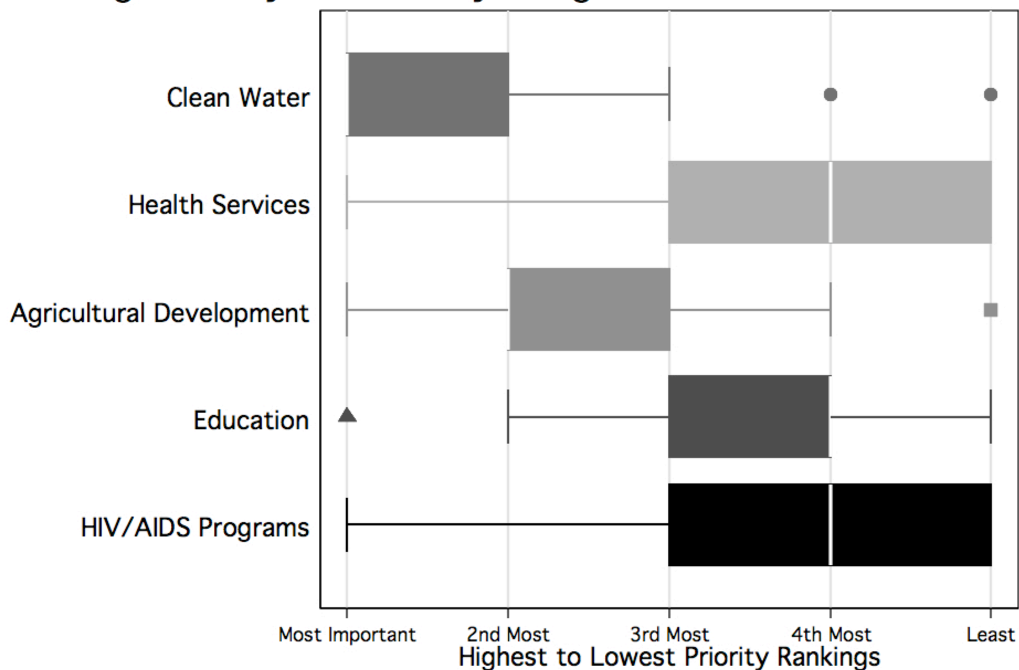
	Clean Water	Health Services	Agricultural Development	Education	HIV/AIDS Services

HIV-positive (n=123)	2.09	2.98	2.73	3.68	3.54
HIV-negative (n=2568)	2.00	2.96	2.61	3.57	3.86

To supplement the individual-level data in 2008, we conducted a special study of 135 village headmen, also referred to as chiefs. Headmen represent the lowest level of the governance structure: they chiefs are responsible not only to higher levels of the government but also to those whom they govern, who expect chiefs to administer justice and, especially, to "bring development to the community", which means to bring external resources. Because we wanted to know whether the chief's dual responsibilities to those above and below gave him a different perspective on AIDS exceptionalism, we asked them to rank community priorities, using the same questions that were asked of the survey respondents.

Figure 5 shows that headmen express preferences that prioritize Clean Water, much like the villagers do (average score of 1.7). Second most important was agricultural development (average score of 2.3). Third most important was education (average score of 3.5), but was closely followed by health services (average score of 3.5). Least important was HIV/AIDS programs (average score of 4.0).

Figure 5: Ranking of policy priorities by village headmen in rural Malawi (MLSFH 2008)



The final data set permits us to assess the frequency with which AIDS is discussed in informal social networks, relative to the attention given to other topics. Beginning in 1999, field assistants were asked to simply pay attention to mentions of AIDS that occurred during the course of their daily lives: they were not to interview, but simply to listen to what was said in public and then to write down the who-said-what-to-whom in a journal, thus providing access to what people are saying to each other rather than to an interviewer with a clipboard or a tape recorder (for details, see Watkins and Swidler, 2008). The journals show a great deal of talk about AIDS, and have been valuable for providing an unusual perspective on rural responses to the epidemic (e.g. Kaler 2003, 2004; Watkins 2004; Santow et al 2008). Because the field assistants only wrote about conversations related to AIDS, we could not assess the frequency with which people talk about AIDS compared to other potential topics. Thus, in 2005 we asked a core group of the field assistants to systematically keep track of all significant daily conversations (instead of daily activities, as in time-use diaries) over a period of seven days. But unlike time-use surveys, information was not collected retrospectively at the end of the day or the next day through a third party interviewer but directly by the participants through near real-time logging of all significant daily conversations. This approach thus limits omissions due to recall lapse or selective memory. Additional background information about each conversation and the conversation partners involved was also collected through a short standardized form (contact diary).[10]

Economic survival is the predominant subject of conversation, occuring 32% of the time or about one out of three conversations.[11] Conversations about AIDS are less frequent, with a frequency of 14% or 26%, depending on measurement. A conservative measure of AIDS conversations as referring only to "AIDS”,[12] "Death", and "Funerals" occurred only about 14% of the time. A more inclusive measure of AIDS conversations occurred 26% of the time; the additional conversations related to domestic matters.[13] The latter measure probably exaggerates the ranking of AIDS in informal conversations, since the domestic matters coding categories include many other aspects of AIDS than services. For example, a favorite topic of conversation is gossip about sexual networks, with commentary about the likelihood that in a particular partnership one or both of the partners is infected, or will be infected; another frequent topic is discussion about divorces and separations provoked by one spouse’s conclusion that the other spouse will “bring AIDS into the family.”

6. Conclusions

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10 Several strategies were used to preserve as much as possible the random nature of the experiment and to prevent journalists from changing their daily routines or selectively picking and choosing topics of conversation, conversation partners or settings: (1) all journalists were asked to participate in the experiment during the same period, (2) systematic recording of all significant conversations (not just about AIDS) with logging of the starting time, subject and brief summary was required, (3) recording was performed from wake-up time until sleeping time and (4) systematic time sampling was used over 2 weeks by alternate days (i.e., conversations started to get recorded on Monday 11 July, then Wednesday 13 and so on, totaling seven days of daily conversations).

11 Coded conversations for economic survival include: Money (e.g., Prices for basic commodities), Food (e.g., Maize flour), Famine, Work (e.g., Vending, Casual labor, Doing/Opening a business), Farming (e.g., Poultry), Property (e.g., Deceased property, Property selling, Land ownership and decision-making), Mobility, and Poverty.

12 Coded conversations for AIDS include: Girls/women are dangerous, Prostitution, Soldiers carelessness, and Free ARVs.

13 Domestic matters include conversations coded for Marriage (e.g., Separation, Divorce, Wedding, Fidelity issues), Family (e.g., Caregiving, Complain about family member, Orphans), Children (e.g., Child abuse/exploitation), Husband (e.g., Polygamy issues, Complains about husband), Initiation (e.g., Advantage/disadvantage), Household (e.g., Help for household chores, Household matters, Drinking, School).

This paper contrasts the supply of resources for HIV prevention and AIDS treatment and mitigation provided by a generous international community that sees AIDS as an exceptional disease with the demand for these resources by individuals in sub-Saharan Africa. Data from the multi-country Afrobarometer survey show that even in some countries with exceptionally high HIV prevalence, 50% or more of respondents preferred resources be devoted to problems other than AIDS; moreover, our analysis of Afrobarometer data shows that demand does not depend on respondents' perception of the extent of the problem, measured by personally knowing someone with AIDS. To explore the demand in more detail, we used data from rural Malawi, a country similar to most others in the region in terms of its high HIV prevalence and its poverty. Responses to survey questions in both 2004 and 2008 showed that respondents gave higher priority to other problems in their lives: for most, clean water, food security, and monetary concerns were seen as more important than AIDS. A similar question asked of chiefs, with responsibility for the welfare of the whole village community, produced similar responses. An analysis of topics of conversations in local social networks appears to contradict these results: conversations about AIDS were almost as frequent as conversations about income survival. We believe, however, that this is because conversations about AIDS were often gossip about the scandalous sexual behavior of others, and no doubt especially enjoyable.

The multiple data sources permit us to conclude with confidence that rural Malawians, like the critics of AIDS exceptionalism, would prefer fewer resources be allocated to AIDS and more to other critical day-to-problems, amongst which the provision of clean water ranks very high. Rather surprisingly, even those most likely to benefit from the new stream of money for ART, the HIV-positive respondents in our study, expressed preferences for Clean Water, Agricultural Development, and Health Services over additional AIDS services in their area.

We have only one source of data, the Afrobarometer survey, for other high-prevalence countries in sub-Saharan Africa, but it is consistent with our findings for Malawi. With respect to funding for AIDS, donor preferences trump the preferences of the people whom the donors believe they are assisting. Although the global supply of AIDS services, and particularly access to antiretroviral treatment, is being scaled up across sub-Saharan Africa, we expect that the additional supply will continue to surpass local demand.

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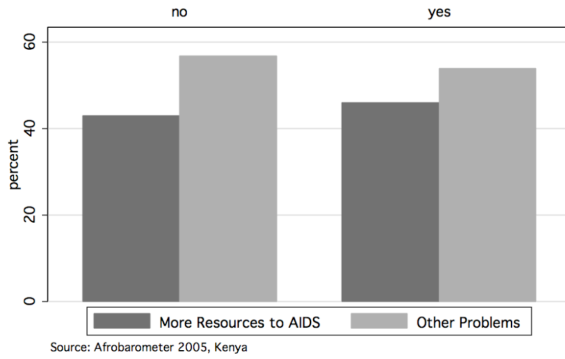
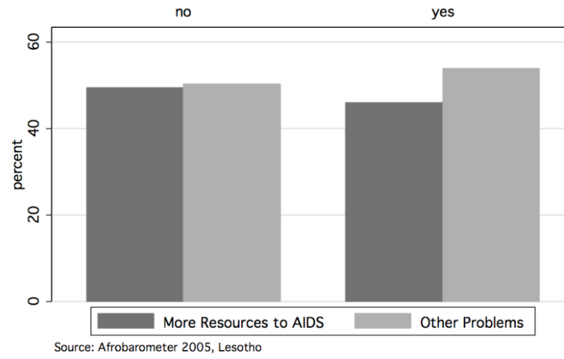
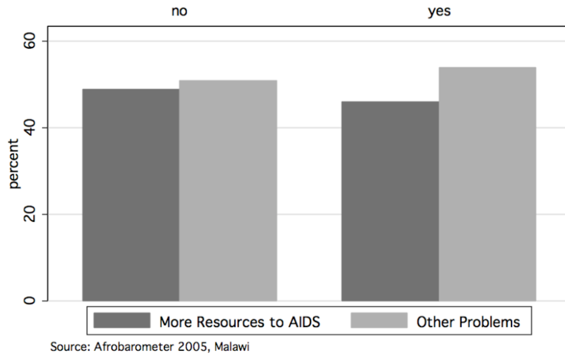
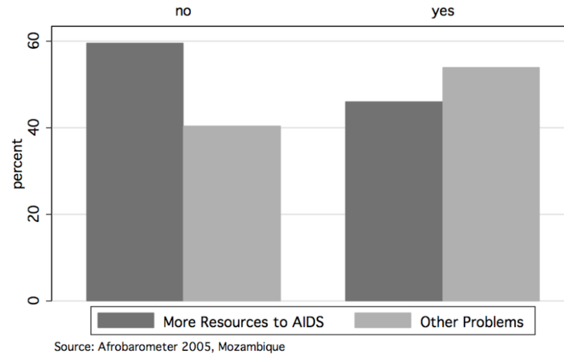
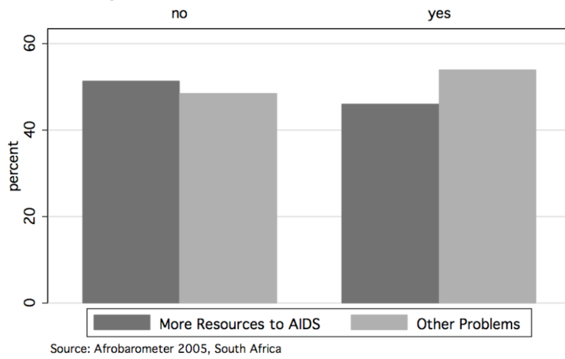
Appendix A: Prioritization of AIDS in the High-Prevalence Countries of East and Southern Africa

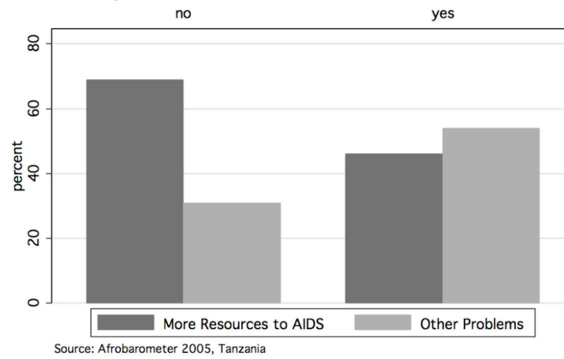


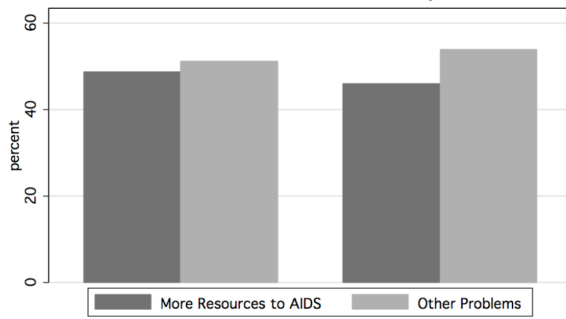


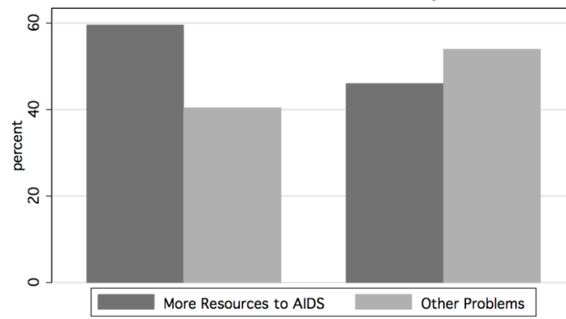


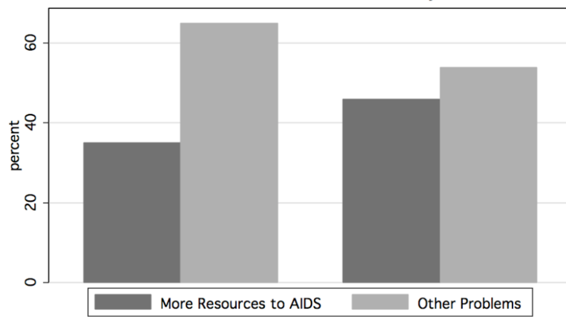







Should more resources be devoted to AIDS or other problems?
Do you know a close friend or relative who has died of AIDS?
no
yes
percent
0
20
40
60
More Resources to AIDS
Other Problems
Source: Afrobarometer 2005, Uganda


Should more resources be devoted to AIDS or other problems?
Do you know a close friend or relative who has died of AIDS?
no
yes
percent
0
20
40
60
More Resources to AIDS
Other Problems
Source: Afrobarometer 2005, Zambia


Should more resources be devoted to AIDS or other problems?
Do you know a close friend or relative who has died of AIDS?
no
yes
percent
0
20
40
60
More Resources to AIDS
Other Problems
Source: Afrobarometer 2005, Zimbabwe