

# AIDS Exceptionalism: The View From Below<sup>1</sup>

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## ABSTRACT

**Objective:** To analyze public demand for increased AIDS services in African countries with generalized AIDS epidemics.

**Setting:** 18 countries in sub-Saharan Africa; rural Malawi.

**Design:** This is a mixed methods study employing multiple data sets at different levels of aggregation. The 2005 Afrobarometer survey provides data on respondent preferences for the allocation of budget resources to AIDS compared with other problems. These are analyzed at the national level, taking HIV prevalence and the proportion of respondents with proximate experiences with AIDS into account. We use data from individuals who participated in a longitudinal study in rural Malawi and who were asked to rank their important problems and their preferences for allocation of resources to AIDS services compared to other health and development services. These analyses take HIV status into account. They are augmented by a special survey of village headmen, who provide the perspective of the lowest level of government officials. We also draw on qualitative data to assess the validity of individual reports and to interpret the findings.

**Participants:** The cross-national Afrobarometer survey included 25,397 survey respondents; the data from two panels of the longitudinal survey in rural Malawi covered approximately 4,000 respondents; the survey of village headmen covered 122 headmen, one in each of the villages included in the sample for the longitudinal survey. Qualitative data include 39 semi-structured interviews with village headmen and logs kept by five field assistants chronicling the topics of conversations for a period of 7 days with a total of 142 participants.

**Main outcome measures:** The demand for increased AIDS services, as measured by the preferences for increased resources devoted to AIDS compared to other uses for public resources. Importance of AIDS compared to other problems, as measured by respondent worry about AIDS and frequency of conversation on AIDS topics.

**Results:** Analysis of multiple sources of survey data are consistent in showing a weak demand for AIDS resources compared to the demand for resources for other issues (Afrobarometer) and specifically when compared to the need for resources for health and development more generally (Malawi survey data and

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1 The views and opinions expressed in this paper are those of the authors and do not necessarily represent those of the United Nations.

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village headman data). National HIV prevalence does not predict country-level demand for more resources to AIDS and reporting losing a loved one to AIDS (Afrobarometer) and HIV serostatus (Malawi survey respondents) also fails to predict strong demand for AIDS resources.

Conclusions: Multiple data sources suggest weak demand for AIDS resources in the parts of Africa hardest hit by AIDS. Although the data from rural Malawi show that rural residents are fully aware of the risk of dying from AIDS, other problems are perceived as more pervasive and urgent.

## **WHAT THIS PAPER ADDS**

Whereas scholars and practitioners debate AIDS exceptionalism in international corridors of power, little is known about local demand for AIDS services in sub-Saharan Africa, where AIDS has reached pandemic proportions. This study combines analyses of cross-national public opinion data with survey and qualitative data from rural Malawi to assess the relative demand for AIDS services compared to other health and development needs.

## **INTRODUCTION**

The AIDS epidemic has stimulated an outpouring of foreign aid intended to help governments and individuals in sub-Saharan Africa respond to the epidemic. AIDS has been treated as “exceptional,” a crisis of such magnitude that it should be prioritized over other health and development problems.<sup>5</sup> AIDS exceptionalism is perhaps best defined by the 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 from the international community. The initial privileging of AIDS met only minor resistance. More recently, and especially as huge sums have been allocated to dramatically expand the provision of HIV Counseling and Testing, prevention of mother-to-child transmission, and antiretroviral treatment, and with little evidence of effective prevention activities for the general population (Padian et al. 2008), 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 assume that they are HIV-positive? This paper examines the view from below, from those whom 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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<sup>5</sup> Whiteside (2009: pp. 4-12) provides a more thorough history of AIDS Exceptionalism.

a high prevalence of HIV and great poverty.

### **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 (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 seek well-paid positions in the AIDS industry rather than to address more prevalent causes of illness and death seen in public health facilities (Shiffman 2008, citing Brugha et al. 2004; Caines and Lush 2004; Caines et al. 2004, and Garrett 2007; for similar arguments, see Behrman, Behrman and Perez 2008 and Deaton, Forsten and Tortora 2008). Sridhar and Batniji (2008) compare international funding disbursements across disease by share of mortality; though HIV/AIDS accounts for less than 5% of deaths worldwide, the US spent nearly 49% of its international health aid budget on HIV/AIDS in 2007.

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.

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 that has taken the lead in advocating for increased funding for HIV prevention and AIDS treatment. Not surprisingly, his critique provoked an outpouring of responses, some supportive but most not.<sup>6</sup>

### Aid for AIDS in rural Malawi

At the time of the last census, in 2008, the population of Malawi was slightly over 13 million (National Statistics Office 2008). With a national HIV prevalence among adults of 11.8% in 2007 (UNAIDS 2008), AIDS in Malawi is a problem not just for urban areas (17%) but also for rural areas (11%) where more than 80% of the population lives (National Statistical Office [Malawi] and ORC Macro 2005: 230-232). Gross national income per capita in Malawi was US\$170 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).

In addition to aid for general health services and reproductive health services, Malawi has received a great deal of aid specifically earmarked for AIDS, as shown below; the figures for sub-Saharan Africa as a whole are shown for comparison. About 27% of all development spending in 2007 (excluding debt forgiveness) in Malawi is for AIDS (Panel A); the equivalent figure for all sub-Saharan Africa is approximately 11% (Panel B). To anticipate our findings that there is a much greater demand from rural Malawians for clean water than for AIDS services, note that aid to Malawi in 2007 for improving water supply was US\$4 million, compared to \$151.7 million for AIDS.

For Malawi:

Panel A.	Current Prices (USD millions)	2002	2003	2004	2005	2006
	<b>Total for AIDS disbursement (STD control including HIV/AIDS + Social mitigation of HIV/AIDS)</b>	<b>8.4</b>	<b>17.3</b>	<b>54.3</b>	<b>65.6</b>	
	Other development spending excluding debt forgiveness, from all official sources (ODA+OOF)	217.5	327.1	337.4	366.6	400.0
	<b>All Official Flows Combined Net (ODA+OOF) excluding debt forgiveness</b>	<b>225.9</b>	<b>344.4</b>	<b>391.7</b>	<b>432.3</b>	<b>400.0</b>
For other sectors	Education	22.6	33.3	35.5	31.0	
	Health	28.6	35.6	35.4	37.1	
	Reprod. Health and FP excluding STD/AIDS	11.0	18.6	15.3	9.7	
	Water supply	6.5	10.2	6.8	6.9	

For sub-Saharan Africa:

<sup>6</sup> 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>.

Panel B.	Current Prices (USD millions)	2002	2003	2004	2005	2006
	<b>Total for AIDS disbursement (STD control including HIV/AIDS + Social mitigation of HIV/AIDS)</b>	<b>239.5</b>	<b>611.9</b>	<b>1,171.7</b>	<b>1,743.4</b>	<b>1,881.2</b>
	Other development spending excluding debt forgiveness, from all official sources (ODA+OOF)	9,018.3	12,493.7	15,276.4	19,063.7	20,814.4
	<b>All Official Flows Combined Net (ODA+OOF) excluding debt forgiveness</b>	<b>9,257.8</b>	<b>13,105.6</b>	<b>16,448.1</b>	<b>20,807.1</b>	<b>22,695.6</b>
For other sectors	Education	896.2	1,492.2	1,663.0	1,585.6	1,848.3
	Health	666.8	934.1	1,163.8	1,512.1	1,786.6
	Reprod. Health and FP excluding STD/AIDS	111.1	157.9	114.3	114.5	133.9
	Water supply	263.8	340.0	432.2	539.1	704.6

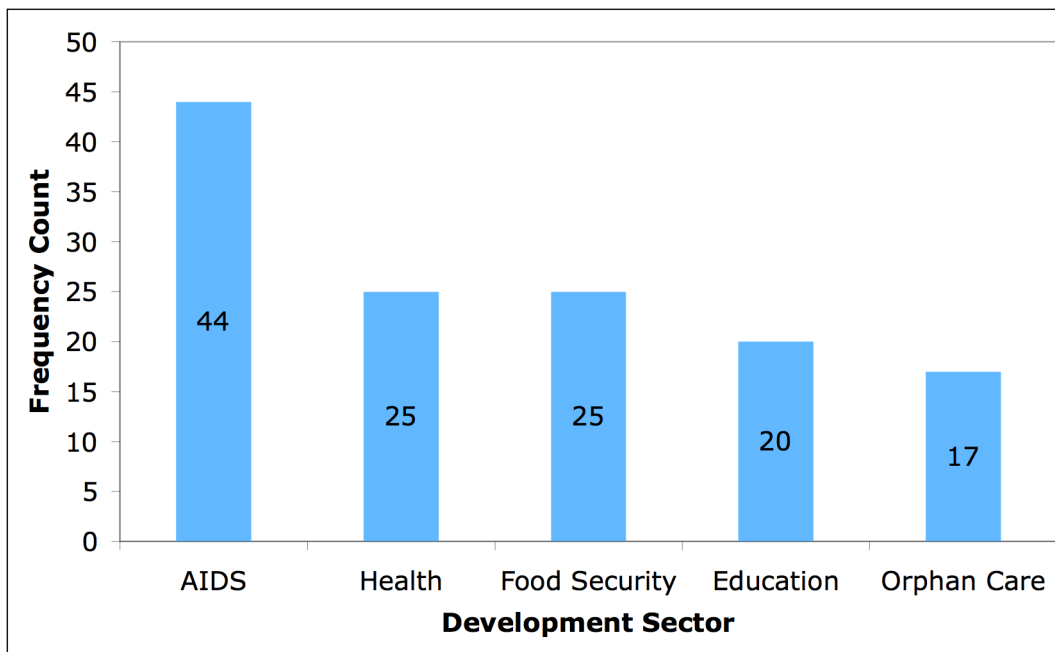
Source: International Development Statistics Online (2009)

The primary services that aid for AIDS supports are the prevention of mother-to-child transmission of HIV, HIV counseling and testing and antiretroviral therapy. Initially available only in specialized facilities in the two large cities, between 2005 and 2007 access to these services was expanded to all district hospitals and, in the case of HIV counseling and testing, to smaller local facilities in the district. These funds have also permitted media campaigns to raise awareness of AIDS and how to prevent HIV, workshops to teach village volunteers the principles of orphan care and home-based care for the chronically ill, as well as supporting the National AIDS Commission, which is charged with developing AIDS policy and coordinating the programs of the government and a multitude of non-governmental organizations (NGOs).

The NGO sector has increased substantially due to AIDS. Figure 1, taken from Morfit (2008), shows the population of NGOs registered with CONGOMA, the government agency that coordinates NGOs in Malawi, by development sector.

Figure 1: Sector labels used by NGOs registering with the Malawi NGO Board, 2002-2007

(Total NGOs = 139).



The figure above is cross-sectional, but Morfit provides a sense of the relative increase in AIDS NGOs compared to other development sectors, based on newspaper employment advertisements. For the period 1985-89, there were no advertisements for employment in AIDS: the two largest NGO employment sectors were agriculture and relief, each accounting for 25% of NGO advertisements.<sup>7</sup> By the most recent period, 45% of NGO job advertisements were in AIDS; 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 forthcoming). 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 forthcoming).

Debates over AIDS policy – especially AIDS exceptionalism – typically occur at a high level in the international community. To learn on which side of the AIDS exceptionalism debate sub-Saharan Africans fall, we now turn to 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.

## DATA AND METHODS

We begin by describing the data collected in the 2005 round of the Afrobarometer survey, which we use to provide an overall view of the demand for AIDS resources across multiple countries in sub-Saharan Africa. We then turn to richer data from a longitudinal study in a single setting, rural Malawi.

The Afrobarometer is a public attitudes survey using a national probability sample of the voting age

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<sup>7</sup> The relief section is unusually large in this 1981-84 period due to refugees from war in Mozambique, who began arriving in large numbers in 1986.

population and is conducted in 18 African countries: Benin, Botswana, Burkina Faso, Cape Verde, Ghana, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mozambique, Namibia, Nigeria, Senegal, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe. As our measure of demand for AIDS services, we used responses given when participants were asked to which of the following two statements they agreed:

Statement A: The government should devote many more resources to combating AIDS, even if this means that less money is spent on things like education.

Statement B: There are many other problems facing this country beside AIDS; even if people are dying in large numbers, the government needs to keep its focus on solving other problems.

Because we expected responses to be influenced by participants' experiences with AIDS, we analyze the association between variation in their reported demand for AIDS services and their experiences with the epidemic, measured by the 2004 national-level HIV prevalence data published by UNAIDS and by individual responses to an Afrobarometer question measuring whether they had lost a relative or close friend to AIDS.<sup>8</sup>

The data for rural Malawi were collected in conjunction with the Malawi Longitudinal Study of Families and Households (MLSFH), a study of the role of social networks in responses to the AIDS epidemic and to the introduction of modern family planning. The spine of the MLSFH is a panel survey of individuals that includes questions on AIDS-related attitudes and behavior, health, religion, economic circumstances; the MLSFH also tested consenting respondents for HIV.<sup>9</sup> The survey, conducted in villages in three districts, was not designed to be representative of the overall rural population; however, the sample characteristics have been shown to be similar to those of the national-level rural population surveyed by the Malawi Demographic and Health Surveys that covered nationally representative samples (Bignami et al 2003; Anglewicz et al. 2009). In the two rounds of the MLSFH survey that we exploit below, the sample size is approximately 4,000 and includes adult and adolescent men and women.

Whereas the Afrobarometer asks respondents only whether they want more resources to be provided for AIDS, the MLSFH asks questions that permit comparing the demand for AIDS services with the demand for other services. 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. Interviewers categorized open-ended responses using the following precoded sources of worry: (a) AIDS-related health problems, (b) non AIDS-related health problems, (c) food security, (d) other monetary concerns, (e) other concerns about family, (f) other issues, and (g) no worries. In 2008 we explicitly asked approximately 4,000 respondents provide a rank order of their demand for various services that might compete with their demand for AIDS services. Respondents were read the following script:

Now, I would like to ask you your opinion on programs in this area. People have said they would

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<sup>8</sup> The question asked, "How many close friends or relatives do you know who have died of AIDS?" Responses were changed to have a binary value: all respondents who reported 0 were coded as 0, all respondents who reported values greater than or equal to one were coded as 1. Respondents who reported not knowing were treated as missing values.

<sup>9</sup> A detailed description of the MLSFH is provided at [www.malawi.pop.upenn.edu](http://www.malawi.pop.upenn.edu).

like programs to improve life here in this area. Some programs that could improve life would be: more access to clean water, increased health services, more agricultural development, better education programs, and more HIV/AIDS programs. Unfortunately, the money available for these programs is very limited. If you had the chance to pick which programs were most important and which were not, how would you rank these five programs? There is no right or wrong answer; I just want to know what you think.

Respondents were then asked to rank each of the five policy preferences (clean water, health services, agricultural development, education, HIV/AIDS services) in order of importance, where a score of 1 is most important and a score of 5 is least important.

Supplementing the MLSFH survey data, in 2008 we conducted a survey of 122 village headmen, also referred to as chiefs, in each village of the MLSFH study sites.<sup>10</sup> Village headmen are the lowest level of the governance structure: they are responsible both to higher levels of the government and to those whom they govern, who expect village headmen to administer justice and, especially, to “bring development to the community”, which means to bring external resources. Because we wanted to know whether the village headman’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 policy prioritization question that was asked of the 2008 MLSFH panel survey respondents.

Our 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. Previous analyses of qualitative data had shown discrepancies between what was said about AIDS in formal settings (survey and semi-structured interviews) and in the course of spontaneous conversations in natural settings, based on the ethnographic work of field assistants who lived in or around the MLSFH villages. Under the assumption that relative frequency of conversation about AIDS is an indication of its relative importance, in 2005 we asked field assistants (living in the MLSFH Southern district with higher HIV prevalence) to systematically keep track of all significant daily conversations that they overheard or in which they participated over a period of seven days. The conversations were logged at the end of each day, thus limiting omissions due to recall lapse or selective memory. Additional background information about each conversation and the conversation partners involved was also collected in a contact diary.<sup>11</sup> Five field journalists wrote about 113 significant conversations involving a total of 142 conversation partners with whom they spoke during the study period.

## RESULTS

### Cross-national analysis of demand for resource allocation to AIDS

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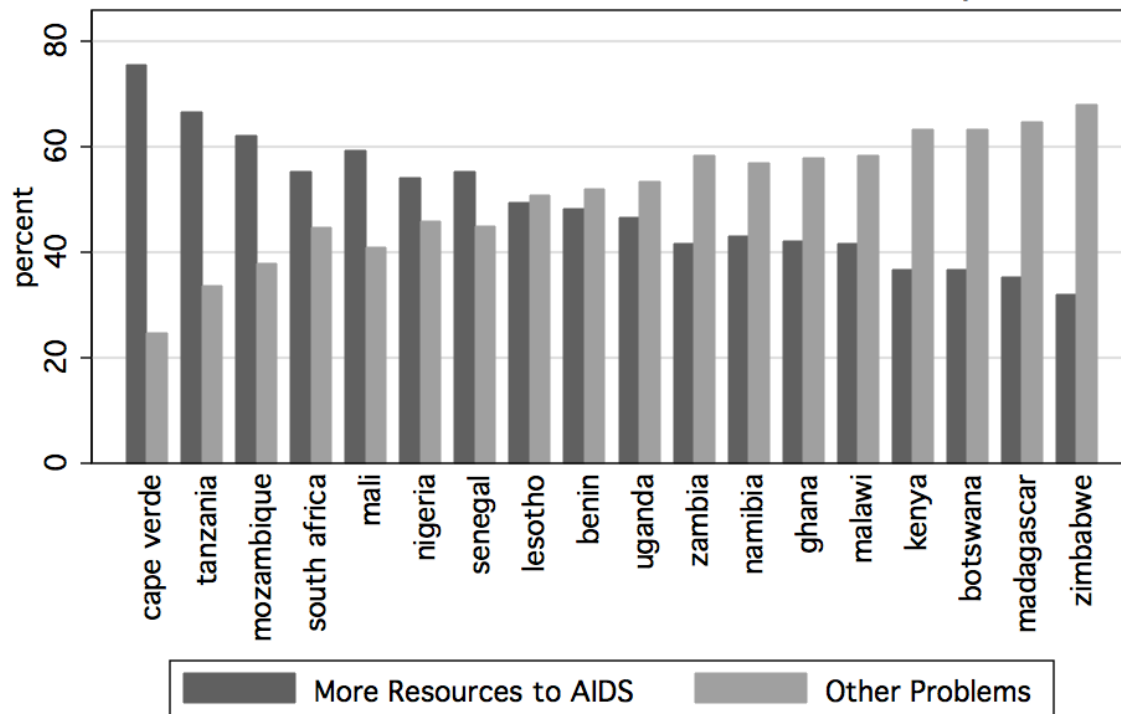
<sup>10</sup> Though most widely known as chiefs and also referred to by scholars as traditional authorities or traditional leaders, in this paper we refer to the local leaders of villages as village headmen because the terms “traditional authority” and “chief” have specific hierarchical connotations in the Malawian context.

<sup>11</sup> 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).

Data from the Afrobarometer study show that there is, in effect, a country-level debate on AIDS exceptionalism. The tall dark bars in Figure 2 below show that of the 18 countries, seven prioritized resources for AIDS (Cape Verde, Tanzania, Mozambique, South Africa, Mali, Nigeria, and Senegal); the other 11 countries prioritized problems other than AIDS. Strikingly, 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 2

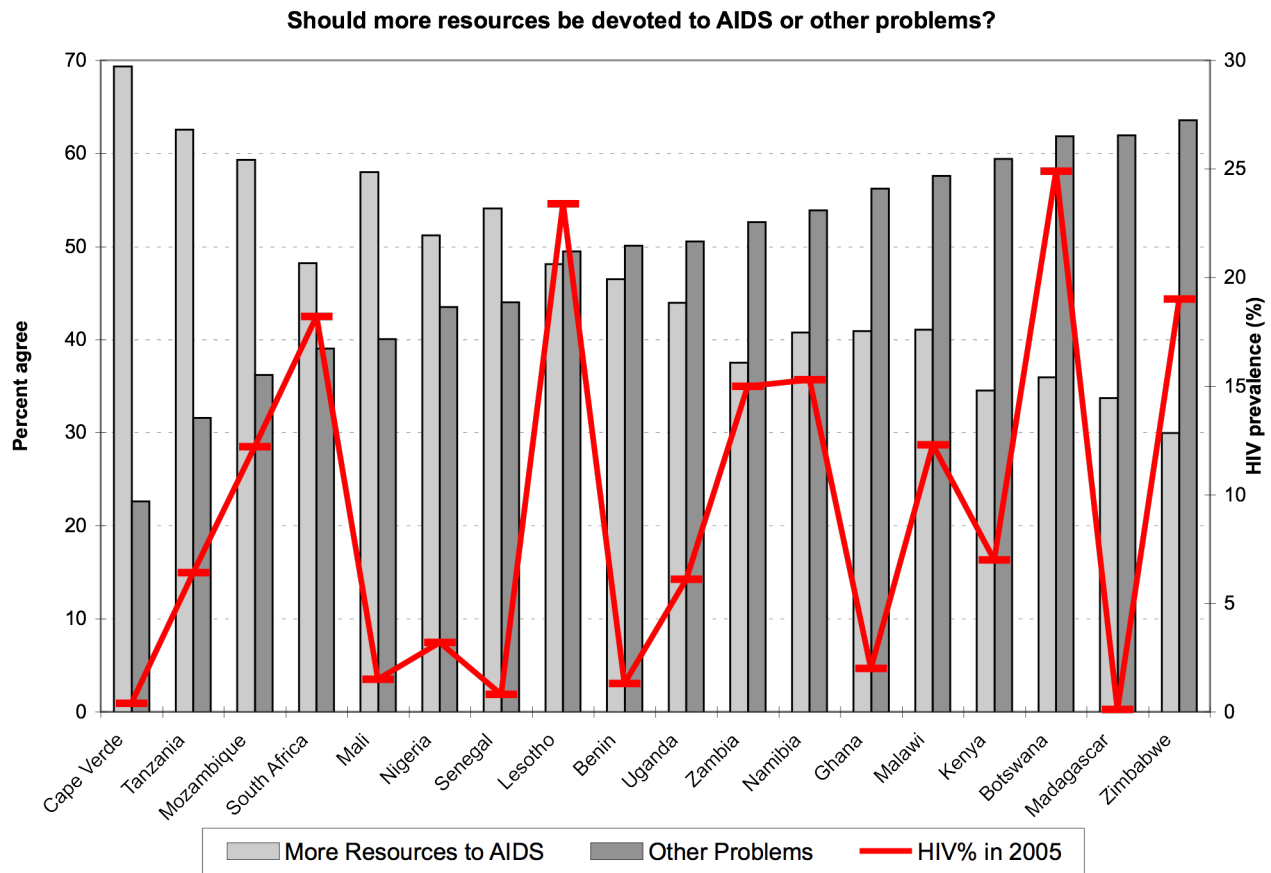
Should more resources be devoted to AIDS or other problems?



Source: Afrobarometer 2005

Figure 3 plots the same histogram, but also includes a trend line for national HIV prevalence. Plotting national HIV prevalence over the demand histogram shows no clear relationship between higher HIV prevalence and stronger demand that resources be devoted to AIDS relative to other problems.

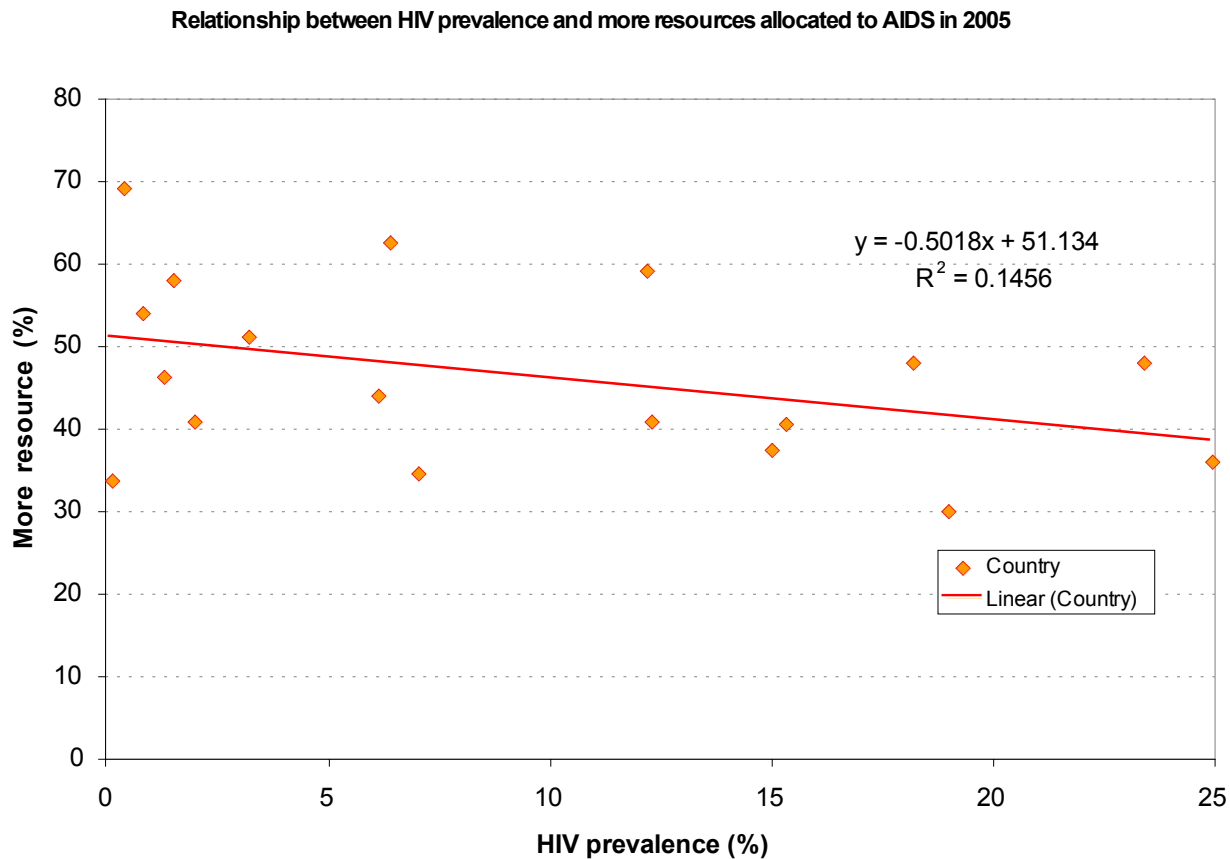
Figure 3



Sources: Afrobarometer (2005); UNAIDS (2006).

One could make the case that in countries with higher HIV prevalence, AIDS exceptionalism had already resulted in the provision of sufficient resources, leaving unmet needs for resources to address other problems. This would imply an inverse relationship between prevalence and the demand for more AIDS resources, which is what we observe in Figure 4. The statistical relationship, however, is, very weak ( $R^2=0.146$ ), suggesting that this explanation is incomplete.

Figure 4: HIV prevalence and whether more resources should be allocated to AIDS



Sources: Afrobarometer (2005) and UNAIDS (2006).

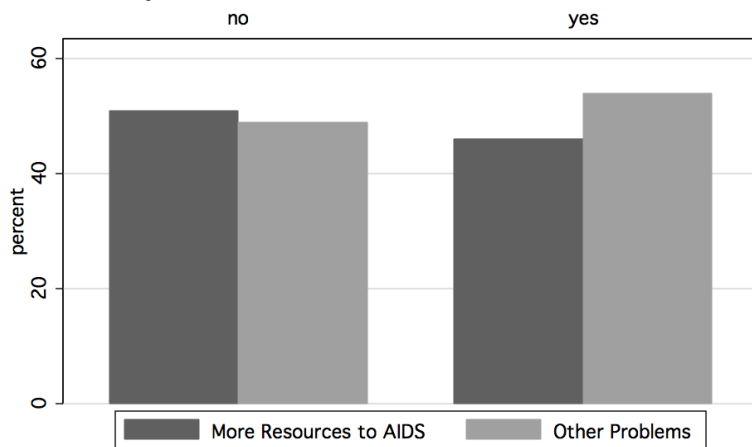
Perhaps, however, the debate over more resources for AIDS is a function of the respondents' own serostatus or, since few are tested, their subjective estimate of their serostatus.<sup>12</sup> Although Afrobarometer does not collect data on HIV serostatus, respondents did report on whether they knew 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 2009a). We aggregated the data for all 18 countries, and separated responses by whether the respondent had lost a relative or friend to AIDS (see Figure 5).

<sup>12</sup> 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).

Figure 5

Should more resources be devoted to AIDS or other problems?

Do you know a close friend or relative who has died of AIDS?



Source: Afrobarometer 2005

Those who reported that they had not had a proximate experience of AIDS mortality were split on whether to devote more or fewer resources for AIDS. In contrast, those who knew a relative or friend who had died of AIDS were *less* likely to demand additional resources be devoted to combat AIDS, and were more likely to demand resources be devoted to other problems. This pattern persists even when disaggregating the data by country (not shown).

The findings of our analyses of Afrobarometer data are surprising, given the much higher prevalence of HIV in sub-Saharan Africa and the perception, from afar, of a region ravaged by illness and death and coping with the burdens of AIDS orphans. In particular, one would expect that AIDS would be most salient to those who had witnessed its effects, and that they would prioritize AIDS over all other problems. It may be, however, that our analyses are misleading, due to the limitations of the Afrobarometer data. One limitation is that the data do not include the serostatus of the respondents; perhaps those who are themselves HIV infected do indeed prefer that more resources be devoted to AIDS. Another, and potentially more important, limitation is that “other problems” may be too unspecific: the survey does not require respondents to rank their preferences for resources to support a variety of other services.

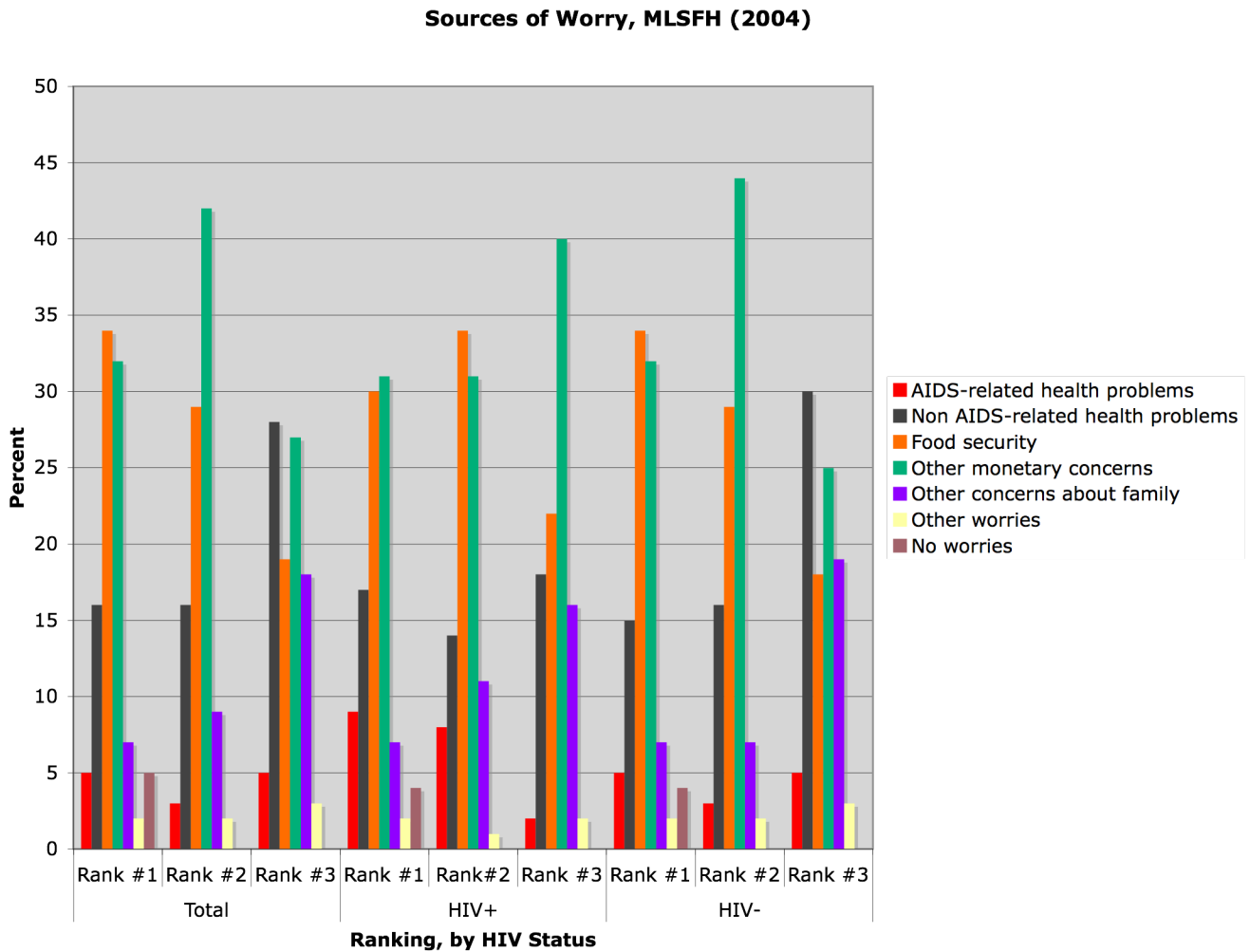
To address these limitations, we turn to data from rural Malawi. By combining data from several sources, we can provide a fuller—although still not complete—picture of the view from the perspectives of villagers.

### **Prioritizing AIDS in rural Malawi**

When respondents in the 2004 round of the MLSFH were asked to recall their major sources of worry in the past year, they primarily mentioned food security and other monetary concerns. Figure 6 shows that AIDS ranked low on respondents’ priorities, even among those whom the survey subsequently found to be HIV+ (the survey preceded the testing). Food security, money and health issues not related to AIDS

are the top three concerns, mentioned by more than 80% of respondents.

Figure 6: Top three sources of worry in 2004 for MLSFH respondents, by HIV status



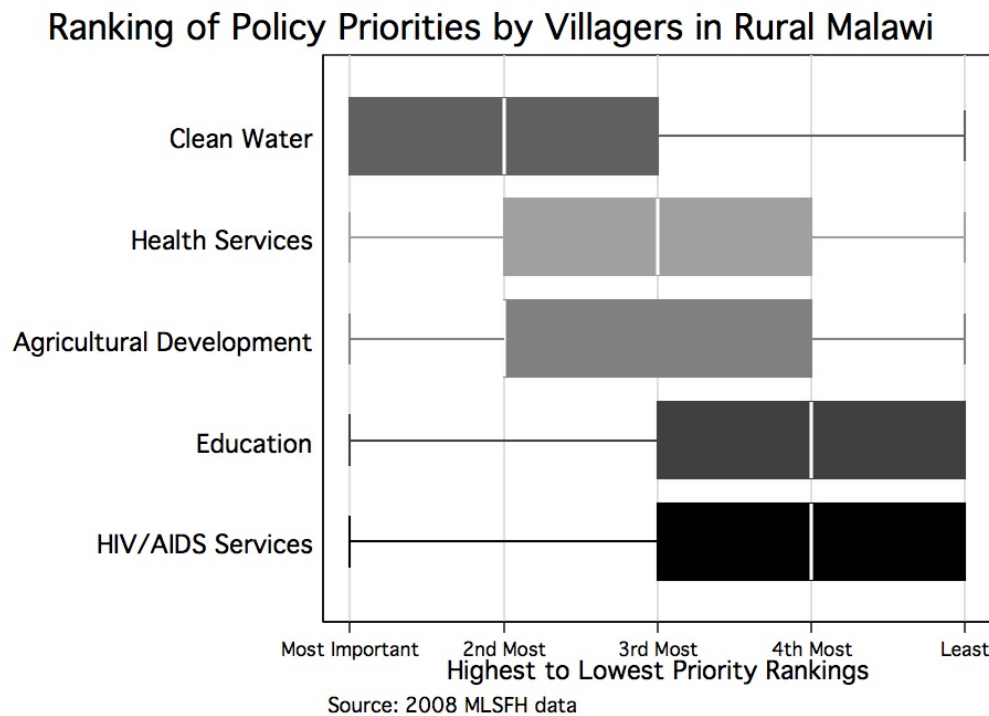
At the time of the 2004 round of the MLSFH, the primary AIDS services provided by government and NGOs—Nevirapine for pregnant women, HIV counseling and testing, and antiretroviral therapy--were available only through a few facilities with narrowly-defined target populations. By the most recent round 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 by 2008 far more respondents had come to appreciate AIDS services and will thus demonstrate stronger preferences for

13 The respondents’ low priority ranking for AIDS was not a demonstration of denial that AIDS is 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).

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. Figure 7, which presents boxplots of villagers' priorities, shows that AIDS services ranked last among the five options. Most important was Clean Water (average score of 2.0), followed by Agricultural Development (average score of 2.6), Health Services (average score of 2.9), Education (average score of 3.6) and, finally, HIV/AIDS services (average score of 3.8).

Figure 6: Ranking of policy priorities by villagers in rural Malawi (MLSFH 2008)



By 2008, most of the respondents had been tested at least once. The availability of HIV status for most of the respondents permits an analysis of policy priority by serostatus.<sup>14</sup> In Table 1, we see that 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.

<sup>14</sup> In 2004, 91% of respondents consented to HIV testing; of these, two-thirds received their results (the others were temporarily away at the time the results were available, had migrated or died, or had not wanted to know their results. For further details, see Onyango et al, 2009.

Table 1: Average scores of villagers' policy rankings, lower scores meaning more important

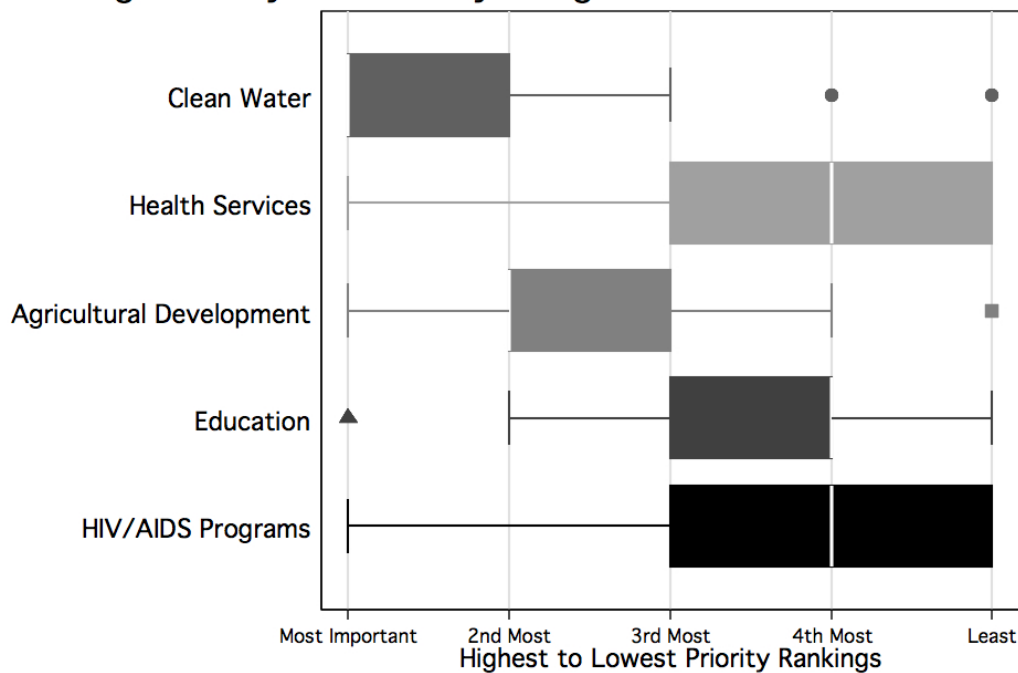
	Clean Water	Health Services	Agricultural Development	Education	HIV/AIDS Services
HIV-positive (n=123)	2.09	2.98	2.73	3.68	3.54
HIV-negative (n=2568)	2.00	2.96	2.61	3.57	3.86

Source: MLSFH (2008)

Prioritization of public policies by village headmen closely matched villagers' priorities. Figure 8 shows that headmen's first priority is the same as villagers: despite the dual responsibilities of the headmen to the government and to the members of their village, on average, they take the same side as the villagers in the debate over AIDS exceptionalism. Again, Clean Water (average score of 1.7) is the highest priority, HIV/AIDS Services the lowest. Although the headmen of all the villages were interviewed, HIV status is available only for those headmen who were in the MLSFH sample, and thus we cannot analyze headmen's priorities by their HIV status.

Figure 8

### Ranking of Policy Priorities by Village Headmen in Rural Malawi



Source: MLSFH (2008)

We have analyzed data from two waves of the MLSFH survey and from a survey of headmen. Despite differences in the wording of the questions in the MLSFH, a time difference of four years, and the differences between the MLSFH sample and the population of headmen, the answers are quite consistent. It may be, however, that the respondents in these two categories have not been completely frank.<sup>15</sup> Thus, before drawing firm conclusions about the policy priorities of rural Malawians, it is prudent to raise questions about the validity of the rankings presented above.

A characteristic of the interactions between the MLSFH research team and respondents is that respondents hope that their participation will benefit them materially (Swidler and Watkins 2009). In rural Malawi, there is a strong norm of reciprocity. Villagers see themselves, and are, as quite poor, whereas they perceive that Malawians working for the government or for foreigners are relatively wealthy, as indeed they are. Over and over, interviewers, supervisors and project ethnographers reported that people asked, “How will this benefit me?” Thus, in responding to questions that ask for their greatest problems or how they would rank their preferences for various interventions, they may be assessing what problem the wealthy are most likely to want to address and thus prioritize this problem in their reports.

Semi-structured interviews with the village headmen provide some elaboration of their rankings. Headmen were asked why clean water was such a high priority and both general health services and HIV/AIDS programs ranked so low. Headmen said that if there were clean water, the village would not need health services; further probing about people in the village sick with AIDS led one headman to point out that even those sick with AIDS need clean water to stay healthy (Dionne 2009b).

A second set of data collected by local ethnographers permit an indirect assessment of priorities. If the ranking of AIDS has been misreported in the formal context of a survey or semi-structured interviews, then we should find that when villagers talk with each other rather than with an interviewer with a clipboard or recorder, AIDS would be a more frequent topic of conversation than, say, topics that have to do with illnesses and deaths from causes other than AIDS, with the inadequacies of the school system, or with the difficulty of surviving on subsistence agriculture alone. We thus took advantage of another project, in which field assistants living in and around one of the MLSFH sites were asked to simply listen to conversations during the course of their daily lives—going to the borehole for water, riding a bus, walking to a funeral—and to recall and record in a notebook any conversations about AIDS (Watkins and Swidler 2009). In 2005, we also asked five of the field assistants involved in this conversational journals project to keep a log of conversations, regardless of topic, for seven days over a two-week period. Five assistants logged 113 significant conversations involving a total of 142 conversation partners with whom they spoke during the study period. We then coded the logs by topic.

Economic survival is the most frequent topic of conversation, accounting for 32% of the conversations.<sup>16</sup> Conversations about AIDS (coded as “AIDS”,<sup>17</sup> “Death”, and “Funerals”, accounted for 14% of the conversations; these included only a few conversations that mentioned the availability of free

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<sup>15</sup> Our comparative analyses of the MLSFH survey data with data from surveys in Malawi and in Kenya that were conducted by the Demographic and Health Survey have shown evidence of systematic misreporting (Miller et al. 2001; for other analyses of the quality of MLSFH data see Bignami et al. 2003 and Anglewicz et al. 2009).

<sup>16</sup> 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.

<sup>17</sup> Coded conversations for AIDS include: Girls/women are dangerous, Prostitution, Soldiers’ carelessness, and Free ARVs.

antiretroviral therapy or the costs and benefits of HIV testing. Conversations coded as “domestic matters” sometimes refer to AIDS in the course of talking about the behavior of others, such as stories about divorces and separations provoked by one spouse’s suspicion that the other spouse will “bring AIDS into the family.” Only if we include as an “AIDS conversation” the 26% of conversations coded as domestic matters, does AIDS surpass economic survival. The ranking of conversational topics is thus similar to the policy preference rankings of the MLSFH survey respondents in that other concerns appear to be more salient than AIDS, and far more important than AIDS services, while economic survival (which in these subsistence agricultural communities is related to Agricultural Development) ranks at the top.<sup>18</sup>

## DISCUSSION

This paper provides a new perspective on the debate over AIDS exceptionalism. This debate has been occurring far from the rural areas where most of the population of the countries profoundly affected by the pandemic live. Here we ask what position those most affected by AIDS would take in this debate, were they asked.

Our results support those who are critical of AIDS exceptionalism. 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. 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. A similar question asked of chiefs, with responsibility for the welfare of the whole village community, produced similar responses.

Qualitative data convince us that the survey rankings are reasonably valid. Interviews with chiefs provided insight into their reasoning: for example, they said that AIDS affected only a few but clean water is important for everyone. An analysis of the frequency of topics of conversations in local social networks supports these results: economic survival (i.e., money-related matters, but also food, famine, work and farming) dominates daily conversations, followed by various domestic issues in which AIDS only appears through association with other personal matters and through gossip about the scandalous sexual behavior of others, topics that would be of great interest even in the absence of AIDS.

These 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-day problems. It is not that rural Malawians do not understand that they are living through a major epidemic. As early as 1998, members of the MLSFH sample went to 3-4 funerals a month, they were skilled at distinguishing between deaths from AIDS and other causes, and they have been very worried about becoming infected (Smith and Watkins 2005; Watkins 2004). We can offer speculations

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<sup>18</sup> We note that in the previous year, 2004, there was considerable economic insecurity in rural areas due to a drought and high food prices.

as to why the villagers' perspective is so strikingly different from those in the international community who privilege AIDS above other health and development issues.

One line of speculation is that because the proportion of people who could benefit from two of the AIDS-related services that have received substantial amounts of funding, antiretroviral therapy and the prevention of mother-to-child transmission, while large relative to countries outside of sub-Saharan Africa is nonetheless relatively small compared to, say, those who would benefit from a reduction in the prevalence of malaria. In rural Malawi, about 7% of those who were tested for HIV by the MLSFH in 2004 were HIV positive. Of these, only a small proportion of the women are likely benefit from Nevirapine: they have to be pregnant, HIV positive, and attend a health facility that has the drug in stock.<sup>19</sup> Similarly, a small proportion of the 7% who are HIV positive have reached the symptomatic stage of AIDS where they are eligible for treatment. Rural Malawians are well aware that taking ART, while not a cure, can transform someone who is wasting away to their former self; they know that there is medicine for pregnant women to keep their baby from being infected. But unless they experienced the treatment themselves or knew someone they cared about who had, they are unlikely to value these services highly.

The third expensive AIDS service is counseling and testing for HIV, and the barriers to accessing testing are still substantial (Angotti et al 2009). More importantly, many are ambivalent about the value of testing for themselves. Here we draw on the conversational journals project, which began in 1999 and is still continuing. An analysis of the excerpts from the journals shows that when people talked with each other about testing, two-thirds of the excerpts were arguments against testing (Kaler and Watkins 2009). The most frequent (67% of the arguments against testing) were based on the speaker's assumption that he or she was surely already positive: confirming this was not only unnecessary but also would lead to such anxiety that one would die more swiftly. A fear of stigma following a positive diagnosis, often thought to be the major barrier to testing, accounted for, at most, only 9% of the objections to testing.

A second line of speculation is, ironically, related to the widespread dissemination of prevention messages. These have primarily emphasized abstinence, fidelity and consistent condom use. While rural Malawians talk in their social networks about the difficulties of following these messages, the MLSFH surveys show that for the past decade virtually everyone has known that were this advice to be followed, infection could be avoided. The conversational journals show that when people talk in their social networks about someone who appears to have AIDS, the specifics of physical and sexual histories often end with a moral. The moral is sometimes quite explicit: so-and-so was a womanizer and went to prostitutes but would never use a condom; thus, he deliberately chose death (Watkins and Swidler 2009). From that perspective, it would be unjust to shower resources on such people while so many lacked clean water.

A final line of speculation is that villagers recognize that though large amounts of money are said to be

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<sup>19</sup> In 2006, the last year for which data on prevention of mother-to-child transmission is available, only 57% of HIV positive women received Nevirapine, prophylaxis that reduces change of HIV transmission from mother to child. Of the 157 audited antenatal clinics in Malawi, half experienced stockouts of Nevirapine prophylaxis and 27 clinics provided *no* prophylaxis for HIV-positive expectant mothers the entire year (HIV Unit et al. 2007: 25-39).

available for AIDS, they expect little to reach them. A review of newspaper articles provides examples of spending for AIDS that must seem fantastical to villagers living on less than US\$1 a day (\$1=K140 at current rates). For example: “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 radio and newspapers, 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. So far little of the AIDS money has come to the villages to help with the costs of AIDS, such as transport to the hospital, funeral expenses, or school fees for orphans (Swidler and Watkins 2009)). Nor do rural Malawians expect that this would change if new resources were to come to the country for AIDS. The suspicion of corruption is widespread. For example, a field assistant riding a bus heard an old man talking to the other passengers: “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 for the patient suffering [from] AIDS” (Simon 18 March 2004).

In conclusion, we believe that in general rural Malawians have good reason to take a dim view of AIDS exceptionalism: they view other problems as more pervasive and more immediate than AIDS, and they perceive AIDS services have not yet been of great benefit and are not likely to be in the future. This is not, to say that we are convinced that they are right. Over the long run, a much higher proportion of the population will benefit from AIDS services than have already done so. Fewer children will be born HIV positive, more people will be tested and know their HIV status with greater certainty, and more will use antiretroviral therapy to postpone their death. Nonetheless, we think that a greater appreciation of the view from below that we have provided could be helpful to those who want to help those living in high HIV prevalence areas of Africa.

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## **DATA SHARING**

Afrobarometer data is publicly available at [www.afrobarometer.org](http://www.afrobarometer.org). All data from the MLSFH prior to data collected in 2008 are publicly available at [www.malawi.pop.upenn.edu](http://www.malawi.pop.upenn.edu), as are the conversational logs relevant to this paper and a collection of journals from the conversational journal project; the 2008 round of MLSFH data, including village headmen data, will be posted to [www.malawi.pop.upenn.edu](http://www.malawi.pop.upenn.edu) in 2010. Replication files are available from the corresponding author.

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All authors declare that the answer to the questions on your competing interest form are all No and therefore have nothing to declare.

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