Who Gets Antiretrovirals?: Perceptions of Access and Fairness in Malawi’s Option B+

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Introduction

Option B+, the policy that provides lifelong antiretroviral therapy (ART) access to all HIV positive pregnant or breastfeeding women, is being implemented across much of sub-Saharan Africa (The Interagency Task Team. 2015). The policy began in Malawi in 2011 due to a desire to simplify the prevention of mother to child transmission (PMTCT) protocols and to end the practice of frequently starting and stopping pregnant/breastfeeding women on ART common in high fertility contexts. Since then, and despite initial challenges (e.g., low retention (Tenthani et al. 2014)) and high human resources demands (Kieffer et al. 2014)), Option B+ has been lauded for reducing the vertical transmission of HIV, substantially increasing the number of people on ART and reducing horizontal transmission to HIV negative male partners (CDC 2013). To date, ten other African countries have adopted Option B+ and an additional eight are in the advanced stages of implementation (The Interagency Task Team. 2015).

In the years following Malawi’s transition to Option B+, there have been few voices of caution or critique. One exception is Coutsoudis et al. (2013b), which identified a number of ethical, medical, programmatic and economic concerns about the policy. The authors did not argue against the policy, but rather posit that in the face of so many unknowns, the widespread shift to Option B+ across the region was radical and premature. We agree that more scrutiny is needed. Considering that Option B+ completely restructures who can access ART—previously medicine was reserved for those with advanced infections, while now pregnant and breastfeeding women have priority—it is well worth examining the top down policy from the ground up.

One distinguishing feature of the AIDS epidemics in sub-Saharan Africa is that although women are more likely to be infected, men are more likely to die of AIDS (Dovel et al. 2015; Druyts et al. 2013). This is primarily due to men’s limited use of HIV services, ART in particular (Muula et al. 2007). Option B+ targets pregnant/breastfeeding women. In the high fertility contexts where the policy is most common and most appropriate (Coutsoudis et al. 2013a), women are frequently pregnant. Using data from the 2010 Malawi Demographic and Health Survey, we estimate that 80% of all women, and 59% of HIV positive women, between the ages of 20 and 44 had a live birth in the previous 5 years. Should these fertility patterns continue (and if anything, there is reason to believe that improved access to ART will increase fertility among HIV positive women (Myer et al. 2010; Homsy et al. 2009; Makumbi et al. 2011)), Option B+ would massively increase women’s—not just currently pregnant and breastfeeding women—access to ART.

It falls to social scientists to examine perceptions of policies within the societies they affect. Local perceptions need not trump epidemiological or medical concerns, but how a policy is perceived is constitutive of its ethics, as well as it odds of success. After all, a policy that is perceived as unfair or inequitable is unlikely to last.

In this paper, we return to the case of Malawi, where Option B+ started and has the longest history. We ask a population-based sample of rural Malawians about who has access to ART—specifically, which subpopulations are prioritized. Then we ask what, if anything, they would change about the current system of prioritization.

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1 Health status was measured either symptomatically using WHO staging criteria or (where available) through CD4 count machines, which assess the strength of the immune system. Patients who were WHO stage 3 or 4, or who had a CD4 count below a certain threshold (e.g., 350 cells/mm$^3$), could initiate ART.
Data and Methods
We use data from Tsogolo la Thanzi (TLT), a longitudinal population-based study in southern Malawi. In 2015, TLT conducted a ninth wave of data from respondents first interviewed in 2009. The TLT-2015 sample follows women and men first interviewed in 2009, a refresher/comparison sample of women first interviewed in 2012 (all ages 21-31), and the current male sexual partners of female respondents (N of present analyses: 1015 women, 851 men; data collection ended 9/2015 and we expect the final sample to increase by 20%).

TLT 2015 was conducted using face-to-face interviews entered onto tablets. In order to address questions about the perceived fairness of ART policy in Malawi, we implemented an interactive card-sort exercise. Interviewers presented respondents with six physical cards, each depicting a person with HIV (see Figure 1). These six individuals were a (i) sick man; (ii) healthy-looking man; (iii) sick non-pregnant woman; (iv) healthy-looking non-pregnant woman; (v) sick pregnant woman; and (vi) healthy-looking pregnant woman. Respondents were then asked to sort the cards into three piles: those who would (a) definitely get ART at the clinic, those who would (b) maybe get them, and those who would (c) probably not get them. Next, respondents were asked to order the six cards, placing the person who they thought would be most likely to get ART to the person who would get them last. Lastly, respondents were reminded that what actually happens in clinics is not always what one thinks should happen. They were asked, “if it were up to you, how do you think ARVs should be distributed?” Here, they could rearrange the cards from how they perceived clinics distributed them or leave them as they were. Although the level of abstraction in the task may be seen as challenging for a semi-literate population, our interviewers had extensive training on how to introduce and explain the tasks and respondents had completed card sort exercises in earlier TLT waves (see Frye and Trinitapoli 2015). Our analysis of notes interviewers were asked to write after the section indicates that only 5 of 1866 respondents had real difficulty understanding the task.

Figure 1. Depictions of cards used for card sort exercise, Tsogolo la Thanzi, 2015
Note: Original text in Chichewa and read aloud

Analytic Plan
Our analysis of the TLT data proceeds in three stages. First, we use these data to offer a thorough descriptive overview of how rural Malawians think ARVs are being distributed and how they should be distributed. Though simple, we see this as the most important aspect of our contribution. Given the vast literature on the disconnect between official health policies and local understandings of these, it is somewhat surprising that we are the first to have asked the question, “What do rural Malawians think is happening?” Second, we address the question of what is fair by describing and
analyzing the movement we observe between what people think is happening and what they think ought to be happening with respect to ART distribution. Third (not shown here but planned for the PAA presentation), we will employ optimal matching techniques to measure perceived fairness more rigorously and explore ideas about fairness in this context. We operationalize fairness as alignment between what is happening and what should be happening, where two identical sequences constitute perfect fairness and the level of distance between two sequences offers us a way to think about fairness not as a binary, but in terms of degree. We will explore whether fairness is more or less prevalent among those who understand the policy accurately or inaccurately. We will also examine differences by gender, by HIV status, and by recent pregnancy (a status that links women to basic antenatal care, and a subset of women to current PMTCT practices, including Option B+).

Results
Figure 2 presents an overview of local perceptions of who gets ART in Malawi. The six characters are categorized as definitely receiving ART (black), maybe receiving treatment (dark grey), or probably not getting the drugs (light grey). There are four notable patterns here: 1) both sick men and sick women are considered highly likely to get ART; 2) more men than women believe sick men and women will definitely get ART; 3) very few respondents imagine that healthy women or men can access ART; and 4) there is the least consensus about what happens to healthy pregnant women. In subsequent analyses, we discuss differences in these patterns by gender and HIV status; these suggest that HIV+ women are distinct (and more accurate) in their view of how ARVs are distributed, probably because they learn about the policy through their interactions with the health-care system. Because Option B+ has not been widely publicized, it is not surprising that men are less knowledgeable about the exception to longstanding rules about ART access through ill-health.

Figure 2. Perceptions of current ART policy, TLT 2015

Moving beyond the 3-levels of categorization, Figures 3 provides an illustration of how the current priorities of ART distribution are perceived, separately for men and women, using a sequence plot; this approach does not allow for ties but forces the respondent to distinguish among all 6 characters by ranking them 1-6. We see that in the vast majority of cases almost 3/4 (still majority for men but
not as many—just over 50%), sick pregnant women are ranked as highest priority. Both men and women know (with very few exceptions) that healthy men and healthy women get last priority (about evenly split for both men and women). As a rule, both men and women tend to prioritize sick people over healthy people, including the healthy pregnant women. More women than men know that healthy pregnant women trump sick men and sick women; men seem less aware that pregnancy trumps health status in the current set of priorities. In future analyses we analyze these patterns further by gender, HIV status, and socio-economic status.

Figure 3. Sequence plot of 10 most commonly perceived distribution of ART priorities

The simplest analytical lever on the perceived fairness of Option B+ involves focusing on the placement of the healthy-pregnant-woman card between the perceived-reality sequence and the how-things-should-be sequence. Independently of initial placement, movement of this card between sequences indicates whether the respondent believes healthy pregnant women should be prioritized over sick, non-pregnant people or whether symptomatic individuals should have priority. Consistent placement of this card (i.e., no change) is subdivided into two qualitatively distinct groups: 1) those who placed healthy-pregnant women in at least position 2 (usually after sick pregnant women) and left them there and 2) those who placed healthy-pregnant women lower than position 2 (necessarily prioritizing health status over pregnancy) and left them there. Table 1 shows that equal proportions of men and women (around 20%) shift healthy pregnant women up in the ranks when asked about how the world should be (categorization 1). About half this many demote healthy pregnant women in the rank when asked about how a limited supply of drugs should be distributed in a fair world. When considered together with groups who did not move the prioritization of healthy women, just over half of all women believe healthy pregnant woman should be a top priority or at least prioritized more than these women currently believe they are. Only 37% of men in our sample share that opinion.
Table 1. Preferred placement of healthy-pregnant women in queue for ART

<table>
<thead>
<tr>
<th></th>
<th>Move up</th>
<th>Move down</th>
<th>No movement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>High priority</td>
</tr>
<tr>
<td>Women (%)</td>
<td>21.7</td>
<td>10.6</td>
<td>28.5</td>
</tr>
<tr>
<td>Men (%)</td>
<td>19.5</td>
<td>9.2</td>
<td>18.9</td>
</tr>
</tbody>
</table>

Subsequent analyses of the difference between perceived priorities and will use optimal matching techniques to provide a) a descriptive overview of perceived fairness in this population, b) an account of what fairness looks like from a local view, and c) an analysis of socio-demographic differences in accurate understanding of and perceived fairness of Option B+ priorities.

**Discussion**

In this paper, we do not venture to determine what is fair or even what is medically ethical in terms of the allocation of life-saving resources in a context of scarcity. We do, however, argue that shifting priorities in health governance cannot be assumed to be effective unless and until they have been demonstrated as such and unless their implications resonate with local sensibilities. Our study’s contribution is the application of a local and population-based perspective to questions about the implications of shifting priorities in global health policy.
References


The Interagency Task Team. 2015. “Option B+ Countries and PMTCT Regimen.”