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## Access for all: contextualising HIV treatment as prevention in Swaziland

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### ABSTRACT

This article explores how notions of the individual and population are evoked in two ongoing HIV treatment as prevention (TasP) implementation studies in Swaziland. By contrasting policy discourses with lived kinship experiences of people living with HIV, we seek to understand how TasP unfolds in the Swazi context. Data collection consisted of eight focus group discussions with people living with HIV who were members of support groups to examine their perspectives about TasP. In addition, 18 key informant interviews were conducted with study team members, national-level policy-makers and NGO representatives involved in the design of health communication messages about TasP in Swaziland. Thematic analysis was used to identify recurrent themes in transcripts and field notes. Policy-makers and people living with HIV actively resisted framing HIV treatment as a prevention technology but promoted it as (earlier) access to treatment for all. TasP was not conceptualised in terms of individual or societal *benefits*, which are characteristic of international public health debates; rather its locally situated meanings were embedded in kinship experiences, concerns about taking responsibility for one's own health and others, local biomedical knowledge about drug resistance, and secrecy. The findings from this study suggest that more attention is needed to understand how the global discourse of TasP becomes shaped in practice in different cultural contexts.

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### KEYWORDS

Treatment-as-prevention; Swaziland; expectations; localisation; implementation research



### Introduction

This article examines tensions between notions of the individual and the population in policy-makers' and people living with HIV's expectations about HIV treatment as prevention (TasP) in Swaziland. The possibility of using HIV treatment as a prevention technology received vast scientific and political attention when the high-profile HPTN052 trial showed a significant decrease in sexual transmission of HIV through early use of antiretroviral therapy (ART) in serodiscordant couples (Cohen et al., 2011). "Early", also called "Immediate" ART, refers to starting treatment immediately upon diagnosis, instead of determining the start on the basis of disease progression and the status of the immune system (for which, in the past, CD4+ count was used as the key marker).

Modelling studies have suggested that expansion of ART coverage could also be effective in reducing transmission on a population level (Granich, Gilks, Dye, De Cock, & Williams, 2009). This hypothesis is currently under evaluation in over 50 countries and is

implemented through a variety of approaches to expand coverage, such as Universal Test and Treat (UTT) strategies which typically include repeated home-based HIV screening interventions, and less intensive efforts of offering immediate access to ART in routine health-care practice without employing population-wide HIV screening activities (Granich et al., 2011). During the first international TasP workshop organised in May 2011 in Vancouver, TasP was defined as "the secondary preventive benefit (as it relates to HIV and TB transmission) of expanding ART coverage among people living with HIV" (Granich et al., 2011, p. 447). Following this initial conceptualisation of TasP in global discourses, in this article, we consider TasP to be all approaches that involve expanding treatment (including UTT) which place an emphasis on using ART for secondary prevention purposes.

In the past years, substantive debates have taken place amongst scientists involved in TasP trials about the (lack of) evidence concerning the individual-level health benefits and risks associated with immediate initiation

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of ART in sub-Saharan Africa (De Cock & El-Sadr, 2013; Delva, Fleming, & Chingandu, 2013; Lundgren, Babiker, Gordin, Borges, & Neaton, 2013; Sigaloff, Lange, & Montaner, 2014). Sub-Saharan Africa has the highest number of HIV infections, estimated at 70% of infections worldwide (UNAIDS, 2015). It is also the place where international donors have invested the most in HIV research and interventions and consequently where the success of TasP on a population level is measured (Nguyen, 2015).

In September 2015, the World Health Organization stated that there is now sufficient proof that earlier use of ART results in better clinical outcomes for people living with HIV compared with delayed treatment and thus recommended immediate ART initiation irrespective of the stage of the disease or CD4+ count for adults, adolescents and children (World Health Organization, 2015). It was recently argued that debate over the individual benefits of early initiation has now been “settled” (De Cock & El-Sadr, 2016). However, little is known about how the scientific debates relating to early initiation and TasP were conceived of by projected users (people living with HIV) or those involved in its design and implementation.

In this article, we present insights from people living with HIV and key actors involved in designing health communication messages in two ongoing implementation studies that aim to understand the effects of early treatment in routine health-care practice in Swaziland. The two studies, initially known as TasP pilots, went through a cycle of name changes and are currently implemented as “Early Access to ART for All” (EAAA) through the *MaxART*<sup>1</sup> consortium and Médecins Sans Frontières.

Although the term TasP is no longer widely used in global health discourses, we (continue to) use it here because the term itself and the inherent significance it placed on the *collective* good have been central to emerging notions about the individual and population in our study context. Specifically we ask: how does the concept of TasP affect enactments of responsibility at the level of the individual and at the level of the nation state?

### Study context

The Kingdom of Swaziland is a country of around 1.1 million people located in Southern Africa. It has one of the highest HIV prevalences in the world, estimated at 26% for 15–49-year-olds (Ministry of Health, 2012). Multiple and concurrent sexual partnerships, age-disparate sexual relationships, income inequality, gender inequality and sexual violence and migration are cited

as key drivers of Swaziland’s HIV epidemic (National Emergency Response Council on HIV and AIDS [NERCHA] 2014). Prevalence is higher amongst women than men with the largest difference in prevalence amongst young women under 25 years old compared to young men (26% versus 5%, respectively) (Bicego et al., 2013). About 40% of the population is under 15 years of age, and 63% live in poverty (World Bank, 2013). ART only became available through the public sector in 2004, and the stark consequences of the HIV epidemic, such as accelerated death rates, drop in life expectancy, and increasing numbers of orphans, have been described as a humanitarian crisis (Whiteside & Whalley, 2007).

Ethnographic studies about the effects of HIV/AIDS on families in Swaziland illustrate how kinship ideals of caregiving, responsibility and affinal ties can be challenged and revalued during moments of destitution (Golomski, 2014; Reis, 2008). In idealised concepts of kinship and social organisation, a Swazi family is patrilineal, patrilocal and patriarchal (Kasenene, 1993). Marriage signifies the linking of two families, rather than two individuals, whereby in-marrying daughters-in-law pay deference to husbands and in-laws (Golomski, 2015; Kuper, 1986).

### Methods

The data presented here are part of a larger ethnographic study analysing social and political processes affecting the implementation of TasP in Swaziland. This article draws on qualitative data collected with people living with HIV and key informants in two phases. Between March and June 2013, we conducted eight focus group discussions (FGDs) with members of support groups for people living with HIV to understand the perceptions of people living with HIV about starting treatment early before the start of the EAAA implementation studies. We sampled purposively to select support groups that were meeting in or near facilities to be included in the EAAA study. Three FGDs were held at facility-based support groups, two of which were supported by UNICEF’s mothers2mothers programme, which provides mentoring services to pregnant women living with HIV. Five FGDs were conducted with community-based support groups affiliated with the Swaziland Network of People Living with HIV. In total, 88 respondents (71 women and 17 men) participated. Three short stories (“vignettes”) about hypothetical characters were used to guide discussion. The FGDs were conducted in siSwati by a research assistant and a note-taker. All discussions were audio recorded (after participants had consented), transcribed by the facilitator, and translated into English

by an experienced translator, whose translations were crosschecked by the facilitator.

The EAAA studies started enrolling patients in 2014 to evaluate the effects of offering early ART in selected rural public health facilities in two different regions in Swaziland. Because of the similarity in objectives and timing of the two studies, an effort was made to collaborate in terms of presenting a unified message about EAAA to the study populations. Purposive snowball sampling was used to select key actors involved in the studies' design of health communication messages. The first author conducted eighteen key informant interviews with EAAA study team members ( $n = 10$ ), national-level policy-makers ( $n = 6$ ) and NGO representatives ( $n = 2$ ) between February 2014 and February 2015. All key informant interviews were conducted in English, transcribed and coded by the first author and analysed using NVivo 10. Data were analysed thematically and themes were coded inductively. The analysis was guided by a grounded theory approach in which the conceptual framework is not generated from a prior hypothesis, but from the data itself (Green & Thorogood, 2004). The study received ethical clearance from the Swaziland Scientific and Ethics Committee and the Amsterdam Institute for Social Science Research Ethical Advisory Board at the University of Amsterdam. All participants gave verbal consent to record the interviews. Each respondent has been anonymised and is represented in this text by a code beginning with R.

## Findings

### Access for all – responsibilities at the national level

EAAA study team members and national-level policy-makers mentioned the annual TasP workshops in Vancouver and the HPTN 052 HIV Prevention Study as key moments in relation to the emergence of the term TasP. About half of the key informants interviewed had participated in international fora outside Swaziland in which TasP was discussed. Key informants interviewed used the terms “TasP”, “Test and Treat” and “EAAA” interchangeably to refer to offering early antiretroviral treatment to all HIV-positive individuals irrespective of their CD4 count or illness stage. One of the national-level policy-makers explained that the term TasP used by international organisations and scientists involved in the study design “hijacked” the national AIDS programme's own path towards upscaling access to treatment:

The name of treatment as prevention is new, relatively new since the HPTN 052 study, that is when treatment as prevention language came up, but prior to that we have been discussing as clinicians that what is the best standard to offer an HIV positive person, and we have always said that the best standard to offer an HIV positive person is to offer them ART. I still think it's unnecessary to use that term [treatment as prevention]. That's why I, eh, we had to insist that it's early access to ART for everybody, for all. (R12, female, policy-maker)

During the messaging development workshop jointly organised by the two studies to develop the study slogan and health communication materials, the term TasP was also critiqued for being unclear and potentially being seen as a substitute for condom use. For example, an EAAA study team member involved in the workshop argued;

Treatment as Prevention, though we still know it's Treatment as Prevention but we then ended up coming up with Early Access to ART for All, that would be more acceptable ... because if you put it as Treatment as Prevention then you would be opening some doors for people not using condoms. (R02, male, EAAA study team member)

The reluctance to promote treatment as a potential HIV prevention technology was often related to memories about the communication strategies for a previous HIV prevention campaign focusing on male circumcision. The campaign slogan “Circumcise and Conquer” (*Soka Uncobe*) was believed to have indirectly encouraged reckless behaviour among circumcised men and their sexual partners (Adams & Moyer, 2015).

Furthermore, *Soka Uncobe's* international donor misunderstood how authority in Swazi society is structured and consequently how decisions at the individual level were made. A policy-maker involved in the male circumcision campaign explained:

There are causes for *Soka Uncobe* not to work: it was foreign, and the way it was foreign, it was not easy for a local Swazi to accept it. Because they came with the idea of a movement, to say this will be a movement and they will just tell the king to tell every man to circumcise. Never in the history of Swaziland a king has actually told anyone to do anything in treatment, in health issues, nor in agriculture issues, nor in works or whatever I can mention ... And then came the white people who wanted to talk to the [Swazi] people and went around all over [Swaziland] themselves. I said you guys look this is not the way to do it. Go with us [Ministry of Health] not alone but they didn't want to listen. (R16, male, policy-maker)

The policy-maker points at a common misconception of Swazi leadership, including Kingship, as top-down and absolute. Swaziland has a dual monarchy, the King is regarded as “father” and his mother, the Queen Mother,

as the “mother” of the nation (Matsebula, 1972). The duality of governance at the level of the nation state rests on the division between one arm led by the King in council with the Prime Minister and another arm led by the King (*Ingwenyama*) in council with the chiefs. Together, they share the responsibilities of governance, and the King rules through them. Chiefs are described in the Swaziland constitution as “father[s] of the community” (Root, 2014). Like fathers, they are responsible for the well-being of their dependents (residents of their chiefdom). As the policy-maker quoted above points out, the male circumcision campaigns failed to effectively consult the chiefs. In contrast, one of the main activities undertaken by the EAAA team in their community mobilisation work was to visit all chiefdoms and to seek approval for the study. During such visits, great effort was made to have an official representative of the Ministry of Health present, whereby the Ministry recognized the fatherly role of the chiefs. Reflecting on how the government officials explain the EAAA study to the chiefs in such meetings, a study team member involved explained:

For the community, they [Ministry of Health] tried to put it into the context for the community to understand like, they take them back down memory lane to say what are the effects of HIV that you have witnessed since 2003? They [the community] tell you people were dying every hour, we had so many orphans. And then they [Ministry of Health] try to link that to EAAA, what do you think now, if all those relatives of ours who were dying had started treatment on time, and they get better, what happens to the orphans, what happens to the mortality rate. So it's sort of like to say it's something that can aid to, apart from reducing the mortality, even the development of the country. Each parent would grow up seeing their own kids, looking after their own kids. (R07, female, EAAA study team member)

The EAAA studies purposely avoid using the term “TasP” and prevention benefits of early ART are not made explicit in study flyers developed to inform study communities: “Early Access to ART for All suppresses the virus, if ART is taken correctly and consistently for life and is used together with condoms”. However, during the exchanges with chiefs and other members of the study communities, questions around viral suppression and condoms use were often asked. During such exchanges, members of the EAAA study team shared information about the secondary prevention benefits of ART whilst at the same time stressing condom use.

Hence, apart from the concerns about the name of the study, the channels and approach through which information was communicated to the population were also seen as part of the responsibility of the government. The following quotation from a study team member

involved in community mobilisation activities illustrates the relation between the importance given to the study slogan and the responsibility of the nation state:

One of the challenges was that you [Government of Swaziland] have allowed people to die, why didn't you see this as a strategy that would work, why did we [Swazi nation] have to lose so many lives of the Swazi's and now you are coming in to say treatment is also a prevention strategy, why wait until now. So which is why then Early Access to ART for All becomes friendly because if you say Treatment used as Prevention, people will turn around and say look at the life expectancy in Swaziland, it dropped from 60 something to I think 43. Why did we have to wait up to that level? (R11, female, EAAA study team member)

### **Responsibility at the individual level**

In our discussions with people living with HIV who are part of support groups, it seems that motivations of starting ART early were shaped by realities of Swazi kinship relations, in particular marriage. Marriage is considered a permanent contract and the production of children is an essential fulfilment of the women's part of the contract (Kuper, 1986). Rights of fatherhood are acquired through bride price (*lobola*) transactions of cattle (or cash equivalent to cattle) from the man's to the women's family. By paying *lobola*, children are made legitimate and become entitled to the benefits of the father's lineage and provide women with a valued status in the community and future security, which make divorce difficult and rare (Kuper, 1986). Data from the most recent Demographic and Health Survey show that only 3% of women and 4% of men were divorced or separated, and 18% of currently married women are in a polygynous union (Central Statistical Office, 2008).

In the narratives of support groups members, particularly those of women, we found a recurrent theme about (broken) trust in relation to motivations of starting ART early. For example, a female participant in a facility-based group argued:

My husband knows that I take them [ART]. You hear him say that you smell of ARVs. On the issue that the chances of infecting others will be reduced, that will demand that people be faithful, as long as people are unfaithful, I don't see it working. Because he will sleep around without a condom and come back with a drug resistant virus ... as a wife [I tell you]: Mind your own life, worry not about him sleeping around. (F05)

Another female in the same support argued:

I tested before and I was HIV negative. We continued having sex without a condom. When I told him

[husband] to use it, he refused and said 'I will use the condom when I'm with my secret lover (*Makhwapheni*), I paid *lobola* [bride price] for you and you still belong to this household' ... After 7 months I did another test and I was diagnosed HIV positive. I was so stressed. I spoke with the nurse and she tested both of us and we were confirmed HIV positive. (F03)

Although participants argued that condoms were not used consistently, especially in marriage, the possibility of perceiving ART as prevention conflicted with grave fears of acquiring drug resistance. Participants referred to current HIV counselling messages that emphasised the particular importance of condom use when one is on ART to avoid infection with a drug-resistant HIV strain.

Today, we know that when I am on treatment and my partner is not, I infect her with a worse HIV strand and you may find that by the time she starts the treatment her HIV strand might be drug resistant, deeming the treatment ineffective, and [she] ends up dying. (M5)

Finally, one of the main motivations support group members expressed about starting ART early was to avoid being *seen* to be sick:

I remember in our chief's places we, HIV positive people, were given free Mealie Meal [milled maize], they [neighbors] would ask me; "Why are you queueing for the sick people's food because you are not sick!" I started my treatment before I fell sick, so most people don't know, they never saw me coughing. What I mean is that people will agree [to start ART early] because they don't want to fall sick when everyone points a finger at you. (F02)

Describing HIV treatment as a method of prevention thus conflicted with lived kinship experiences as well as the lay biomedical knowledge about drug resistance. Rather than being concerned with individual or population benefits, participants' stories were also about survival due to access to ART and about caring for one's partner and others in new socialities such as support groups.

## Discussion and conclusions

Our data suggest that policy-makers and people living with HIV resisted the TasP terminology by framing it as (earlier) access to HIV treatment for all rather than HIV prevention. Locally ascribed meanings were concerned with taking responsibility for one's own health in which taking TasP did not fit in well with local biomedical knowledge, kinship dynamics and secrecy. At the national level, policy-makers' careful navigation of the study slogan, messages and approaches to community mobilisation enacted the responsibility of the state as

the provider for the Swazi nation. The fact that the study name highlighted access to treatment for all was thus important in order to convey the continuity and responsibility of the government for the nation.

Insights into discourse making are important because they unveil the processes and rationalities that shape how public health interventions are translated into practice. Furthermore, they help us to understand how and why TasP can be explained differently in specific country contexts. Indeed, how systems, institutions and structures deal with the reframing of meanings and associations traditionally ascribed to HIV treatment that is increasingly seen as prevention is a key domain of enquiry for social sciences (Keogh & Dodds, 2015). In this regard, our findings illustrate the importance of understanding local meanings ascribed within such a reframing, which is not always dominated by similar concerns about benefits or interests.

In a review of acceptability studies of TasP by HIV-positive individuals, the three included studies (carried out in Australia and the USA) provided scarce information about how TasP was explained to and perceived by study participants (Young & McDaid, 2014). A qualitative article exploring perceptions of TasP among communities affected by HIV in Scotland found that participants struggled with the re-framing of HIV treatment as a prevention method because they felt that it was hard to believe that someone living with HIV might not be infectious (Young, Flowers, & McDaid, 2015).

This article addresses a gap in research on the views of people living with HIV about TasP in resource-poor settings. Our discussions with support group members indicate that the meanings of TasP and starting ART early (before one becomes visibly ill) are incorporated into existing socialities such as kinship relations, and should be seen in relation to specific local moral worlds (Mattes, 2012). Other ethnographic works in African contexts reveal similar tensions between individual risks and benefits and collective or public goods in global health research (Reynolds, Cousins, Newell, & Imrie, 2013; Stewart & Sewankambo, 2010). Furthermore, our findings indicate that early access to ART does not preclude other structural challenges faced by people living with HIV, such as poverty, stigma and secrecy, also noted in other resource-poor settings (Moyer, 2015).

Research about different biomedical HIV prevention technologies, such as vaginal microbicides (Montgomery, 2012) and pre-exposure prophylaxis (Rosengarten & Michael, 2009), has shown that such technologies embody normative projections about future users, which may not translate between locations. In a similar

way to what Rosengarten and Michael (2009) describe about the consultations and research informed by the “expectations of community opposition” in PrEP trials, the multiple uses of TasP, especially its form as a secondary prevention method, disappeared into the background.

Our findings contribute to an understanding of such translations by paying critical attention to the specificity of context in TasP implementation. Additionally, we show how the acceptability of public health interventions by intended beneficiaries can be improved by understanding locally framed responsibilities.

## Note

1. MaxART (Maximizing ART for Better Health and Zero New HIV Infections) is a multi-disciplinary consortium consisting of the Government of Swaziland (Ministry of Health), Stop Aids Now; the Clinton Health Access Initiative, Global Network of People Living with HIV; Swaziland Network of People Living with HIV; Southern Africa HIV and AIDS Information Dissemination Service; National Emergency Response Council on HIV and AIDS; South African Centre for Epidemiological Modelling and Analysis; and the University of Amsterdam.

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## Disclosure statement

No potential conflict of interest was reported by the authors.

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