Reframing HIV treatment as prevention in eSwatini

Transformations of a public health intervention in context

Vernooij, E.

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Transformations of a public health intervention in context

Eva Vernooij

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Eva E. Vernooij

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Reframing HIV Treatment as Prevention in eSwatini

Transformations of a public health intervention in context

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Faculteit der Maatschappij- en Gedragswetenschappen

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CHAPTER 1

Introduction

The Kingdom of eSwatini[1] has the world's highest HIV prevalence rate, estimated at 27% among 15-49 year olds (UNAIDS, 2020). Since the first HIV infection was diagnosed in 1986, eSwatini has experienced a steep rise in HIV infections which succumbed to a generalized epidemic, with a reported 46% of households having at least one HIV positive member in 2017 (Government of the Kingdom of Eswatini, 2019). Over the last decade, eSwatini has become a key site for public health interventions aiming to control the epidemic and international global health research evaluating different HIV prevention strategies (Adams & Moyer, 2015; Bärnighausen et al., 2019; Mkhwanazi, 2020; Walsh et al., 2017). One such intervention was the *early* initiation of antiretroviral therapy (ART) by people living with HIV, which aimed to improve their clinical outcomes while yielding the additional benefit of preventing onward transmission once viral suppression is achieved, also known as HIV treatment as prevention (TasP) (Granich et al., 2011). "Early" ART, also called "immediate" ART, refers to starting HIV treatment as soon as possible upon diagnosis instead of on the basis of disease progression and the status of the immune system. In eSwatini, the roll-out of early ART was accompanied by different mixed-methods implementation studies aiming to evaluate early treatment initiation and its social, economic, epidemiological, and health system effects in different regions and among different population groups (Adams & Zamberia, 2017; Khan et al., 2020; Parker et al., 2015).

One of these studies was carried out by the *Max*ART (Maximizing ART for Better Health and Zero New HIV Infections) program, a multi-disciplinary consortium, which conducted a research project to examine the "real world" impact of the early initiation of ART through its implementation in a government-managed health system (Walsh et al., 2017). As one of the anthropological researchers working within the *Max*ART study team between 2012 and 2018, I examined the design of the research project and the rollout of early ART in health facilities and study communities to investigate how the intervention was understood, framed, and used by both its designers and users. Throughout my six-year engagement with *Max*ART, the research project was transformed from a "HIV treatment as prevention proof of concept study", focused on evaluating the impact of early ART on reducing new infections, into the Early Access to ART for All (EAAA) study, and was introduced in study communities as a new approach to HIV care (SAN! and CHAI 2010, 32).

In this thesis, I provide an ethnographic account of the transformation processes through which TasP, as a public health intervention, was shaped and reshaped in context at different levels: in policymaking; in the health system; and by its users living in study communities, people living with HIV, and support group members. Doing so, I seek to contribute to social science—particularly anthropological—explorations of how contexts and phenomena (in this case TasP) reciprocally shape each other (Bond et al., 2016a; Brives et al., 2016; Dilger & Hadolt, 2020; Dilley, 1999). Furthermore, this thesis aims to provide insights relevant to public health research and implementation science that seek to better understand how local contexts affect the delivery and outcomes of TasP in various countries,

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[1] In 2018, the country's name was changed from Swaziland to eSwatini [Place of Swazi] by King Mswati III to mark 50 years of independence from British rule. In this thesis I primarily use the new name, eSwatini, but as fieldwork was conducted prior to the name change, some chapters refer to the country as Swaziland.

which is considered a “top implementation science priority for the next decade” (Brault et al., 2020, 249; Perriat et al., 2018).

Social science studies of biomedicine and technology in Africa have examined the different kinds of transformations that occur when biomedical interventions travel through and across varying social contexts.[2] Anthropologist Vincanne Adams argues that over the last decades a transformation has occurred within the field of practice now commonly referred to as Global Health,[3] which she calls the “scientization” of public health (Adams 2013, 60). The scientization of public health insists that public health interventions increasingly need to be *evidence-generating* interventions, meaning that they must prove that they achieved success because it was designed as an experiment using statistical techniques to guarantee generalizability. This development results, according to Adams, in an erosion of the need to examine how interventions fit (or do not fit) within local contexts and how those contexts mediate intervention success or failure, which were areas of rich ethnographic work in international health and development in the past (Ferguson, 1994; Justice, 1986). In response, Adams and Biehl (2016) called for anthropologists to adopt a “critical global health” perspective to study the experimental contexts of evidence-generating interventions whilst questioning interventions’ underlying logics and critically assessing their (unintended) consequences (for examples in the field of HIV, see Benton, 2015; Biruk, 2012; Crane, 2013; Lorway 2017; McKay 2018, Mkhwanazi 2020; Nguyen 2015).

A common theoretical focus in critical ethnographies of global health is to study how people *respond* to incoming technologies. This approach emphasizes the generative effects of interventions on new ways of being and relating to oneself and others in specific social contexts, often employing a Foucauldian perspective to study the effects of disciplinary power on local populations (e.g., Igonya 2017; Kenworthy 2017; Mattes 2011; Nguyen 2010; Prince 2014). In this thesis, rather than focusing on the experimental underpinnings of how evidence is generated and its effects, I examine how interventions are transformed *in situ* (through their implementation) in eSwatini. So doing, I reveal not only the ways in which people respond to interventions, but also how interventions are actively shaped by political, temporal and organizational dynamics of the implementation process. Thereby, I seek to contribute new (medical) anthropological insights into how the contextualization of interventions is done and how this can be investigated through the integration of ethnographic research within the rapidly growing field of implementation science in global health.

The five empirical chapters of this thesis, published as articles in both anthropological and public-health-oriented journals, reflect the dual positioning of this thesis, couched as it is between anthropology and public health. Together, the chapters reveal the locally specific framings, dynamics, and practices through which TasP,[4] and associated interventions,

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[2] See for example; Both 2017; Laet and Mol 2000; Hardon & Moyer 2014; Montgomery 2012; Muller-Rockstroh 2011; Nguyen 2009; Twagira 2020; Wendland 2010; but this is a non-exhaustive list.

[3] In the twenty-first century the term Global Health has emerged as a field of expertise concerned with “the *global* connectedness of disease and of the people that govern and respond to them”, which before was referred to as “international”, “world”, or “tropical health” (Yates-Doerr & Maes 2019: 1).

[4] I chose to use the term TasP in the introduction and discussion of this dissertation as it was this term which sparked debate in eSwatini in the early stages of the implementation study regarding the need

evolved and are transformed in context. Besides local contextualization, I show how a research project is adapted to temporal shifts in global health research and (inter)national HIV policy changes, which affect how implementation science is practiced and for what purpose(s) it is used. This thesis thus takes a "critically applied[5]" approach (Scheper-Hughes, 1990; Whitacre, 2019) to studying the making of public health interventions, highlighting the influence of national-level policymakers, local health workers and community-based actors, people living with HIV, support group members, as well as anthropologists as active co-constructers of public health interventions rather than passive recipients or critical observers outside of it.

The overall objective of this thesis is *to examine the transformation processes through which HIV treatment as prevention became shaped and reshaped in context in eSwatini.* The five chapters discuss transformations of TasP at three different levels; in policy discourse[6] (chapters 2 and 6), in the public health system (chapter 3) and within the EAAA study communities (chapters 4 and 5). Together, they seek to answer the following research questions: What kind of political dynamics and temporal circumstances shaped the introduction of TasP in eSwatini? How do local health workers frame and integrate early ART in counselling messages? How does the implementation of early ART affect (dis)engagement by HIV-positive people with HIV treatment and support group transformations in study communities?

In the remainder of this introduction, I first explore the emergence of HIV TasP as a global public health strategy, then offer a background of the *Max*ART program and an overview of the historical, social, and political-economic structures underlying the HIV epidemic in eSwatini. Subsequently, I position this thesis in relation to critical medical anthropological research about biomedical interventions and explore different disciplinary approaches to studying context and contextualization processes. Finally, I discuss the different phases of data collection; the main research sites, people, and collaborations involved; and end with an outline of the articles that comprise the chapters of this thesis.

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for adaptation of this popular global health discourse to better "fit" the country context. In chapters 3 and 4 the terminology "test and treat", "test and start", and "universal test and treat" are used to refer to the intervention of starting ART as soon as possible upon diagnosis, which resemble the more commonly accepted terminology in policy circles and public health journals throughout the later stages of the implementation study. More recently, the term TasP has started to regain popularity and is reappearing again in public health publications (see for example Brault et al., 2020).

[5] A "critically applied" medical anthropology approach was proposed by medical anthropologist Nancy Scheper-Hughes (1990) as an alternative for the "clinically applied" medical anthropology as practiced by physician-anthropologists during the early years of the discipline's inception in the 1960s. A critical applied approach, she argued, should strive towards calling into question the "commonsense grounds and assumptions upon which biomedical knowledge and practice is build" (Hughes 1990, 191). The term "critically applied" anthropology has recently been taken up by Ryan Whitacre (2019) and others in a special issue concerned with understanding what such an approach might offer for bridging the scholarly divide between "applied" and "critical" anthropology in anthropological engagements with biomedical interventions such as HIV pre-exposure prophylaxis (PrEP). For other recent critical reflections about the co-construction of anthropologists to Global Health, also see McKay (2019) and Yates-Doerr & Maes (2019).

[6] With policy discourse I refer to the way "policy actors socially and publically define and handle problems" (Kroesen & Broër 2009, 195).

The emergence of HIV treatment as prevention as a global health strategy

Since the discovery in the 1980s that the human immunodeficiency virus (HIV) is the causative agent of acquired immunodeficiency syndrome (AIDS), the disease has attracted a tremendous amount of scientific attention from a plurality of disciplines within the social sciences, humanities, and biomedical sciences (Fajardo-Ortiz et al., 2017). The development in 1996 of combination antiretroviral therapy (ART), which involved three different medicines that together dramatically reduced HIV/AIDS-related illness and death, was a significant landmark in the history of the disease (Lange & Ananworanich, 2014). The life-prolonging antiretroviral drugs work by controlling the replication of HIV in the body, which allow the immune system to recover and halt, or at least delay, the progression from HIV to AIDS (Rosengarten, 2009). However, in the first years after the discovery of effective HIV treatment, ART was primarily accessible in high-income countries, and was scarcely available in other parts of the world, as it was estimated by UNAIDS that nearly 8,000 people per day died of AIDS in the "developing world" (T' Hoen et al., 2018; UNAIDS, 2000). By the year 2000, two-thirds of the world's people living with HIV resided on the African continent, but less than 1% had access to ART in the sub-Saharan African region ('t Hoen et al., 2011). Debates about treatment access among policymakers and Western scientists at the time were shot through with doubts and anxieties concerning the ability of impoverished African patients to be "adherent" to treatment—that is, to take the antiretroviral drugs consistently and on time (Crane, 2013; Hardon & Dilger, 2011; Kinsman, 2008). Failure to do so could produce drug-resistant virus strains, which might render treatment ineffective.

When at the beginning of the new millennium global AIDS activism drove down the prices of generic antiretroviral drugs, large-scale ART provision became a real possibility for African countries (Kinsman, 2008). Increasingly, HIV/AIDS became framed as a humanitarian emergency demanding global intervention by the newly established Global Fund to Fight AIDS, Tuberculosis and Malaria; the Clinton Health Access Initiative (CHAI); and the US President's Emergency Plan for AIDS Relief (PEPFAR), by former US president Bush, which provided much of the financial basis for implementing the scale-up of HIV treatment throughout sub-Saharan Africa. By 2008, nearly 3 million people were on ART in sub-Saharan Africa, representing an unprecedented intervention by foreign governments and international non-governmental agencies (Nguyen, 2009). However, still only 44% of people living with HIV in the region who were in need of treatment, according to the World Health Organization's (WHO) standardized guidelines, had access (WHO, 2009). Since the publication of the first standardized WHO ART guidelines in 2002, recommendations to start HIV treatment were based either on clinical staging[7] or on CD4 cell count diagnostic tests (if available). CD4 counts indicate the strength of the immune system; as HIV destroys CD4 cells (a type of white blood cell), the number of CD4 cells usually drops as the HIV infection progresses. Between 2002 and 2009, the WHO recommended starting HIV treatment if the CD4 count was below 200 cells/mm^3 or in clinical stage 3 or 4. In 2010,

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[7] The WHO system refers to "four hierarchical clinical stages ranging from stage 1 (asymptomatic) to stage 4 (AIDS). Patients are assigned to a particular stage when they demonstrate at least one clinical condition in that stage's criteria" (Weinberg and Kovarik 2010, 203).

an updated WHO guideline recommended starting ART if the CD4 count dropped below 350 cells/mm^3, a measurement primarily informed by the results of a randomized clinical trial that showed that earlier treatment was beneficial for the person living with HIV as it reduced the mortality rate by 75% (WHO, 2010).

In subsequent years, the further scale-up of HIV treatment became increasingly advocated, not only because of the life-prolonging potential and health improvement benefits associated with starting treatment at higher CD4 counts, but also because of the possibility to prevent onward transmission. The biology behind using HIV treatment as prevention is based on ART's ability to suppress the amount of HIV virus in blood (the viral load), a principle that has been used in programs focused on the prevention of mother-to-child HIV transmission since 1994 (Connor et al., 1994) The possibility of using ART to prevent onward sexual transmission has been a topic of many, mostly observational, research studies (see Attia et al., 2009; McNairy et al., 2013 for review articles). The term treatment as prevention (TasP) itself has been claimed and promoted by a group of biomedical researchers from the British Columbia Centre for Excellence in HIV/AIDS under the leadership of Dr. Julio Montaner, who has been conducting epidemiological modeling to investigate the population effects of the expansion of HIV treatment in Canada's BC province since the mid-1990s (Montaner et al., 2006). In 2010, Montaner and colleagues published results from their province-wide study, which showed that as ART treatment expanded, HIV incidence decreased; but, since their report was based on an ecological study, causality could not be established. Still, the BC center registered the term "TasP" as a form of intellectual property, apparent from its use of the circled R symbol on its website, where TasP is referred to as "made-in-BC" strategy.[8]

The study which became regarded globally as a scientific landmark providing the biological rationale that ART can prevent sexual transmission, was the multi-site clinical trial HPTN 052 (Cohen et al., 2011). Conducted in nine different countries across four continents, the HPTN 052 trial showed that among 1,763 serodiscordant couples there was a relative reduction of 96% in the number of linked HIV transmissions in the early therapy group in which the HIV-positive partner started ART when having a CD4 count between 350–550 cells/mm^3. This was compared with the delayed group, who started ART when their CD4 count fell below 250 cells/mm^3 (Cohen et al., 2011). In 2011, the HPTN study was selected as the annual scientific breakthrough by the journal *Science*, and commended for its "profound implications for the future response to the AIDS epidemic" because it provided definitive proof that "HIV treatment as prevention works" (Cohen et al., 2011). But whilst the HPTN 052 data provided the biological rationale of using treatment as prevention on an individual level, this did not prove that the scaling up of ART would reduce HIV incidence at the population level (see Nguyen 2015 for a critical analysis of the construction of TasP as a global health strategy).

The epidemiological basis for TasP came from a group of researchers working for the World Health Organization who developed a mathematical model suggesting that "mass

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[8] http://www.bccfe.ca/tasp/about

treatment" could eliminate HIV incidence to below 0.1 % per year (Granich et al., 2009 but see Velasco-Hernandez et al., 2002 for an earlier version of this idea). The model predicted that annual universal voluntary HIV testing for every person older than 15 years and the immediate starting of ART (instead of waiting until the CD4 count to drop below a specific threshold) for individuals diagnosed with HIV would eliminate the HIV epidemic within 10 years. They called this approach "test and treat." The WHO's test and treat model generated a lot of interest among scientists and policymakers, but also critiques from epidemiologists regarding the unrealistic assumptions underlying its design—e.g., the assumption of a 100% uptake of annual HIV testing (Wilson, 2009). Some questioned its limited "real-world" applicability in relation to under-resourced health systems in sub-Saharan Africa, where health workforce shortages, weak laboratory infrastructure, and fiscal constraints would limit the feasibility and sustainability of mass treatment (De Cock et al., 2009). Others called the test and treat strategy "extremely radical", criticized its focus on a "medical intervention for public health benefits rather than individual patient's benefits" (Garnett & Baggaley, 2009: 10), and pointed out risks of drug toxicities, especially when given to immunocompetent individuals who would not otherwise require treatment.

In 2010 the WHO and UNAIDS launched the "Treatment 2.0" initiative, which involved a range of technological interventions to address concerns about the implementation of TasP in under-resourced settings. The initiative aimed to "catalyze the next phase of HIV treatment", through "innovation and efficiency gains" to "maximize the preventive benefit of antiretroviral therapy" (WHO, 2011: 3). This approach proposed a range of efficiency measures and managerial solutions to simplify the regulation, procurement, supply, and use of HIV treatment. This was to be achieved through the research and development of "smarter and better pills" and the introduction of task-shifting procedures and point-of-care diagnostics (as substitutes for laboratory infrastructure). These would allow more people living with HIV to be initiated on HIV treatment, specifically in under-resourced settings. This meant that the scale-up of ART was not necessarily only about one single intervention or about providing earlier access to ART; it was about the incorporation of a range of new biomedical technologies (such as viral load testing), health system management ideologies about efficiency and innovation, and new social forms (including community-based adherence clubs, discussed later on).

The notion of mass treatment and the political framing of HIV as a disease that could be eliminated in the near future also sparked a lot of debate among social scientists. Scholars warned that the emphasis on promoting biomedical technologies as key to HIV prevention overshadowed the necessity to address the underlying social and political-economical structures affecting HIV acquisition and transmission (Nguyen et al., 2011; Kippax and Stephenson 2012). Consequently, HIV prevention is reframed as an exclusively biomedical matter and other preventative measures are being discredited. Others asserted that TasP contributed to the medicalization of HIV prior to sickness by regarding people as ill before diagnosis or when still asymptomatic (Sugarman 2013). Such critics suggested that antiretroviral medicines were being equated with healthcare, an example of what Biehl (2007, 1086) called the "pharmaceuticalization of public health." Other critiques were based on the possible social impact and ethical underpinnings of population-based experiments involved in TasP, as well as and the geopolitical stakes underlying its arrival as a global health strategy beyond its scientific rationale (Lachenal 2013; Nguyen 2015). Generally, social scientists often took a critical stance and called for a skeptical approach to studying the social consequences of TasP and the "political economy of hope" it generated (Dodds 2013). In a position paper about TasP, the Global Network of People Living with HIV (GNP+) stated that "the primary purpose of ART for someone who is HIV-positive is to benefit their own health; preventive benefits are important but secondary considerations," and that "science is still unclear as to whether HIV treatment over 350 CD4 delivers net benefit or net harm," betraying a rather cautious stance of global HIV activists towards TasP (GNP+ 2012, 2). Social science scholars working alongside TasP trials in African countries warned for a possible "responsibilization effect" occurring alongside of TasP, whereby promotion of early ART might lead to placing (more) blame and responsibility on the HIV-positive individual for preventing HIV transmission (Bond et al., 2016b, 432). Social scientists studying attitudes towards TasP in high-income settings, where access to immediate treatment and viral load testing was more readily available, showed that health providers and people living with HIV reported ambivalence regarding starting HIV treatment solely to achieve preventative benefits (Newman et al., 2015 and Young et al., 2015). Yet qualitative research conducted in Australia showed that there was also enthusiasm about TasP among people living with HIV, related to a possible de-stigmatizing of serodiscordant sexuality and possibly reframe this as safe and legitimate (Persson 2016).

These critiques and uncertainties notwithstanding, mass treatment and the powerful rhetoric of elimination encouraged a surge of over 50 research projects aiming to test the effectiveness of TasP in the real world, of which the majority took place in Africa (Granich et al., 2011). The main objectives of such studies were to understand the feasibility, acceptability, cost-effectiveness, and impact of early initiation of ART on HIV incidence, mortality, ART adherence, retention in care, and drug resistance in different study contexts (e.g., resource-poor vs resource-rich settings, clinical trials vs implementation studies) and among different populations (key populations vs the general population). One of the studies was undertaken by the *Max*ART program in eSwatini, which positioned itself amid other ongoing TasP evaluation studies in the region as a study designed to answer "critical implementation questions" and "determine the 'real-world' potential of this new prevention intervention" in the context of a government-managed healthcare system (Walsh et al., 2017, 6).

Implementation of TasP in the real world: The MaxART program in Eswatini

The Kingdom of eSwatini is a small landlocked country, bordered by South Africa and Mozambique, with a population of just over 1 million, of whom the majority are young (56% are <25 years) and living in rural areas (76%) (Central Statistical Office 2019). Eswatini is a former British protectorate and attained independence from the United Kingdom in 1968. It has since been governed through the *Tinkhundla*[9] [constituencies] political system. This system is characterized by a decentralized dual-government structure, with the "modern"

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[9] The word *Tinkhundla* (plural of *Inkhundla*) means "communal meeting places or centres" (Mamba 2006 in Marrengane 2021).

arm run by the prime minister and the "traditional" arm run by the chiefs, who report to the king and his mother, called the queen mother, who rule together in a dual monarchy (Matsebula 1987). Administratively, the country is divided into four regions sub-divided into 55 constituencies. Each of these comprise a cluster of chiefdoms or royal villages[10] [*Imiphakatsi*] headed by a chief or prince. Whilst elections are held every five years and allow constituents of each *Inkhundla* to elect a local representative to take a seat in parliament, the monarchy appoints many of the members of the executive, legislative, and judicial branches, including the prime minister, making the country to be widely referred to as Africa's "last absolute monarchy" (Golomski 2015). At the local government level, the chiefs (also referred to as "traditional leaders"), who assume their position through hereditary right rather than elections, have considerable power not only politically, but also in socio-economic terms (Simelane et al., 2012). They are responsible for the distribution of Swazi Nation Land, which includes nearly half the country's land, itself held in trust for the nation by the king (Rose 1992). Furthermore, chiefs, together with their advising councils, are regarded as the "custodians of Swazi culture," and are increasingly being targeted by health interventions (including *Max*ART HIV-related interventions [Simelane et al., 2012, 12]) as key to promoting the uptake of biomedical health services in local communities.

Whilst historically the king and the queen mother have been regarded as symbolic parents of the *emaSwati* [the people referred to as "ethnic Swati," who make up the majority of the population) and are considered of emotional and spiritual importance to the wellbeing of the nation, the current King Mswati III has faced legitimacy problems since he was crowned in 1986 (Kuper 1986; Reis 1996). The royal family's growing economic prosperity and their control over the country's main industries (including sugar and minerals, as well as several media companies) stand in stark contrast to the precarious livelihoods of the majority of the population, of whom 59% are estimated to live below the national poverty line (earning less than US$1.9 a day) (WFP 2021). Especially in rural areas, where agriculture forms the backbone of the economy and 70% of the population engages in subsistence farming, production is often not enough to meet household food needs (Madonsela 2006). The high levels of income inequality and high unemployment rates, especially among youths (15–24 years), of whom 47% are unemployed (CSO 2019); the enduring HIV epidemic; and the lack of democratic freedoms have been linked to growing anti-monarchy sentiments and pro-democracy protests[11] (IPSS 2021).

In 1986, the first HIV-positive sample was drawn from a patient admitted to the large mission hospital in the city of Manzini, the commercial hub of eSwatini. Since laboratory infrastructure was limited at the time, blood samples were taken to South Africa for HIV

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[10] Royal villages date back to pre-colonial times and were established by former King Mswati II (1840–1868) to facilitate greater control by the royal family over the periphery, which acted as a form of royal bureaucracy (Khoza 2002).

[11] Past pro-democracy protests in eSwatini (of which most prominent occurred in 1994/1995 and 2011) were generally led by trade unions, yet protests from May 2021 onward have been more fragmented in terms of leadership and generally youth-led. They were sparked by the unclear circumstances related to the death of a student and a government-issued decree banning Swazi citizens from delivering petitions to their local *Inkundhla*, and have involved violent confrontations with police and security forces (IPPC 2021 and Cabrita 2021).

testing until a team of Ministry of Health staff, trained in HIV testing in Sweden, subsequently established in-country HIV testing services in Manzini (Dlamini 2015). In 1987, the Ministry of Health created an AIDS task force consisting of medical doctors, lab specialists, and health educators, which became known as the Swaziland National AIDS Programme (SNAP) and would lead the health sector response to HIV and AIDS in the coming decades. In the early years of the epidemic, before ART became available, SNAP focused efforts on increasing HIV-related health services; facilitating health education; encouraging behavior change; and organizing education sessions for traditional leaders and healers, industrial companies, and schools (Kanduza 2003). In 1989, a group of people living with HIV organized themselves in the Swaziland AIDS Support Organization (SASO) and, supported by SNAP and international NGOs, started sharing their testimonies in communities with the aim of reducing stigma and fighting discrimination. But it was only in the late 1990s that AIDS became an undeniable and tangible reality: the number of deaths rose exponentially and AIDS patients filled the majority of hospital beds, with industries affected because of sickness absence. In 1999 King Mswati III declared HIV/AIDS a national disaster (Kanduza 2003).

Subsequently, an additional national governance body was established, the National Emergency Response Council on HIV/AIDS (NERCHA) to coordinate a multi-sectoral response to HIV and AIDS and channel funds received from the prime minister's office and the Global Fund to various HIV organizations in the country. NERCHA listed behavior change as its main priority and focused most of its resources on education, awareness creation, and individual-level interventions (Hickel 2012). According to economic anthropologist Jason Hickel (2012), this led to a de-politicizing of HIV and AIDS and overshadowing of historical and economic structures underlying HIV transmission, including the colonial and post-colonial underdevelopment, the collapse of subsistence agriculture, and the nation's continuous economic dependence on migrant labor under poor conditions in the South African mining and sugar industries (see also Packard 1984). Yet the response to the epidemic became highly politicized when, during the early 2000s, the king implemented ceremonial chastity rites (from 2001– 2005), known as *Umcwasho*, as a form of HIV prevention. This involved a ban on sexual intercourse for young women aged between 15 and 19 years. If caught "in action," the involved male would be fined a cow by their community. The king himself was also fined as he chose five new wives during this period, some of whom were below 19 years old (Kandaza 2003; Reis 2008; Golomski 2019). Social anthropologist Casey Golomksi (2019) has suggested that, since the *Umcwasho* intervention, HIV-related global health discourses increasingly started implicating the Swazi kingship as a problem of gender and, by extension, "Swazi culture" as a main contributor to HIV transmission.

Only in 2003, ART started to become available free of charge in the public sector, after the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreements were lifted, allowing countries to import generic antiretroviral drugs, but until 2006 it was only provided in 14% of eSwatini's health facilities (WHO 2008). Before that time, some SASO members were able to access ART by enrolling in a private clinic in Mbabane, which established the first ART pilot programs in the early 2000s (Matsebula 2014). In 2004, mortality rates started dropping (van Schalkwyk et al., 2014), but the number of new infections (incidence) remained high for many years (Bicego et al., 2013). The decentralization of ART at primary-care level resulted in a need to expand the healthcare workforce. This was made possible through task-shifting initiatives and the introduction of a new cadre of lay health workers, the "expert clients"; people living with HIV who assisted with counseling, ART initiation, and adherence monitoring (Dlamini-Simelane & Moyer 2017a). This helped to increase the number of people initiated on ART, but it could also negatively affect the quality of care provided in some facilities (Ibid). Anthropological research has shown, however, that among adults and adolescents, despite greater access to HIV testing and antiretroviral therapy during the early years of HIV treatment scale-up, HIV stigma has persisted and that by disclosing their HIV status people would risk their "economic livelihood, marriage, friendship, dignity and life itself" (Root 2010, 535). Women (and married women in particular) appeared to be at greater risk of losing their livelihood after HIV status disclosure due to the organization of kinship and marriage systems (Shabalala et al., 2016; Dlamini-Simelane & Moyer 2017b).

MaxART

*Max*ART (Maximizing ART for Better Health and Zero New HIV Infections) was a partnership between the government of eSwatini, the Dutch nongovernmental organization Aidsfonds (previously called Stop AIDS Now!), and the American agency Clinton Health Access Initiative (CHAI). The partnership aimed to increase access to antiretroviral treatment in eSwatini to improve clinical outcomes for people living with HIV and reduce new infections. The initiative for *Max*ART was originally conceived by Aidsfonds around the time at which the World Health Organization (WHO) and the Joint United Nations Programme on HIV and AIDS (UNAIDS) presented their Treatment 2.0 framework in 2010. Aidsfonds was created in 1985 by a group of gay men from Amsterdam who started a fundraising campaign to support their friends dying from AIDS (Aidsfonds 2021). Since then, Aidsfonds has evolved into a large organization that funds research, interventions, and "innovative community solutions" that seek to improve the rights and health of communities infected and affected by HIV (Ibid, 7). CHAI was founded in 2002 by former US president Bill Clinton and adopts a "business-minded approach" by working closely with national governments, regulatory agencies, and the pharmaceutical industry to increase access to HIV treatment and other biomedical products, resembling the UNAIDS Treatment 2.0 model. In 2011, Aidsfonds, CHAI, and the eSwatini Ministry of Health jointly wrote a proposal and received 8.8 million euros from the Dutch Postcode Lottery Dream Fund to achieve their goal of maximizing ART. With a diverse range of organizations[12] involved, the *Max*ART consortium embarked on a six-year program broken into two phases. The key activities and actors involved in the different phases of *Max*ART are depicted below in a schematic (figure 1).

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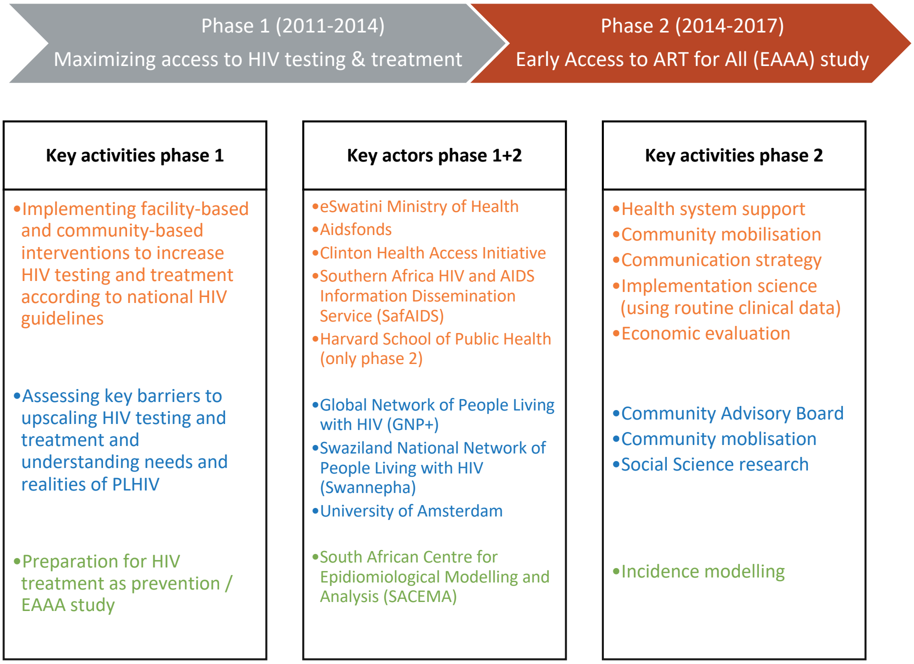
[12] The *Max*ART consortium is comprised of Aidsfonds, Clinton Health Access Initiative (CHAI), Swaziland National Network of People Living with HIV (SWANNEPHA), the Global Network of People Living with HIV (GNP+), the South Africa Centre for Epidemiological Modelling and Analyses (SACEMA), the Southern Africa HIV and AIDS Information Dissemination Service (SAFAIDS), and the Centre for Social Science and Global Health (SSGH) at the University of Amsterdam.

The first phase (2011–2014) involved a range of “demand creation” interventions to increase the uptake of HIV testing and ART initiation across the country’s four geographic regions. These interventions followed the national HIV treatment guidelines, which at the time recommended initiating ART at CD4 counts below 350 cells/mm^3 or at clinical stage three or four. Whilst Aidsfonds provided overall guidance to the *Max*ART program from the Netherlands, CHAI coordinated *Max*ART in eSwatini and increased access to ART through a range of managerial, technological, and health system interventions. For instance, it purchased and organized the rollout of CD4 point-of-care diagnostics and nurse-led ART initiation schemes, to facilitate and accelerate HIV treatment initiation. It also introduced a suite of business innovation techniques called Fast Track into communities to, in 90 days, solve “well-defined challenges” (Walsh et al., 2020, 3), defined by *Max*ART as the low uptake of HIV tests by men and adolescents. CHAI had a close working relationship with the Swazi Ministry of Health, with which they collaborated on several other projects related to the procurement and supply chain management of antiretroviral drugs, the elimination of malaria, and health sector reform. During *Max*ART meetings, CHAI staff often sat next to the Ministry of Health’s policymakers, arrived early at meetings so as to prepare the government’s PowerPoint presentations and talking points, and acted as liaisons between other *Max*ART partners and the Ministry of Health.

The primary demand-creation activities at the community level were organized by the Southern Africa HIV and AIDS Information Dissemination Service (SafAIDS), which conducted country-wide community dialogues and HIV literacy training for local community leaders so as to increase demand and support for HIV testing and treatment. The responsibility of the Swaziland Network of People Living with HIV (SWANNEPHA), the national umbrella organization for HIV support groups, was to inform partners of the “human rights and needs” of people living with HIV and to make sure demand-creation interventions were designed accordingly. To achieve this, the organization carried out a large-scale survey of 900 people living with HIV, of which nearly half were approached via the organization’s affiliated support groups (SWANNEPHA and GNP+ 2014). Additionally, SWANNEPHA conducted focus group discussions within the support groups to gauge members’ interest in forming “community ART adherence clubs,” a new ART delivery model first introduced by Médecins Sans Frontières (MSF) in Mozambique in 2008 and further developed in South Africa (Decroo et al., 2011). The community-based clubs were designed to make drug refills easier for HIV-positive people who were considered “clinically stable” on ART while simultaneously decreasing the workload of health workers, which was inflated due to the increase in people eligible for ART in facilities following treatment scale-up interventions (Venables et al., 2019).

Besides the research conducted by SWANNEPHA, anthropological researchers employed by the University of Amsterdam undertook long-term ethnographic studies to understand how social structures (namely gender and kinship) affected the uptake of HIV testing and treatment under then-current treatment guidelines (Adams & Moyer 2015; Shabalala 2017; Dlamini 2017). They also gathered opinions and expectations regarding the future implementation of TasP (Adams and Zamberia 2017). Furthermore, the South Africa Centre for Epidemiological Modeling and Analyses (SACEMA), was responsible for developing an epidemiological model to analyze and predict the effects of TasP (to be implemented in *Max*ART's second phase) on HIV incidence, mortality, and morbidity using the routine data collected in government health facilities. All seven organizations met bi-yearly in eSwatini to present their work and discuss progress and ongoing challenges in face-to-face meetings, often chaired by policymakers from the Swaziland National AIDS Programme (SNAP).

Figure 1: Schematic *Max*ART program

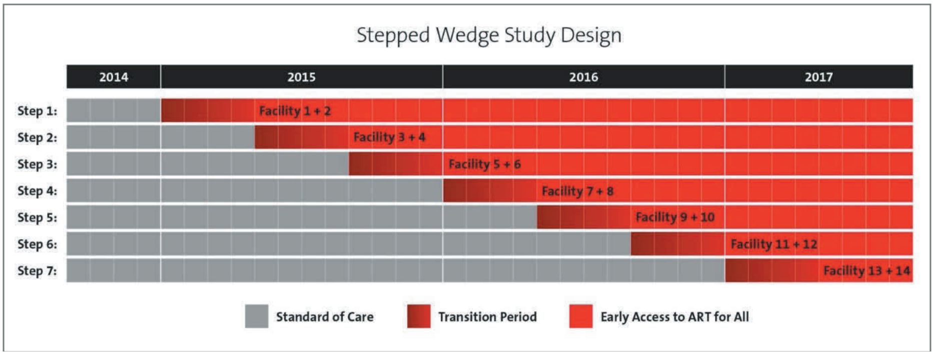


(Graphic by author)

The second phase (2014–2017) of the *Max*ART program consisted of a three-year research project named "Early Access to ART for All" (EAAA) that took place in one of eSwatini's four geographic regions: Hhohho region, located in the north west of the country. The EAAA study's overall aim was stipulated in the research protocol as follows; "to generate the evidence needed to more fully understand what is required to successfully implement an EAAA strategy in a public health sector in sub-Saharan Africa" (Walsh et al., 2017, 2). The research project was designed to assess the impact of providing early access to ART on retention in care (measured by whether an individual was still on ART after 12 months) and viral suppression versus the then-current CD4 threshold-based treatment guidelines (Walsh et al., 2017). The EAAA study was conducted in 14 government health facilities in the northern Hhohho region that had been purposely selected for certain features (e.g., having at least one nurse trained to initiate HIV-positive patients on ART). Additionally, the selection of the region and participating study facilities was influenced by a desire to avoid overlapping with other TasP-related intervention studies focused on improving ART initiation and retention (McNairy et al., 2015) and with early initiation for pregnant and breastfeeding women implementation studies (Parker et al., 2015 and DiCarlo et al., 2019). The EAAA target population was made up of adults (18 years of age and older) and excluded pregnant and breastfeeding women.

As opposed to the traditional parallel-arm Randomized Control Trial (RCT), in which an intervention is compared across two separate "arms," the EAAA study adopted a stepped-wedge cluster design in which all clusters (consisting of paired health facilities) eventually receive the intervention; only the timing when they receive the intervention is randomized (see figure 2 for the EAAA study design). The stepped-wedge design has been a common method of implementation science in under-resourced settings because it is regarded as a means to improve equity and the acceptability of an intervention that has been shown to be effective (Yapa & Bärnighausen 2018). However, whether early treatment had in fact already been proven effective was still a topic of scientific debate at the start of the EAAA study. There were several large RCTs ongoing in the region designed to assess the clinical benefits and harms associated with starting ART immediately after diagnosis (Lundgren et al., 2015; Temprano 12136 ANRS Study Group 2015). In 2015, early study results from one of these trials showed a reduction in HIV mortality and morbidity in the early ART group, after which the WHO released early guidance that stated that ART initiation should be initiated for any person living with HIV at any CD4 count, which they referred to as "treat-all". The change in WHO guidance has been described in policy circles as ushering in a new "era": the treat-all era (Fox and Rosen 2017).

Figure 2: EAAA stepped wedge study design



(Source: Walsh et al., 2017: 4)

The EAAA study was overseen by the primary research team (PRT), which consisted of the Principal Investigator (PI), who was the director of the Swazi Ministry of Health's National AIDS Programme (SNAP), and co-investigators of the seven different *Max*ART consortium organizations involved, as well as additional international biostatisticians and public health researchers from Harvard University, who assisted with the study design and statistical analysis of research findings. The day-to-day implementation of the EAAA study was coordinated by CHAI and carried out by the extended research team (ERT), which consisted of the coordinators of the seven consortium organizations in which I participated as the social science research coordinator. The ERT first met weekly and later bi-monthly at the CHAI office in Mbabane, the country's capital, to discuss study enrollments, updates, and challenges. As the social science research coordinator (employed through the University of Amsterdam), I was part of a team that conducted mixed-methods research in a selection of study facilities and communities (further discussed in the Methods section). Other research undertaken consisted of implementation science (using routine data collected in the participating health facilities that related to a range of clinical and health system-level outcomes[13]), economic evaluation, and epidemiological incidence modeling (Walsh et al., 2017). Whilst the collection of routine clinical data was referred to as "implementation science" by *Max*ART, this was not reflected in *Max*ART's primary outcome measurements, which focused on assessing the impact of early ART on retention in care and viral suppression rather than analyzing the underlying processes, reasons, and mechanisms that may have explained the (un)successful uptake of early ART. The social science research (conducted independently of the clinical research team) was expected to provide insights into the "black box" of implementation processes and suggest useful strategies for improving intervention uptake.

One of the self-defining features of the EAAA study was that it aimed to evaluate the implementation of TasP in a *government-managed* setting rather than a clinical trial setting in which additional resources, infrastructures, and interventions are added to improve the care provided. The question of what the optimal standards under which to implement TasP *were* led to various discussions among consortium partners. Whereas SWANNEPHA was keen to improve psychosocial support and community-based structures to support people living with HIV's engagement with early ART (for example by forming community adherence clubs), such additions were seen at the time by the Ministry of Health as being beyond the scope of the national standard of care, meaning they were not to be included in evaluations of the implementation of EAAA within government settings. Except for three nurses employed as "clinical mentors" by the EAAA study, who alternated their visits between 14 facilities to support study enrolments, no additional health workers were placed inside the study facilities in order to avoid ameliorating the national standard of care. Data clerks traveled each week from CHAI's office in Mbabane to the 14 study facilities to extract the routine data available in the paper-based chronic care files filled in by the facility staff. Yet several diagnostic infrastructures necessary to measure the study outcomes, such as viral load testing and resistance testing, were not routinely accessible via eSwatini's governmental health system. These were subsequently added for study purposes. Because of limited laboratory capacity at the national reference laboratory, viral load samples were analyzed by Médecins Sans Frontières in the southern region of Shiselweni, where they conducted a

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[13] Primary outcomes were retention in care and viral suppression. Secondary outcomes were mortality; visit adherence; drug resistance; tuberculosis; ART uptake; cost per patient per year; patient satisfaction; provider satisfaction; and patients' employment, income, and education (Walsh et al., 2017).

similar EAAA implementation study. Midway through the study, an EAAA laboratory specialist was hired to support the national reference laboratory to start implementing a centralized and routine viral load-monitoring system. Additional point-of-care CD4 machines were also purchased by *Max*ART in order to decrease the loss of valuable study results (as blood tests results were repeatedly lost during the transfer of samples from facilities to regional laboratories). Drug resistance testing was not available anywhere in the country, and therefore blood samples were shipped to the TasP® laboratory of the British Columbia Centre for Excellence in HIV/AIDS in Canada.

The ways in which the EAAA study was run mimicked the strictly controlled governing and scientific principles common to RCTs. The EAAA study was overseen by several bodies advising, reviewing, and evaluating its implementation, including an international scientific advisory board, a data safety monitoring board, a national-level policy advisory group, a study steering committee, and a local community advisory board (CAB). Furthermore, the order in which each health facility transitioned to the intervention (offering early initiation of ART) was randomized, and the health workers, study participants, and majority of the research team were blind to the timing of the transition. This was to control the behavior of health providers, study participants, and part of the study team. As a result, rather than conducting country-wide demand-creation activities, as was done in the first phase of *Max*ART, the activities of the community level-focused organizations SafAIDS and SWANNEPHA were re-termed "community sensitization" and constrained to a 20–30 km radius around each study site. Community adherence clubs were not implemented so as to prevent "contaminating" the study. The sensitization activities involved meeting with local leaders and so-called community resource groups (e.g., community health workers and HIV support group members) of each chiefdom in the catchment area of the study facilities to announce the study and discuss any concerns. Furthermore, SWANNEPHA conducted human rights training sessions related to EAAA for its affiliated support groups and managed the community advisory board (see Mlambo et al., 2019 on the *Max*ART CAB). All these various activities were meticulously planned in an implementation schedule outlining the weekly activities of each organization for the next three years, and were coordinated via the EAAA research manager seated at CHAI. As the blinding process of the intervention was impractical for the different implementation teams, several of the extended research team coordinators, including myself, managed to convince the study management to unblind us as to the transition order, reflecting differently positioned consortium members and their power to enact changes.

Contextualizing biomedical interventions: Science, politics, and knowledge transformation

Whilst HIV treatment as prevention (TasP) is considered a new global health phenomenon, the public health "test and treat" strategy of mass screening and collective treatment has been a common medical strategy of colonial medical services to treat infectious diseases (including malaria, sleeping sickness, yaws and syphilis) since the early twentieth century (Lachenal 2013). Colonial test and treatment programs had racial underpinnings and relied upon coercive measures to treat colonial populations, writes historian of science Guillaume

Lachenal (2013). These test and treat programs functioned as *exceptional* operations, supported by special funds and staff, governed with ad hoc laws, and operating largely independently of other health services, resembling in these ways the exceptional status of HIV in global health funding today (Benton 2015). The relationship between biomedicine and governance has been a focal area of critical medical anthropological studies of biomedicine, HIV, and global health in Africa (and beyond) (Decoteau 2013; Crane 2013; Hardon 2012; Mkhwanazi 2020; Montgomery 2010; Nguyen 2005; Prince & Marsland 2013). Many such studies have analyzed biomedical interventions through the lens of what Foucault termed "biopolitics" or "biopower"—"a power over life" constituted by techniques of disciplining and surveying the biological processes of individual bodies and whole populations (Foucault 1976, 243). In the field of HIV, this has evolved into a rich body of ethnographic work examining how HIV-related biomedical interventions (e.g., adherence counseling or viral load tests) have the potential to engender new ways of relating to oneself (subjectivity) and to produce biosocial collectives oriented around forms of self-care (Biehl 2007; Igonya 2017; Kenworthy 2017; Mattes 2011; Nguyen 2010 and 2013; Prince 2014; Race 2001). Yet, many (post-) Foucauldian social studies of biomedicine also caution against making reductionist claims that suggest that "interventions simply produce disciplined subjects, simply *work*" (Geissler, Rottenburgh, & Zenker 2012, 11). Rather, they direct attention to the agency and creativity of actors who participate in the shaping and reshaping of biomedical interventions in particular social contexts (Gerrets 2012; Hardon 2012; Leach & Fairhead 2011), as well as toward the incompleteness of any disciplining project, particularly in some African countries where the power and reach of the state are limited (Kelly 2012; Kenworthy 2017; Lachenal 2013; Street 2014). Furthermore, critical studies of international development and biomedical research illustrate how interventions are designed with particular assumptions, logics, and dreams underpinning them, and explain how these often obscure the historical and social conditions underlying the problem the interventions aim to target, possibly contributing to their failures (Adams 2016; Crane 2013; Ferguson 1994; Mosse 2013; Mkhwanazi 2020). For example, Nolwazi Mkhwanazi (2020) argued that the dream of "total control" (141) by international agencies over a mass male circumcision campaign in eSwatini in 2011, framed as an emergency intervention and defined by an obsession with reaching targets and limited input from local staff and national governmental actors, contributed to the failure of the campaign, with less than 10% of the target population circumcised.

Besides studying the biopolitical dimensions of biomedical interventions, social scientists have highlighted social, cultural, temporal, and historical circumstances that inform how people respond to and appropriate (new) biomedical knowledge, technologies, and global health interventions, which are often reinvented and re-signified in multiple ways during their travels in and through contexts of scarcity (Hardon & Moyer 2014; Desclaux 2014). For example, in her study on how people living with HIV in Senegal responded to recurring policy changes related to the prevention of mother-to-child HIV transmission, Alice Desclaux (2014) argued that such responses were shaped by whether people belonged to an HIV social network, their social and gendered positioning in society, and their economic situation. Other anthropologists studying the acceptance and understanding of long-standing medical research programs in the Gambia have illustrated how parents participating in vaccine trials reinterpreted some elements of the trial within their own understandings of infant care, revealing interactions between new biomedical knowledge and existing public framings and forms of healthcare practices (Fairhead et al., 2006). These same researchers noted the importance of comprehending the healthcare delivery context in which research is conducted, as well as the historical legacy of past interventions, which was found to influence people's perceptions of research and care.[14] Based on their readings of how people respond to new biomedical knowledge and health interventions, Leach and Fairhead (2007, 4) suggest one helpful analytical strategy: focusing on the "forms of knowledge, value and social commitment—that people bring to an issue, and which shape their anxieties about it, whether positive or negative," which they refer to as "framings" of an issue. They argue that it is crucial to analyze how different framings of a problem interact and shape each other. In doing so, the focus is shifted from an analysis of the power of textual framings, a common approach of "framing theory" as it is used in various social science disciplines (Entman 1993), to an understanding of how particular framings of a problem translate into action.

Building on these insights, I seek to explore the contextual framings actors bring to TasP and explore how these shaped and reshaped what TasP is in practice(s). Whilst *Max*ART's EAAA study was primarily a research project, rather than looking at knowledge *production* processes, the focus of this thesis is about knowledge *transformation*—i.e., how the notion of TasP was given different meaning(s) at different levels by national and local actors involved in the design and implementation of the EAAA study. Rather than following the science and politics through which HIV TasP became constructed as a global public health strategy (this has already been done by Nguyen 2015), I examine the ways in which TasP was constructed at the grassroots level and the framings that eSwatini-based actors—in particular state-level policymakers—brought to the issue. These national-level governmental actors, as Eileen Moyer (2019) argued, have often been left out of anthropological analyses, which have focused on translating between the "global" and "local" players. This thesis thus focuses on the *praxis* of how knowledge gets translated into interventions—that is, the processes and acts through which it is shaped and comes to be (van Bemmel 2017, 14). Hence, rather than taking what might be considered a top-down Foucauldian approach to studying transformations of disciplinary power through which global health interventions affect local populations, this thesis takes an empirical bottom-up approach to studying the praxis of knowledge transformation so as to assess how TasP was constituted in the Kingdom of eSwatini and the kinds of ambiguities this constitution exposed regarding the practices and use of implementation research (chapters 2 and 6), (dis)engagement with HIV treatment (chapters 3 and 4) and transformations of support groups as (bio)social forms (chapter 5). Together, the chapters reveal the potential and limitations of the disciplinary effects of biomedical interventions and the disconnections between the promise of TasP as a global pathway to the elimination of HIV and the precarious everyday living conditions

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[14] Also noted in other ethnographies of biomedical research in Africa, such as Kelly (2012), Reynolds et al., (2013), and Geissler (2011).

of HIV-positive and HIV-negative people in eSwatini, for some of whom HIV has remained a disease that can be anticipated rather than prevented.

Theoretical perspectives: Context and contextualization across different disciplines

One key concept in this thesis, as well as in both public health and social science studies of health interventions, is the notion of *context*[15]—yet what context is and exactly how it matters are often not made explicit in analyses of health interventions (Paparini et al., 2021; Greenhalgh & Manzano 2021). Brives et al., (2016) distinguish three different ways scientists approach context when analyzing biomedicine and evidence-based practices: either as *representational*, *interactional* or as *ontologically multiple* (170). In renderings of context as representational (characteristic of public health research, especially those conducted in controlled settings), context is regarded as something separate from and outside of an intervention, to be described in objective and positivistic terms (Dourish 2004). For example, in a comparison of the clinical trial characteristics of the five different TasP trials conducted in Africa (including the *Max*ART EAAA study), Perriat et al., (2018, 3) define the *trial context* as the "key demographic and socio-economic characteristics of the populations living in the trial areas, health services available in the trial areas, and their HIV epidemiological profiles". The representational approach thus sees context as a set of variables that can be adjusted for comparative purposes and included in a statistical analysis to control its possibly confounding effects on trial outcomes (Brives et al., 2016; May et al. 2016).

In an *interactional* approach, contexts are perceived as relational, dynamic, and contested, in line with anthropological relativist assumptions that social realities are continuously made, repaired, and remade in locally situated interactions (Asdal & Moser 2012). For example, in *The Context of Medicines*, anthropologists Susan Reynolds Whyte and Sjaak Van der Geest (1988) define context in studies of medicines as "the constellations of cultural meanings and social relations within which medicines exist in a given time and place" (Whyte & Van der Geest 1988, in Dilger & Hadolt 2020, 3). Here, context appears as the ever-widening embodiments of an object in systems of social relations and meanings. Whilst context is a central organizing concept within the discipline, social anthropologist Roy Dilley (1999) writes that the concept has been given rather limited scrutiny and treated as self-evident in anthropological analyses. The "problem of context", according to Dilley (1999), lies in its "unboundedness"—that is, in the difficulty of accounting for the co-production of the investigated phenomenon and context and of deciding what contexts matter and to whom.

In the broad and rapidly growing field of implementation science, the circumstances that might be considered contextual "confounders" in randomized control settings are actually the conditions of practice under investigation (May et al., 2016). In an article about the opportunities of implementation science in so-called "resource-poor countries," Yapa and Bärnighausen (2018) argue that often the *resources* to deliver interventions (including health workers, drugs, supply chains, and healthcare facilities) feature as part of the context

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[15] The etymology of the word "context" suggests it developed from the Latin word—*contextere*—meaning to weave or join together (Dilley 1999, 4). In conventional speech, context commonly refers to the environment in which something exists and that gives meaning to phenomena and objects (House 2008).

and are used to explain implementation success and failure. But also for implementation scientists, who generally hold a less reductionist view of context and acknowledge it as dynamic and unstable, "context is a problem" (May et al., 2016, 1), because of *practical* reasons. Attempts to define and describe it have to encompass so much, including social, economic, and political organizational contexts. According to Rhodes and Lancaster (2019), whilst implementation scientists might acknowledge context as relational (and thus as similar to the interactional approach), they still hold intervention and context as separate fields and perceive health interventions as "*separate* from, yet s*haped* by, their implementations; as pre-*existing* but *traveling* objects made *prior* to their situated implementations" (Rhodes & Lancaster 2019, 3, emphasis in original).

A third approach to the study of context, Brives et al., (2016) suggests, is to follow how multiple contexts are produced in evidence-based practices, which might be referred to as an "ontologically multiple" approach. Such an approach is more characteristic of the field of science and technology studies (STS), wherein scholars generally reject the idea that context exists independently of the researcher's gaze and rather consider the actions (practices) through which multiple realities are constantly enacted and come into being (Asdal & Moser 2012; Law & Singleton 2014). In a review of STS engagement with the notion of context, Asdal and Moser (2012, 293) argue in favor of understanding contextualization as an action *done* by scholars, which they call "contexting" (see also Mann 2015).

It is thus apparent that for both implementation scientists and within social science the notion of context is a slippery term for practical, epistemological, and/or ontological reasons. Yet the concept is also acknowledged by these disciplines as worthy of (more) scholarly attention. My approach to context resonates most closely with the interactional approach; I set out to explore how TasP is made meaningful to different actors at different levels, and what kind of transformations such a process entailed. Yet, the expectations from the EAAA study team were for the social science researchers to approach context as representational, and tease out the exact contextual facilitators and barriers affecting uptake with the ultimate goal of suggesting strategies to improve uptake of early ART. The articles that I brought together in this thesis therefore present an amalgamation of the representational and interactional approach to context, reflective of my multi-positionality as an insider in the public health-oriented *Max*ART study team and as a critical ethnographer, a binary further discussed in a methodological reflection in chapter 6.

Methods and thesis overview

During my engagement with the *Max*ART program between 2012 and 2018, I carried out data collection through various arrangements. These can be separated into three different phases: 1) a *pre-intervention* phase prior to the start of the EAAA study (2012–2013); 2) an *intervention* phase, during which the EAAA study was implemented in 14 facilities in northern Hohho region (2014–2017); and 3) an *ethnographic*[16] research phase, in which I

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[16] The ethnographic research phase partly overlaps with the intervention phase. Whilst the ethnographic phase lasted shorter than the intervention phase, and ended earlier, in this Methods section, I discuss the intervention phase first in order to align with the structure of the dissertation chapters.

undertook participant observation during the first year of the EAAA study in one community (2014–2015). In the following paragraphs, I briefly describe the main research sites, the kinds of data gathered, and the various people and collaborations involved in each phase. More detailed information about specific data collection methods is provided in the methods sections of each article (chapters 2 to 6) that make up this thesis. For each phase, a separate research protocol was written that received ethical clearance from both the Swaziland Scientific and Ethics Committee and the University of Amsterdam.

During the *pre-intervention* phase, I spent four months in eSwatini (from April to July 2013) conducting a qualitative research study in collaboration with a *Max*ART colleague, Mandla Mehlo, who worked for the Swaziland Network of People Living with HIV (SWANNEPHA). The overall goal of this study was to provide insights about the local realities and views of health workers and people living with HIV regarding the future intervention (early ART). A particular focus of the study was the communication of the possible *benefits* of early ART, a topic of much concern and uncertainty at the time. We designed the qualitative study together with two of my PhD supervisors, Ria Reis and Anita Hardon, who were also involved in *Max*ART as social science principal investigators. Mandhla and I composed a team of four local research assistants and provided a week-long training session in qualitative research methods before engaging in data collection for two months in eight different facilities, where we spent one month each. Data collection occurred through observations, interviews with health workers and people living with HIV, and focus group discussions with HIV support groups. Furthermore, Mandhla and I conducted key informant interviews with health facility in-charges, policymakers, and HIV community-based organizations. This yielded an enormous amount of data, which Mandhla and I presented to *Max*ART in a face-to-face meeting in July 2013 (the EAAA study was initially scheduled to begin in September 2013). I subsequently carried out further thematic content analysis of interview transcripts and observational fieldnotes. One key insight that arose from this phase of data collection was that, unlike in international public health debates, which tend to be concerned with the individual or population *benefits* of TasP, participants' framings of (early) ART were embedded in locally situated concerns about the individual's responsibility for their own health and others. Behind these concerns, the preventative potential of treatment conflicted with grave fears of acquiring drug resistance. This argument is explored in **chapter 2** of this thesis.

During the *intervention* phase (2014–2017), I co-designed a mixed methods social science research study and coordinated the day-to-day data collection. This coordination entailed training and supervising a team of two Swazi research assistants in qualitative data collection, introducing our research in facilities and assisting with key informant interviews, liaising with other EAAA teams to obtain access to EAAA study participants, preparing data analysis sheets, overseeing data entry, organizing preliminary data analysis sessions, presenting weekly updates to the other EAAA teams, and arranging housing and logistical support for the research team. For the first six months I undertook this role when living in one of the study localities in northern eSwatini. The main portion of data collection was conducted by the two research assistants in nine of the 14 health facilities included in the EAAA study. Together with epidemiologists from the Amsterdam Institute for Global Health and Development (AIGHD), we designed a semi-structured questionnaire to assess HIV-positive people's experiences of ART initiation before and after the EAAA study started. The research assistants interviewed over 600 people to assess the changes in self-reported adherence, condom use, stigma, disclosure, and the quality of interactions with health providers after EAAA was introduced, as these were topics that had been hypothesized by *Max*ART and others as practices that might be (negatively) affected by TasP (Shafer et al., 2015; Young & McDaid 2013). The analysis of the survey data was done by colleagues from the AIGHD and the published article is not included in this dissertation given the quantitative nature of the publication (Molemans et al., 2019). The main qualitative research conducted by the research assistants included observations and interviews within the selected health facilities to understand how health workers were advocating EAAA to their "clients" (the common term in public health discourse used for HIV-positive people visiting health facilities), and how HIV-positive people responded to the offer of starting ART early.

When I returned to the Netherlands in February 2015, I remained involved in weekly, sometimes daily, calls with the research assistants and attended separate bi-monthly meetings with the entire EAAA study team. I also paid biannual visits to eSwatini to attend face-to-face meetings. When I started maternity leave at the end of 2016, two University of Amsterdam colleagues, Fortunate Shabalala and Christopher Pell, took over my coordinating responsibilities and led the writing-up of the findings of the qualitative research conducted during the intervention phase. In **chapter 3**, we assessed how health workers explained the EAAA study's rationale and its benefits to prospective study participants across eight different health facilities. We found that, when enrolling clients into the EAAA study, health workers adapted the main TasP messages to the clients' desire to hide the visible signs of illness and highlighted as the primary benefit of early ART the unlikeliness of being *seen* to be sick. In turn, they downplayed the potential prevention benefits to avoid discouraging condom use. In **chapter 4,** based on the qualitative interviews with HIV-positive people who were classified as "lost to follow-up"[17] in the EAAA study database, we explored the chain of events that led to the eventual discontinuation of ART. This revealed the disconnection between the government-managed health system and the precarious and mobile living conditions of people living with HIV.

Besides my involvement as the social science research coordinator, I wrote a separate PhD research protocol to enable more in-depth research into the unfolding of the EAAA study in one of the designated study communities, with financial support from the University of Amsterdam. This allowed me to simultaneously conduct 12 months of ethnographic fieldwork (between February 2014 and February 2015), during which I stayed for 10 months in one of the EAAA study sites in Ntfonjeni *inkhundla*. Ntfonjeni is located in the Hhohho region, in the far north of the country. The *inkhundla* has an estimated population of 20,000 people and is bordered by South Africa's Mpumalanga province, known

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[17] In *Max*ART, lost to follow up (LTFU) was defined as "clients who stopped ART refill for three months or longer from the date of last appointment and were not registered as either deceased or transferred out from the study sites" (Shabalala et al., 2018, 3).

for its coal and (former) gold mines, which frequently attract local men from Ntfonjeni, where employment opportunities are limited (Simpson et al., 2019). It is one of eSwatini's 18 Rural Development Areas, and has received support from various international organizations since the 1970s to improve the crop and livestock production of peasant farmers (Sithole et al., 2014). Besides maize cultivations and small livestock holding, another source of income is cannabis [*dagga*] production, illicitly grown in plots in the mountainous border zone and sold to dealers in South Africa. Due to this informal cannabis economy, Ntfonjeni's population was described to me by a local health worker as having a more typically urban commercial "mindset," whereby people were in a rush and therefore difficult to engage in health interventions.

I selected Ntfonjeni as a research site primarily because of my PhD advisor's connections in the area, who undertook research about epilepsy and medical pluralism there in the 1980s (Reis 1996). A former diviner, a type of traditional healer,[18] and avid Jehovah's Witness working as an HIV counselor in the regional hospital kindly hosted me for the first couple of weeks and facilitated introductions to the traditional leaders of the chiefdom. These were necessary to be allowed granted access to do research within the community. Another important connection was a matron (senior nurse officer) in charge of the public health unit of the regional hospital, who facilitated introductions with Ntfonjeni's local health clinic and helped me find a more permanent living location (with an HIV counselor working in Ntfonjeni's clinic, with whom I shared a house within walking distance of the clinic). Due to several reasons, of which limited funding was the foremost, the EAAA study started only in September 2014, one year later than originally planned. This meant that I was able to spend several months in Ntfonjeni before the study started, which allowed me to build up rapport with both community-based and facility-level actors. The disadvantage was that I was not able to observe as much of the rollout out of TasP in Ntfonjeni as originally planned.

In the community, I spent most of my time visiting four support groups during their bi-monthly meetings in different chiefdoms, two of which were newly formed and another two of which were being "revived" (partly due to the encouragement of different TasP actors, including *Max*ART). During my visits, support groups worked on (re)writing their constitutions and discussing membership criteria and plans for income-generating activities, which provided insights into the (trans)formations of the groups and the (in)significance of illness status as a membership criterion. I participated in some of the groups' activities, such as making Vaseline-based skin products and attending health education sessions provided by different (inter)national actors, including *Max*ART. Such education (by various donors) was a constant throughout the different phases of the HIV epidemic. The majority of the support group members were Swati. Some grew up in South Africa, but all spoke siSwati.[19]

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[18] Different typologies for traditional healers exist in eSwatini, of which the main two types are diviners, *tangoma* (sg. *sangoma*), who received medical knowledge through ancestral possession, and herbalists (*lugedla* or *inyanga yemitsi*, specialist in medicine) who receive medical knowledge through a learning process (Reis 2000, 63).

[19] Since independence (1986), English and siSwati have been recognised as the two official languages spoken in eSwatini. Whilst English is the language of the government and health administration, and the language I spoke with health workers, siSwati is the dominant language in many social circles, especially in rural areas.

My siSwati language skills were sufficient to hold simple conversations with those in the support groups but too limited to conduct in-depth interviews. Hence, when I visited support group members in their homes to learn more about their personal circumstances and motivations, I sought help from a female field assistant from the neighboring *inkhundla*, who provided direct translation that enabled further probing during interviews. Through these interviews I learned that support groups appeared to be attractive to people with different kinds of chronic conditions besides HIV, but also for people without any illnesses; they catered to a need for social solidarity that transcended diagnostic status. Rather than merely responding to rationales of donors who intended to use the groups to scale-up HIV treatment, I found that local actors, such as rural health motivators [*bagcugcuteli*[20]], were actively shaping the composition of support groups so as to remain responsive to what Manderson and Smith-Morris (2010) call the "chronicities of everyday life"—that is, the life conditions that shape the risks and consequences of diseases. Consequently, it appeared a condition of "chronic awareness" of anticipated illness was fostered and encouraged through health education in the support groups. These insights are discussed in **chapter 5** about the transformations of HIV support groups during the time period in which TasP unfolded.

Beyond my fieldwork with support groups, I also spent several weeks in Ntfonjeni's clinic, primarily observing the ART initiation and adherence counseling practices carried out by HIV-positive women employed as expert clients. During my observations, the expert clients assigned me the role of "TB screening officer," which involved asking all HIV-positive people coming for ART refills five questions about tuberculosis (TB) symptoms using a screening tool. The expert clients argued they had no time to fill in this tool themselves during busy days. My time in the clinic enabled me to linger on in the clinic when the EAAA clinical trainers visited the facility staff and informally discuss the EAAA intervention with staff, which helped to undertake critical ethnography *of* global health interventions (Pigg 2013). Furthermore, I conducted participant observation within the EAAA study team itself, making extensive notes during team meetings, participating in the development of the communication strategy, and pre-testing the main EAAA study messages. In Ntfonjeni, I also attended various introduction meetings with traditional leaders and EAAA training sessions for community resource groups, of which support groups were the primary targets. Once the EAAA study finally started in September 2014, I started spending more time in Mbabane, partaking in weekly EAAA team meetings and coordinating the mixed methods research. As time passed, it became increasingly difficult to navigate the dual role of critical ethnographer and EAAA study team member. I reflect on this in **chapter 6**, where I discuss the tensions and consequences of my multipositionality that affected my interactions with consortium members and clinic staff.

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[20] The Rural Health Motivator (RHM) program was created in 1976 by the government of eSwatini in an effort to decentralize healthcare and to provide every household with basic primary health care and health information (Walker et al., 2020). During the time of fieldwork, an estimated 5000 RHMs were employed within the RHM program, making them the largest cadre of community-based health workers (Geldsetzer et al., 2017). In Ntfonjeni, there was at least one RHMs active in each chiefdom.

Finally, in **chapter 7**, I draw together theoretical insights from the empirical chapters to tease out the main conclusions, reflections, and contributions of this thesis regarding the contextualisation of biomedical interventions more broadly and the reframing of TasP in eSwatini specifically. In doing so, I attempt to put the insights of this thesis in the context of the recent findings of other social science research that has studied the implementation of TasP, particularly in sub-Saharan Africa. I highlight how locally constituted values of responsibility, well-being, and solidarity underlie the transformations of policy discourses, counselling messages, and support groups during the implementation of early ART in eSwatini. Further, I reflect on how the temporal, organisational, and social dynamics of global health research and policymaking shaped how implementation science and early ART became used by the various actors involved, including HIV-positive people and national-level policymakers. I end by offering several suggestions for future anthropological engagements with TasP, context and implementation science.

CHAPTER 2

Access for all: Contextualizing HIV treatment as prevention in eSwatini

Eva Vernooij, Mandhla Mehlo, Anita Hardon, Ria Reis

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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 fieldnotes. 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 conceptualized 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.

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 has been used as the key marker).

Modeling studies have suggested that expansion of ART coverage could also be effective in reducing transmission on a population level (Granich et al., 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 HIV Treatment as Prevention (TasP) workshop organized 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" (Ibid, 447). Following this initial conceptualization 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 of ART in sub-Saharan Africa (de Cock & El-Sadr, 2013; Delva et al., 2013; Lundgren et al., 2013; Sigaloff et al., 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 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 (WHO, 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 *Max*ART 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 HIV treatment as prevention 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 (MOH, 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). Antiretroviral therapy 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 idealized concepts of kinship and social organization, 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 analyzing 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 National Network of People Living with HIV (SWANNEPHA). 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 facilitator 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 cross-checked by the facilitator and note-taker.

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 18 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 analyzed using NVivo 10. Data were analyzed 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 anonymized 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 Treatment as Prevention (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 organizations and scientists involved in the study design "hijacked" the national AIDS program'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 organized by two studies to develop of 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 behavior 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 country's 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 wellbeing 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. By contrast, one of the main activities undertaken by the EAAA team in their community mobilization 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 was also seen as part of the responsibility of the government. The following quotation from a study team member involved in community mobilization 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 fulfillment of the women's part of the contract, as argued by social anthropologist Hilda Kuper (1986). Rights of fatherhood are acquired through bride price *(lobola)*, transactions of cattle (or cash equivalent of cattle) from the man's to the woman'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 (Ibid). 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 (CSO, 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* [brideprice] 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 counseling messages that emphasized 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 treatment as prevention 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 mobilization 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 inquiry 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 United States) 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 it was hard to believe that someone living with HIV might not be infectious (Young et al., 2015).

This article addresses a gap in research on the views of people living with HIV about TasP in under-resourced 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 work in African contexts reveal similar tensions between individual risks and benefits and collective or public goods in global health research (Reynolds et al., 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 under-resourced 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.

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CHAPTER 3

“Then her neighbor will not know her status”: How health providers advocate antiretroviral therapy under universal test and treat

Christopher Pell, Ria Reis, Njabuliso Dlamini, Eileen Moyer, Eva Vernooij

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ABSTRACT

Universal test and treat (UTT) – antiretroviral therapy (ART) for all HIV-positive individuals regardless of CD4 count – is the World Health Organization's recommended treatment guideline. UTT has implications for health providers' workload in areas of high HIV prevalence and for their understandings of ART and HIV. This article explores health providers' experiences of implementing UTT in Hhohho Region, Swaziland. Between March 2015 and October 2016, in-depth interviews were conducted with health providers implementing UTT. Interviews were transcribed verbatim and translated into English for qualitative content analysis. Twenty-five providers from eight facilities were interviewed. Respondents encouraged early ART by promoting its overall health benefits, and the possibility of avoiding disclosure and HIV-related stigma in the community. Some health providers downplayed UTT's preventive benefits to avoid discouraging condom use. Respondents suggested that initiating ART immediately after testing could improve linkage-to-care, but recognized that overly hasty initiation might affect adherence. Viral load testing was seen as a potentially useful tool to monitor clients' response to ART. Health providers appropriated stigma to encourage early ART enrollment. This suggests an attentiveness to the social burden of HIV/AIDS, but potentially exacerbates discrimination and conflicts with efforts to reduce HIV-related stigma.

INTRODUCTION

Universal test and treat (UTT) – antiretroviral therapy (ART) for all HIV-positive individuals regardless of CD4 count or disease stage – recently became a WHO guideline (WHO 2015). This policy has clear implications for health systems in areas of high HIV prevalence, which are often under-resourced; under UTT, the number of potential ART clients would increase by an estimated 18 million across sub-Saharan Africa (UNAIDS 2016).

Responding to questions about the feasibility and effectiveness of UTT, several large-scale clinical trials and implementation studies are underway in sub-Saharan Africa (Granich et al., 2011), including one in Hhohho Region, Swaziland (Walsh et al., 2017). Universal test and treat also has consequences for understandings of ART and HIV (Reynolds et al., 2016), particularly because clients initiate ART when asymptomatic. Alongside the ongoing clinical trials and implementation studies, scholars have therefore explored the social and behavioral consequences of extending the availability of ART under UTT, with a view to informing the design and roll-out of this policy (Camlin et al., 2016).

Health providers play a crucial role in implementing UTT, particularly in terms of communicating a policy change that entails visibly healthy individuals beginning a life-long course of treatment (Boyer et al., 2016). Through their messages in clinical encounters, they mediate between clients' understandings of HIV and ART, and UTT's public health aims. This article explores the experiences of health providers who implemented UTT as part of an implementation study in Swaziland. The article examines how health providers explained this policy, and describes how – from the perspective of health providers – UTT influences the process of HIV testing, counseling and disclosure, and ART initiation.

MATERIALS AND METHODS

Setting

In light of its HIV prevalence – at 27.2% in 2016, the world's highest among 15-to-49-year-olds (UNAIDS 2017) – Swaziland was selected as the site for a large-scale UTT implementation study, "Maximizing ART for better health and zero new HIV infections" (*Max*ART).

Between 2014 and 2017, in Hhohho Region, in northern Swaziland, *Max*ART used a randomized stepped-wedge design, with a control, transition and intervention phase, to implement UTT in an incremental fashion across 14 facilities. During the control phase, HIV clients were initiated on ART following the standard Swaziland care model (CD4 count of <350 cells/mm^3/<500 cells/mm^3 [from 2015], or WHO disease stage 3 or 4) (MOH 2015). During transition and intervention, ART was offered regardless of CD4 count or disease stage. During the four-month transition period, study personnel mentored health providers to implement the new care protocol. Clients gave verbal informed consent to participate in *Max*ART (Walsh et al., 2017).

Data collection

The findings presented here are based on interviews with health facility providers at eight (of the 14) UTT facilities. Trained social scientists undertook interviews using a pre-tested guide between March 2015 and October 2016. An exhaustive diversity sampling approach was taken at the eight health facilities (seven rural clinics and one regional hospital). Depending on the facility size, either all available health providers involved in HIV testing and counseling, and ART provision or at least one provider per cadre (expert clients, senior nurses, nurses) were interviewed. The interview guide included questions on their experience with the UTT study, in terms of its impact on HIV testing and counseling, ART initiation and ART. Respondents were asked about their knowledge of the study, how they explained it and its benefits to prospective participants. Interviews lasted between 25 minutes to one hour. Interviews were conducted in siSwati, transcribed verbatim and translated into English for analysis.

Data analysis

Qualitative content analysis was conducted using NVivo 11 Pro (QSR International, Doncaster, VC, Australia). An inductive and deductive approach was taken to the development of a codebook: preliminary codes were based on initial research questions, then, during reading and coding, substantive topics that emerged were subsequently added. The first author (CP) conducted line-by-line coding, consulting throughout with EV and RR. The resultant codes were used to formulate the themes described in the results, which were also discussed with the Amsterdam- and Swaziland-based social scientists.

Ethical approval

Ethics approval was obtained from the Swaziland Scientific and Ethics Committee. Written informed consent was obtained from respondents. Respondents were informed that their responses would be treated anonymously and that confidentiality would be maintained.

RESULTS

In total, 25 health providers were interviewed. The respondents included four senior nurses, 10 nurses, seven expert clients, one volunteer and three providers whose positions were not recorded. Between one and five respondents were recruited from each of the eight facilities. Most of the respondents (20) were female.

The following section outlines the key themes that emerged during the analysis of the interview transcripts with regard to how health providers presented UTT to clients and the process of ART initiation. Another prominent element of the interviews was how health providers also described the implications of UTT for ART initiation and adherence.

Messages about the benefits of early ART

Health providers' messages about the benefits of *Max*ART varied, with no discernible pattern across facilities or cadres. Explanations often focused on clients' overall health, particularly ART helping them to avoid becoming "bed ridden":

> The benefit [of starting treatment early] is that you live long. Also you're not vulnerable to diseases when you are on ART. Plus, the virus doesn't multiply in the body when you've started ART early. Instead, it decreases so you don't reach a stage where you are sick. (Senior Nurse, facility #1).

Respondents outlined how these health benefits had social and economic consequences. Clients could continue paid employment, maintain caring activities and reduce the risk of a costly hospital admission. Avoiding visibly apparent illness was explained to be particularly advantageous: clients could evade disclosing their HIV status to friends and neighbors. Early ART was thus a way of preventing "gossip" caused by visible symptoms, such as weight-loss. Health providers therefore adapted messages about UTT enrollment to attitudes to disclosure to the wider community:

> I explain that [initiating ART early] will be helpful to her when … what can I say … if she does not intend her neighbor to know that she is HIV positive. If she starts taking care of herself early, then her neighbor will not know her status. (Female Expert Client, facility #2).
>
> *Interviewer*: What is it that makes people wish to start on the pills … those that maybe are at [disease stage] stage 1 or 2?
>
> *Respondent*: It's still that they fear getting sick … people fear being noticed …
> (Female nurse, facility #3).

Health providers carefully explained the benefits of ART in terms of HIV prevention, seeking to avoid reductions in condom usage. They made references to the possibility of re-infection and mentioned viral load (VL) to emphasize that the virus would still be present and there would still be some transmission risk. Good ART adherence was also mentioned as a prerequisite for any protective effect. Some respondents described how the preventive benefit of early initiation was an important point to communicate and a potentially motivating factor for clients to adhere to ART:

> *Interviewer*: How do you explain [that starting treatment early reduces the chance of infecting a client's partner]?
>
> *Respondent*: I tell them that when you have started treatment, treatment reduces the viral load in the body. If the viral load in the blood has been reduced, the chanc-

> es that you can transmit [HIV] to your partner are reduced. It is not to say that you will not infect them, because they then misinterpret [the message]. It is not that you will not infect them; you can infect them, but the chances of doing so are reduced. (Female general nurse, facility #3)

Initiating ART (on the day of diagnosis)
Disclosure to one's partner(s) and/or close friends or relatives – difficult to avoid when initiating ART – also impacted enrollment. Respondents suggested that, particularly for female clients, decisions about ART initiation were sometimes influenced by their male partner(s).

Disclosure to one's partners was, however, also seen as an indication of having accepted one's status and being prepared for ART:

> If a woman comes to the facility and tests positive, and agrees to start treatment, when she returns to her partner, the man throws the pills away. We try to talk to them: what do they think would help them? … They say they want to start treatment and they can hide it to their partners; they are ready to start [ART] and they do not want to [die]. (Male expert client, facility #3).

Sometimes the reasons for non-initiation were unknown to health providers: potential clients simply stated that they wished to discuss it at home or think it over.

As part of *Max*ART, clients were able to initiate ART the day of HIV diagnosis. Respondents recognized that initiating ART was a difficult decision with critical implications for clients' future health. For a person who was not emotionally prepared, hasty ART initiation could have implications for adherence. However, a client who did not initiate and returned home – often with the stated intention of discussing with her or his partner – might not return. Although opinions varied about how to identify whether a client was prepared to initiate ART, health providers usually described that the client had the final word on initiation:

> …It seems difficult that you test today [and] then you start on the treatment … Let's say you did not know your HIV status and you must leave the clinic with the ARV pills … you still have to go and disclose … at times that seems like a huge burden … If that person did agree to take the pills and when he welcomes his status it's fine. (Female expert client, facility #1).

Health providers also suspected that some clients were already aware of their status, having previously tested positive yet not been retained in care. Delaying initiation had given them time to come to terms with their diagnosis. Others, respondents suggested, were prompted to initiate on the same day by their partners' HIV status:

> Ok, a lot of people most of the time, those are willing [to initiate] so quickly are people that have tested before somewhere but ran away and then come back because maybe

> they fear something or they have counseled themselves and accepted [their status]. (Female General Nurse, facility #4).

Viral load testing

During the control and intervention phase, the addition of VL testing was a notable difference between the UTT and standard care package. Tests occurred on enrollment, initiation and after six months. Health providers described VL testing in terms of monitoring the quantity of virus in the body, and explained this as a benefit of enrollment, particularly during the control phase. They saw VL testing as a more accurate method of checking the effectiveness of ART than testing the CD4 count, which they viewed as more dependent on the individual's constitution or immune system. According to respondents, clients saw VL testing as a benefit of enrollment and, for some, it had become a way of monitoring the progress of their illness. Respondents also made references to VL testing as a tool to monitor adherence, but identified no specific cases when this had happened:

> I usually explain to them that [VL testing] will help us see if this regimen is good for you or this regimen is not good for you. (Female General Nurse, facility #4).
>
> So [the CD4 count is] not a true reflection of what is happening in your system, but the viral load gives us a true clear picture of what we are doing and how we are doing. And also the viral load shows us clearly your adherence: if you are taking the pills honestly or not. (Female General Nurse, facility #5).

The blood that was sampled from UTT clients also underwent HIV resistance testing during enrollment. When asked about their explanations regarding this test, health providers often reported not remembering talking to clients about it.

Adhering to ART when healthy

Initiating ART with a high CD4 count, when in good health, could have implications for adherence – clients might not see the benefits of sustained ART adherence if they have not yet experienced any deleterious HIV-related health effects. Health providers recognized this possibility but they were generally confident that initiating ART as part of *Max*ART – instead of at a more advanced disease stage – would not reduce adherence. The respondents rather viewed clients' disclosure to their partner, as relevant to whether they were likely to adhere to ART:

> What I see as bad [about initiating ART on the same day as testing] is that the person may not have accepted her status, because you may find that she is overwhelmed… Then yet she will not take [the ART] even at home. (Female Senior Nurse, facility #2).
>
> *Interviewer*: Has [UTT] made [clients] honest when drinking the pills?

> *Respondent*: Yes … it has changed it very much because we tell them that after six months the blood results will tell us whether they are taking pills honestly. (Male volunteer, facility #1).

Respondents identified two additional factors that encouraged ART adherence, particularly as part of *Max*ART. First, they explained that the VL testing could be used to identify non-adherence and suggested that this would discourage non-adherence. Second, the fear of becoming sick (and physical indications of ill health leading to inadvertent disclosure and stigma) prompted adherence.

Practicalities of UTT in health facilities

The practicalities of UTT had implications for the duration of health providers' interaction with clients or potential clients. This was caused by the extra time investment needed upfront with patients to explain the rationale for early ART and VL tests. These changes also led to additional questions to which health providers had to respond. Respondents also mentioned an increased bureaucratic burden of "paperwork and stickers", placing additional demands on their time. Increased time spent on initiation had implications for the time spent on other tasks, such as ART refills for returning clients (which often involved questions as well as collecting and checking medication):

> You discover that we have booked many people to come for refill and the time for that person who is refilling [ART] is short and she will only do her refill without being asked if there are problems with the pills. (Female Expert Client, facility #2).

There were reports that the study design, using an initial control and transition period in which study staff members were present to assist with enrollments, was helpful in terms of managing the extra burden of work. For some respondents, the initial introduction of UTT was particularly challenging but, with time, they got accustomed to the new protocols.

DISCUSSION

For health providers, explaining the changes to the HIV care package and its benefits was the most notable additional task of UTT as part of *Max*ART in Hhohho Region. The following discussion reviews the most prominent influences on these messages: (1) local attitudes regarding HIV disclosure and visible signs of illness and (2) providers' concerns about reducing condom usage. How health providers viewed HIV care and ART adherence under UTT is also discussed.

Appropriating stigma to encourage ART initiation

Since the 1980s, HIV/AIDS-related stigma has been recognized as a barrier to reducing incidence and providing appropriate care (Herek & Glunt, 1988). Research on HIV prevention and care has often highlighted stigma's pernicious impact (Hardon et al., 2006;

Merten et al., 2010; Ware et al., 2009), with a 2013 systematic review identifying stigma as a barrier to HIV testing and ART adherence in low- and high-income countries (Gari et al., 2013). Efforts to address HIV-related stigma have therefore often been incorporated into intervention packages (Brown et al. 2003). In Swaziland, HIV-related stigma – largely experienced as disapproval from the wider community – is ubiquitous and pronounced for women (Shamos et al., 2009; Zamberia, 2011). This was reflected in the responses of health providers – clients were reportedly reluctant to disclose their status to the wider community and feared inadvertent disclosure.

When describing the benefits of enrolling in *Max*ART and initiating ART early, health providers appropriated HIV-related stigma to encourage participation; they appealed to clients' unwillingness to disclose their HIV status to the wider community and their desire to hide the visible signs of illness.

Such an approach may exacerbate HIV-related stigma; health providers are often respected and yield authority that extends beyond the health facility (Feierman, 1985). This approach has potential implications for the wider efforts to reduce HIV-related stigma in Swaziland and sub-Saharan Africa (Grossman & Stangl, 2013; Root, 2010), but health providers did not reflect on the contradiction between seeking to reduce HIV-related stigma to encourage testing and making use of it to encourage ART initiation. Nor did they consider the possibility that they might be compounding HIV-related stigma.

Adapting their messages about UTT in this way, health providers drew on their familiarity with the local *social* implications of HIV. This highlights how health providers are intertwined with the context in which they work (and how their biomedical personae cannot be extricated from their social personae). Ultimately, by promoting ART initiation in a way that ignored the common "confessional imperative" (Hardon & Posel, 2012) of HIV intervention programs, health providers were attentive to clients' social well-being. Indeed, social scientists have – through detailed ethnographic analysis – highlighted how secrecy and limited disclosure can help people living with HIV navigate the social realities they face (Hardon & Posel, 2012).

Downplaying the preventive benefits of early ART initiation

When first proposed as an approach to HIV care, reducing population incidence was envisaged as an important benefit of early ART (Granich et al., 2011). The *Max*ART study was conceived with this aim is mind. However, during the process of design and implementation, particularly because of concerns about the possible impact of messages around ART's preventive value on condom usage, prevention became ancillary to the goal of increasing "access" to ART (Vernooij et al., 2016). This ambiguity towards the preventive benefits of early ART (at a study and international policy level) was reflected in health providers' explanations during enrollment.

Recent research in Swaziland highlights how the determinants of condom usage while on ART are complex, embedded in the local context and informed by concerns about resistance (Vernooij et al., 2016). It is perhaps, therefore, overly simplistic to assume that communicating the preventive value of ART will reduce condom usage. Nonetheless, given the complex circumstances that surround one's infectiousness when on ART – and how this is poorly understood in low- and high-income contexts (van der Straten et al., 2014; Young et al., 2015) – empirical research must directly address its impact.

HIV care and ART adherence under UTT

In Swaziland, stigma and discrimination compounds the logistical demands – the number and frequency of appointments – of ART initiation (Dlamini-Simelane & Moyer, 2017a). Offering ART on the day of diagnosis – as the health providers recognized – has the potential to link more clients into HIV care. This is particularly relevant to the UNAIDS target to achieve 90% ART coverage amongst HIV-positive individuals (UNAIDS 2014). However, for providers, the difficult nature of this decision meant that hasty initiation could have implications for ART adherence.

Initiating ART without HIV-related symptoms could reduce ART adherence (Boyer et al., 2016). In the absence of symptoms, clients might not be motivated to adhere to the treatment. As recently reported in southern Swaziland (Horter et al., 2017), for the interviewed health providers, whether a client had *accepted* her/his diagnosis – inferred from partner disclosure or his/her reaction to the diagnosis – was more important than disease stage on initiation. Interviews with clients who had delayed ART initiation under *Max*ART also indicated that expedited ART initiation does not necessarily accommodate some clients' need for time to come to terms with the diagnosis and the prospect of lifelong treatment (Pell et al., 2018).

In terms of the UTT care package, for clients, VL testing was a notable addition. Little research has addressed how the availability and utilization of VL testing influences client-provider interactions for those on ART. Some health providers described how VL testing enabled the monitoring of clients' health and their response to ART. Such an approach illustrates the potential value of VL testing to improve HIV care. Clients' understanding of VL testing also requires analysis.

CONCLUSION

In Hhohho Region, Swaziland, when implementing UTT, health providers appropriated stigma to encourage early ART. Their acquiescence with discrimination is at odds with wider efforts to reduce HIV-related stigma. However, it suggests an attentiveness to the social realities of people living with HIV/AIDS. Any impact of such messages on stigma and HIV testing requires attention. Explaining the preventive benefits of early ART provoked reflection among health providers and such concerns highlight the need to evaluate the influence of such messages (and early ART) on condom usage. Viral load testing was well-received by health providers but further research is needed on clients' understanding of this technology.

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CHAPTER 4

Understanding reasons for discontinued antiretroviral treatment among clients in test and treat: A qualitative study in eSwatini

Fortunate Shabalala, Eva Vernooij*, Christopher Pell, Njabulo Simelane, Nelisiwe Masilela, Donna Spiegelman, Boyang Chai, Shaukat Khan, Ria Reis*

**These authors are joint first authors.*

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ABSTRACT

Retention on antiretroviral therapy (ART) is critical for the successful adoption of the test and treat policy by sub-Saharan African countries, and for realizing the United Nations programme on HIV and AIDS target of 90-90-90. This qualitative study explores HIV positive clients' reasons for discontinuing ART under the *Max*ART test and treat implementation study in Swaziland. Clients identified as lost to follow-up (LTFU) in the program database, who had initiated ART under the intervention arm of the *Max*ART study, were purposively selected from two facilities. LTFU was defined as stopping ART refill for three months or longer from the date of last appointment, and not being classified as transferred out or deceased. Semi-structured face-to-face interviews were conducted with nine clients and one treatment supporter between July and August 2017. All interviews were conducted in the local language, audio-recorded, summarized or transcribed and translated to English for thematic analysis. Respondents described mobility as the first step in a chain of events that affected retention in care. It was entwined with precarious employment, care delivery, interactions with health workers, lack of social support, anticipated stigma and ART-related side-effects, including the exacerbation of hunger. The chains of events involved several intersecting reasons that occurred one after the other as a series of contiguous and linked events that led to clients' eventual discontinuation of ART. The individual accounts of step-by-step decision-making revealed the influence of multi-layered contexts and the importance of critical life-events. Clients' reasons for abandoning ART are a complex, inextricably interwoven chain of events rather than a single occurrence. Mobility is often the first step in the process and commonly results from precarious economic and social circumstances. Currently the health system poorly caters to the reality of people's mobile lives. Interventions should seek to increase healthcare workers' understanding of the chain of events leading up to discontinuation on ART and the social dilemmas that clients face.

INTRODUCTION

Between 2000 and 2015, the number of people living with HIV (PLHIV) who access antiretroviral therapy (ART) saw a thirty-fold global increase: from 250,000 to more than 17 million (UNAIDS 2016, UNAIDS 2000). With increasing evidence of the benefit of "early" ART initiation in reducing morbidity, mortality, and onward transmission of HIV (Lundgren et al., 2015; Danel et al., 2015; Cohen et al., 2011) the World Health Organization's (WHO) 2015 consolidated treatment guidelines recommended "test and treat": ART for all people diagnosed with HIV, regardless of CD4 cell count or disease stage.

With countries across sub-Saharan Africa (SSA) adopting test and treat, there is a renewed need to ensure long-term retention on ART. Across Africa, the retention of clients in HIV care remains a challenge, with, continent-wide, retention estimated to be 65% at 36 months (Fox & Rosen, 2010). The high attrition rates mainly result from loss to follow-up (Chi et al., 2011; Kranzer et al., 2012; Rosen et al., 2007). This is of concern because interrupting or discontinuing ART can lead to suboptimal clinical outcomes, higher risks of opportunistic complications, loss of income, and death (Makunde et al., 2012; Rachlis et al., 2015). Reasons for loss to follow-up include a lack of food, religious and family influences, use of traditional or alternative medicine, enacted and/or perceived stigma, poor client-provider relationships, improvement in health status and treatment fatigue (Kranzer et al., 2012; Rachlis et al., 2015; Miller et al., 2010). Stemming high loss to follow-up rates is key to sustaining gains made against the HIV epidemic.

In Swaziland, with a reported prevalence of 30.5% among 18-49 year-olds, HIV is the leading public health concern (PHIA Project, 2017). Although HIV incidence reduced from 2.5% in 2011 to 1.4% in 2016, prevalence has remained stable (PHIA Project, 2017; Bicego et al., 2013). By December 2016, 171,266 (of the estimated 220,000) Swazi PLHIV had initiated ART, representing a coverage of 78% (MOH, 2016). Among PLHIV in Swaziland, the 2016 retention at 36 months was 85% (MOH, 2016), indicating relatively high retention in care. Little is known, however, about the reasons for disengagement from care among the remaining 15%.

In general, the population of Swaziland is extremely mobile, within and across borders, and this has been described as a key driver of the HIV epidemic (Whiteside et al., 2003). In 2010, almost half of 946 surveyed Swazi clients identified as lost to follow-up (LTFU) could not be traced because of their high mobility (MOH, 2010a). It is crucial to understand how mobility – absence from one's place of residence for a prolonged period of time – is linked to other reasons for discontinuing ART to design effective interventions to improve retention in care under test and treat. Drawing on interviews with clients identified as lost to follow-up in two public health facilities, this article explores their reasons for discontinuing ART. Ultimately, the aim is to use these data to inform an assessment tool to proactively identify clients likely to discontinue ART and offer them stepped-up counseling and support.

METHODS

Study Setting

Data were collected as part of the social science component of *Max*ART, a multidisciplinary implementation study in Hhohho Region, Swaziland, which examined feasibility, acceptability, affordability, and scalability of test and treat (Walsh et al., 2017). The *Max*ART study protocol is described in detail elsewhere (Walsh et al., 2017). The *Max*ART study population included all consenting adult (above 18 years) PLHIV and ART-naive clients. Pregnant and breastfeeding mothers and/or people who were unable/refusing to consent were excluded. The *Max*ART clinical database included all study participants and was frequently updated with data from the 14 participating public health facilities. The data presented herein were collected at a regional referral hospital and a rural clinic, purposively selected because they were high-volume sites and reported the highest number of LTFU clients in the *Max*ART database. Ethical approval was obtained from the Swaziland National Health Research Review Board.

Data collection

In the *Max*ART database, clients who stopped ART refill for three months or longer from the date of last appointment and were not registered as either deceased or transferred out from the two sub-study sites were classified as LTFU. All LTFU clients from the selected sites were contacted using their mobile phone numbers obtained from the *Max*ART database. The calling researcher explained the purpose of the study to potential participants over the phone and verified whether they had difficulties with taking ART. Potential respondents who confirmed they had stopped treatment were asked whether they were willing to be interviewed about their experiences. An appointment was set with those who agreed and a day before the agreed date respondents were called again to confirm their availability. Before the interview took place, the study purpose was explained again to the participants and written or verbal informed consent was obtained according to the participant's preference. Anonymity and confidentiality were maintained throughout the study.

Clients who were not reachable through their mobile phone number were traced through their listed treatment supporters. For those who could still not be reached, the treatment supporter was interviewed if he or she was aware of the client's HIV status. Among those successfully traced, eleven clients were confirmed as LTFU. All eleven clients (three males and eight females), and one treatment supporter were approached for an interview. One client refused, another evaded the researchers, not keeping four consecutive appointments. In one case, although the client could not be traced, her treatment supporter was interviewed. The findings are therefore based on face-to-face interviews with nine LTFU clients and one treatment supporter. Using a semi-structured topic guide, trained and experienced social scientists carried out the interviews that explored their reasons for discontinuing ART.

Consistent with an inductive approach, interviews were designed to be flexible, following a general, topic-oriented structure. The interview guide contained open questions on reasons for and experiences with discontinuation of ART, HIV testing, meaning of positive results, disclosure, availability (or lack) of a support system at home, the health facility and the community, and intentions to restart ART in the future. All interviews were conducted in the local language (siSwati) and audio-recorded upon consent from clients. Most audio recordings were transcribed verbatim and as data started to become saturated, and with no new themes emerging, the final audio recordings were summarized. All transcripts/summaries were translated to English for analysis.

Data analysis

In consultation with co-authors, FS manually analyzed the data, using a data-driven inductive thematic approach to steer cross-case comparison. According to Thomas (2006, 238), the general inductive approach "allows research findings to emerge from the frequent, dominant, or significant themes inherent in raw data collected, without the restraints imposed by structured methodologies". A narrative approach was also used to elicit an in-depth understanding of the individual contexts in which decisions were made. This was combined with constant comparison as described by Glaser and Strauss (1967). Combining cross-case analysis and within-case analysis helps to maintain the contextual richness of individual experience (Ayres et al., 2003). During analysis, emerging patterns were shared and discussed with EV and RR. Initial findings were discussed with all co-authors.

RESULTS

Respondent characteristics

All clients enrolled in *Max*ART, who initiated ART between January 2014 and October 2016 and were classified as LTFU were eligible for inclusion. From the two selected facilities, 145 clients were identified as LTFU: 81% (n=118) were aged 25-39 years, 58% (n=84) were female, and 57% (n=83) initiated ART with CD4<350 cells/ml. Of the 145 clients, 93 (64%) could not be reached when called because their mobile numbers were either not available, unknown to the person answering or the call was unanswered. Clients (or the treatment supporters of those that could not be reached) were called five times on average.

Fifty-two clients (36%) were contacted by phone. Of these, 26 were actively attending the facility but records had not been updated, 14 had transferred out from the ("mother") facility where the client initiated ART to a new one, and one person had died. During the call, eleven clients (three males and eight females) confirmed having discontinued ART (Table 1).

Table 1. Outcome of contact tracing of the initial LTFU selection *(Source: Shabalala et al., 2018)*

LTFU client categories	Total (N=145)
Unable to contact	93 (64%)
Contacted	52 (36%)
Confirmed LTFU[a]	11 (21%)
Active on ART[b]	26 (50%)
(Self)Transferred Out	14 (27%)
Died	1 (2%)

[a]Clients who had stopped ART for 90 or more days from the last clinic appointment date
[b]Clients who reported that they were still on ART at the same facility where they were reported as LFTU

The chain of events leading to discontinued ART

Initially most respondents reported mobility – relocating residence – as the main reason for discontinuing ART. Further probing revealed more complex circumstances: sub-optimal care from healthcare providers, severity and prolonged medication side effects, fear of stigma, lack of food and social networks were entailed in the process that leads to loss to follow-up. In-depth analysis of individual cases revealed several intersecting reasons that occurred consecutively, as a "chain of events" (Ware et al., 2013). Thus, a series of contiguous and linked events led to their eventual discontinuation of ART. The individual accounts of step-by-step decision-making revealed the influence of multi-layered contexts and the importance of critical life-events.

Mobility as the first step to discontinuation of treatment

For over half of the respondents, the first step in the chain of events towards stopping ART was relocation to another town or community far from the health facility where HIV treatment was obtained. Life events, such as caring for a loved-one residing in another area or changes in employment, often prompted relocation.

> I went to [name of residential area] to look after my brother who was sick… I took the pills with me and left my card thinking that I would not stay long. But the pills were finished while I was still there. (Female client, LTFU 05).

> I had just started working after a long time without a job. Continuing with the pills would have meant I had to ask for a day off every month to go to the clinic. I have children to take care of… My husband died four years ago so I am their [children] only provider. I feared that if I continued with the pills my employer would fire me… I couldn't risk that… Also I quit treatment because I tested when I was still staying at home which is at [name of residential area]. When I found a job in Mbabane, it became too far for me to fetch the tablets at [name of health facility]. (Female client, LTFU 03).

As the previous quote illustrates, the mobility that leads to loss to follow up is related to precarious social and economic living circumstances which led some respondents to choose (continuation of) employment over continuation of treatment. Economic motives were prominent in respondents' explanation of why they stayed away from their place of residence for prolonged periods of time. In some cases, the distance to the mother facility, or a clash in working hours at the facility and those of respondents' jobs made it difficult for clients to continue to access ART. Jobs involving travel, such as driving a taxi or employment far from home made accessing care more difficult. Often, however, mobility alone did not necessarily threaten continued treatment; rather it became a problem in the context of the organization of HIV care in the public health system.

The health system response to mobility

An immediate consequence of mobility was that clients had to (re)gain access to care. Returning after temporary absence meant regaining access to one's previous clinic. Negative experiences with healthcare providers sometimes became intertwined in the process that led to discontinuing ART. A participant who relocated because of her brother's sickness describes:

> I went to the nurses at the ART clinic with the pill container to ask them to at least give me a few pills and explained my situation. But they refused and told me they needed the card to dispense the pills and write on it. I even asked one of the lodgers to go with me to plead with the nurses but they refused. Because I did not have money to go to [the facility where she gets ART] I stopped. After my brother's discharge from hospital I went back to my clinic, but they reprimanded me for skipping the pills for three weeks… The lady who wears maroon told me I was not serious and I am wasting their time. She took me to the counselor who also shouted at me… So I told myself I will not go back there. (Female client, LTFU 05).

Perceived lack of attention or empathy from healthcare providers came to the fore in several accounts. These respondents mentioned that they decided to stop ART after they could not get the assistance they sought. Respondents reported being spoken to ''roughly'', "shouted at" or feeling that the clinic staff ''didn't care''. Such harsh treatment left clients feeling hurt, angry, and humiliated. One such client abandoned care due to poor treatment of her child by the HCWs, when she sought their assistance:

> "My child had problems but they did not want to listen, instead they shouted at me". (Female client, LTFU 09).

Others did not like that they had to "retell their story" to new HCW:

> I have thought about going there [nearest facility in the new residence] but eish, you know I thought now I have to retell my story again. So I thought, eish, I will see as time goes on…That was six months ago. (Female client, LTFU, 09).

For some respondents, the experience of side-effects became intertwined in the process of stopping treatment. As part of initiating ART, clients were informed about the possibility of side effects and assured that they will resolve over a few days or weeks. However, the experience of severe side effects coupled with a perceived lack of attention or empathy from HCWs resulted in some respondents stopping ART:

> I was tired of taking [the tablets] because they also distorted my body shape. It became bad, I started to develop a hump at the back, and my belly was big… [HCWs] told me that the pills were the cause of that… I reported that the pills were giving me problems but they did not do anything about it. They kept telling me it will be better with time but it didn't. It's like they just didn't listen or care about me… So I stopped. I just stopped the pills. (Female client, LTFU 01).

The complex processes resulting in clients abandoning ART also influenced their decisions to re-engage in HIV care. Fear of reprimand by HCWs was a prime reason for respondents' reluctance to re-engage in care.

Economic and social circumstances underlying mobility

Uncertain economic circumstances and unemployment led respondents to seek jobs elsewhere and to food insecurity, which was compounded by the feelings of hunger respondents associated with ART:

> You know my sister, these pills are very good but, ey, they demand that you eat a lot. Because I am not employed and do not have money to buy food I decided to stop taking them. Maybe I will go back when I get a job and are able to buy food. (Male client, LTFU 07).

Others mentioned that ART made them fall ill, which meant lost income or unemployment:

> When I started taking the pills I experienced abdominal pains and diarrhea. They also caused bile… I was very sick and bedridden… I left my workplace to go home because of the sickness caused by the pills… I decided to stop them… I feel ok now [after stopping the ARVs], so I see no reason for returning to start the treatment again, especially because they made me very sick when I took them. (Male client, LTFU 10).

Mobility also disrupted the stability of or accessibility to support networks. A treatment supporter described how the influence of her granddaughter's peers led to her running away from home and abandoning treatment. For one respondent, whose job required him to spend weeks away from home, being abandoned by his wife, who acted as his treatment supporter, led to him stopping HIV treatment:

> When she left I had no one [to fetch the ARVs]… Okay, I missed my appointment but the tablets were still there. Then the tablets got finished and as time went by I just

> thought that there was nothing to do. Then I said let the will of God be done, if I die then I'll die… I reached a time that I gave up since I felt I am no longer a person in my family. They don't like me. I think if I can die maybe. I think I have two or three weeks still deliberating about this… So I am nothing at home so that is why I thought if only it was possible for God to take me, let him take me because I can't commit suicide since it is a sin… (Male client, LTFU 08)

For this man, the negative psychological impact of family troubles became intertwined in the chain of events that led to disengagement from care. But his story also highlights how harmonious social relations (e.g. a supportive partner) may mitigate or compensate for mobility related challenges to continuing antiretroviral treatment.

Negative emotions as a cross-cutting theme

Psychological factors were mentioned by most participants, with negative emotions (e.g. anxiety, fear) shaping decisions about care. As mentioned, nurses' lack of understanding about the circumstances that caused clients' mobility and complicated adherence led to feelings of hurt and anger. Anticipated stigma also featured prominently: concerns about stigma made respondents reluctant to disclose their HIV-status and they sometimes felt continuing treatment could lead to unintentional disclosure. Anxieties about unintended disclosure were related to the risk of partner violence or abandonment, losing a job, or social marginalization and, for some, became an added reason for discontinuing ART. This was particularly the case for women who were economically and socially dependent on male partners:

> I found a partner and I couldn't bring myself to tell him. I did not tell him in the beginning [when we met] so it became hard to continue taking the tablets because he would find out… So I thought what if he became violent, or leave me, something like that. So I decided not to tell him. (Female client, LTFU 01).

For some respondents, a positive health outcome combined with fear of stigma became the final reason to discontinue ART. Having lied to their partners about the pills they were taking while visibly sick made it difficult to continue taking them when they looked well again. Rather than risking being "caught" by her partner, one respondent opted to stop taking treatment:

> My partner could see that I was now alright. So, if I continued taking the pills how could I explain that? So I stopped… He will leave me if I tell him [about my HIV status]. (Female client, LTFU 06).

Mobility figured as a primary trigger in some narratives about loss to follow-up, but ultimately it was respondents' navigation of the precarious social, economic *and* medical landscape that led to disengagement from care. In this chain of events, decisions were shaped by practical reasoning and emotional appraisals.

DISCUSSION

The interviews with LTFU clients in Swaziland reveal how mobility can trigger a chain of events that leads to disengagement from care. In the process that leads to loss to follow-up, mobility is often entwined with precarious employment, care delivery, interactions with health workers, lack of social support, anticipated stigma and ART-related side-effects, including the exacerbation of hunger.

Reasons for discontinuing ART have been typically described as complex (Skovdal et al., 2017; Ware et al., 2013). The thematic analysis revealed similar reasons for disengagement from care to those described by Ware et al. who identified competing social and economic demands, violence, lack of family or community support, and dissatisfaction with care (Ware et al., 2013). Several studies have identified HIV-related stigma as a barrier to accessing ART or retention in care (Anderson et al., 2013; Li et al., 2014). Fear of violence and/or rejection by a partner are commonly reported as a barrier to accessing HIV care, particularly for women. Extensive research highlights the relationship between HIV status and intimate partner violence following disclosure by women (Anderson et al., 2013; Durevall & Lindskog, 2015; Li et al., 2014), including in Swaziland (Dlamini-Simelane & Moyer, 2017b; Mulrenan et al., 2015). In a similar way to stigma, violence can be anticipated or enacted. Across SSA, most women who disclose their HIV status report supportive reactions from their partners, whereas a few experience partner violence and abandonment (Medley et al., 2004). Similarly, in this study, no female respondents described violence; rather they feared that intentional or accidental disclosure of their HIV status would lead to violence. Other studies have also described fear of losing one's job because of HIV (Dray-Spira et al., 2006; Sonnenberg et al., 2011).

The narrative analysis revealed how a chain of events had triggered a series of decisions leading to the discontinuation of treatment. In this process, reasons became intertwined in complex and individualized ways. Respondents initially described relocation or mobility as their main reason, but closer scrutiny of their accounts shows that mobility resulted from complex individual navigations of precarious and specific life circumstances and was often triggered by critical life-events. The death of one's spouse, a brother's serious illness, the marriage break-up of a migrant laborer, or the lack of freedom to refuse mobile employment or a job far from home, are experienced and presented as highly individualized events pertinent to the micro scale of everyday life.

In Swaziland, these events typify the insecure living conditions for the majority and are intrinsically linked with macro-level processes. Respondents who explained their financial predicament and the difficult choices about balancing their responsibility to their own health and caring for others, are victims of a precarious economy affected by the HIV epidemic.

Health policies that steer the procedures for patient transfers from one clinic to another are meso-level structural processes that do not align with the mobile lives of Swazis. Respondents' negative appraisals of their treatment by health staff, and the need to retell their illness trajectories over and over again speak of health providers' frustrations and challenges with structural health system issues – specimen transportation and additional administrative tasks of test and treat – beyond their control. This also pertains to the difficulties of healthcare staff to respond to clients' need for food and medication without the side-effects that undermine their quality of life.

In resource-limited, high-HIV-prevalence settings, the influence of contextually embedded everyday practices and structures means that engagement with HIV services must be considered in relation to other social practices (Skovdal et al., 2017). Ultimately, for Swazi clients, chains of events that complicate such engagement take shape in a context of dynamic and emotionally charged relationships with partners, families, peers and colleagues. Fear of stigma, violence and/or being rejected, and psychological distress related to loss can be the proverbial straw that breaks the camel's back.

The findings suggest that policy interventions to prevent loss to follow-up should be comprehensive, multifaceted, and address the organization of healthcare as well as be tailored to the situations and needs of individual clients. At a health system level, policy makers and implementation scientists should pay attention to how referral systems and inter-facility communications can be improved to support healthcare workers to provide care to mobile clients who need temporary access to HIV care in different localities. Interventions to prevent disengagement from care must consider the varied, complex and processual nature of factors involved in individuals' care trajectories, and recognize the key issues around re-engaging with care.

Because such trajectories are largely unconnected to clients' specific characteristics, but are rather linked to specific occurrences in their lives, healthcare providers must recognize such events as risks to disengagement from care, understand how they accumulate, and be able to effectively intervene. Healthcare providers need (knowledge, attitude and skills) training to help clients overcome difficulties in adhering to treatment or to facilitate re-engagement in care of those who temporarily abandon treatment. Health staff must be informed of the social and economic challenges that LTFU clients face, plus their reasons for stopping ART. They also need an in-depth understanding of clients' efforts to re-engage with care. Training is also needed to strengthen healthcare workers' ability to reflect on their feelings (of disappointment, failure, anger, prejudice) when faced with clients who (temporarily) abandon treatment, to avoid these (understandable) feelings becoming a factor in the process leading to clients discontinuing treatment.

Finally, healthcare workers must be trained to identify signs of disengagement from care and to intervene at any point in the chain of events to help clients re-engage with care. A concise and practical (decision-making) tool that would help staff to attend more closely to clients' dilemmas and needs and identify solutions is needed. Mobility, as a potential starting point for a chain of events that leads to loss to follow-up, should be a focus in this instrument.

Strengths and limitations

This is the first study in Swaziland to explore – from clients' perspectives – reasons for discontinuation of ART under test and treat in a context of high mobility. Combining in-depth thematic and narrative analysis highlighted the complex sequential intertwinements of reasons for disengagement. Using qualitative methods, this study revealed the importance of social and psychological ramifications of critical life-events and structural issues often overlooked in quantitative studies of decision-making. More interviews are needed to establish typical first events and chains of events that lead to disengagement from care. The data reflects the perspectives of clients who had disengaged from care and additional interviews with HCWs, family members, and employers would have been beneficial. A systematic comparison with the narratives from people confronted by similar events and circumstances while continuing treatment would foster understanding of resilience to disengagement from care. Another limitation is that respondents were enrolled in a large intervention study with quality and ethics of care potentially superior to the norm in other facilities.

CONCLUSION

In Swaziland, there have been remarkable achievements in terms of the rates of HIV testing and ART initiation. Disengagement from HIV care however threatens this success. Swazi clients' reasons for abandoning ART are a complex, inextricably interwoven chain of events rather than a single occurrence. During these processes, clients take action to navigate the challenges they face before deciding to stop ART. Mobility – temporary or permanent relocation far from the health facility where HIV treatment was obtained – is often the first event in such a process. Mobility commonly results from complex deliberations weighing economic, social and other circumstances, and becomes a problem because the health system poorly caters to the reality of people's mobile lives.

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CHAPTER 5

HIV support groups and the chronicities of everyday life in eSwatini

Eva Vernooij

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ABSTRACT

Drawing on ethnographic research, I examine the evolution of HIV support groups and biosociality during the “treat-all era” in eSwatini. I show how support groups are shaped by local actors to cater to a need for social solidarity that transcends diagnostic status, and thereby move beyond donors’ HIV-centric rationales to use the groups for HIV treatment scale-up. In this particular phase of the HIV epidemic, I suggest, support groups make up a particular kind of biosociality, which is shaped by shared experiences of structural vulnerability to chronic illness, and a desire to be prepared for future diseases and other misfortune.

INTRODUCTION

In the early years of the HIV epidemic, support groups first arose in response to the lack of AIDS medicines available, the need to cope with feelings of desperation brought on by facing inevitable death, and stigma toward people with the disease (Moyer & Igonya, 2014). In subsequent years, support groups also became spaces of political action where "treatment activists" came together to improve access to, and the quality of, antiretroviral therapy (ART) by challenging the scientific terms and practices of HIV/AIDS clinical trials (Epstein, 1996). Whilst common identities, levels of equity, and political actions characterized the activities of many HIV support groups in Euro-American nation states (Lorway, 2017), anthropological research carried out in low-income settings (e.g., Lyttleton, 2004; Nguyen, 2007; Rhine, 2009) shows how different kinds of belonging and citizenship were fostered in support groups in the absence of state-run public health systems.

From the mid-2000s onward, the availability of HIV treatment has increased, in part due to the vigorous campaigning of treatment activists (Robins, 2006). In under-resourced health systems, the struggle for treatment access has been characterized by governments and donors focusing on sustaining adherence to ART to prevent drug resistance from emerging (Hardon & Dilger, 2011). During this period, support groups became institutionalized and facility-based support groups emerged in hospitals and clinics, often co-created and facilitated by health workers and NGOs. These groups served as an extension of "adherence counseling," helping to produce compliant patients (Mattes, 2011; Mfecane, 2011). Ethnographic research undertaken during the early years of treatment scale-up showed that support groups were attractive to people, not so much because of their political goals but because they offered a chance to (re)gain access to material resources, which assisted in (re)building economic and social lives to adjust to HIV as a long-term chronic condition (Benton et al., 2017; Reynolds Whyte, 2014; Russell & Seeley, 2010; Moyer & Igonya, 2014).

Since 2010, the rollout of large-scale HIV treatment programs has expanded globally and HIV treatment has been increasingly promoted as the main method to end the HIV epidemic (Walker, 2020). The potential use of HIV treatment as a tool to curb onward transmission by lowering people's viral load, also known as "HIV treatment as prevention" (TasP), is the mainstay of the Joint United Nations Programme on HIV/AIDS's (UNAIDS) global strategy to end AIDS by 2030 (UNAIDS, 2014). In 2015, the World Health Organization recommended HIV treatment to be offered to all HIV-positive people regardless of their immunity status (i.e., their CD4 count), which has become referred to in policy circles as the start of the "treat-all era" (Fox & Rosen, 2017). The increased accessibility of HIV treatment has stirred global health rhetoric that HIV is normalized and the conceptualization of HIV as a chronic and manageable disease now underlies current global health "end of AIDS" discourses (Kenworthy et al., 2018; Sangaramoorthy & Benton, 2012). However, this biotechnical starting point for articulating the future of AIDS in relation to the viral suppression of entire populations obscures the continuous uncertainty, complexity, and chronicity that a life with HIV and AIDS involves for people infected and affected by it (Kendall & Hill, 2010; Moyer & Hardon, 2014; Philbin, 2014). HIV treatment scale-up has stimulated governments of low-income countries to seek new ways to sustain mass treatment programs now that ART is promoted for every person living with HIV in the “treat-all” era (Colvin, 2014). One way identified involves encouraging support groups to convert into community spaces where people pick up their ART medications (so-called Community Adherence Clubs) in an effort to reduce the burden on the health system caused by the increased numbers of people eligible for treatment (Grimsrud & Wilkinson, 2021). Such new social forms, as well as the enumerative techniques which underlie the management of a growing population on HIV treatment, have the potential to engender new forms of belonging and to co-construct (group) identities (Sangaramoorthy & Benton, 2012). In this article, I explore the evolution of support groups in the Kingdom of eSwatini, formerly known as Swaziland, a country heavily affected by HIV, and examine the attraction of support groups during the treat-all era, and the kinds of belonging fostered within them.

Biosociality, chronicity, and the attractiveness of support groups

Throughout the different phases of the HIV epidemic, support groups have occupied a key space where (medical) anthropologists studied the relationship between the emergence of social relations and processes of biological self-understanding (Moyer & Nguyen, 2016). Generally, support groups have been regarded as spaces for people living with HIV to discuss concerns about their shared diagnosis (Mfecane, 2011). The formation of new identities and groups based on a shared diagnosis and experience of illness has been coined “biosociality” by Rabinow (1992). Rabinow’s notion of biosociality extends from Foucauldian conceptualizations of “biopower” and “biopolitics” (Foucault, 1976: 243), and refers to power exercised on the body through particular modes of “subjectivation” – processes through which individuals are brought to work on themselves under certain forms of authority “in the name of their own life or health, that of their family or some other collectivity” (Rabinow & Rose, 2006: 197). The notion of biosociality and biopolitics have since been applied to study new forms of citizenship, including biomedical and therapeutic citizenship. In this context, they refer to political claims made by people living with a shared biological condition or therapeutic predicament to (inter)national governing bodies (Benton, 2015; Kenworthy, 2017; Nguyen, 2007; Robins, 2006).

Several scholars have questioned the development of biological identities or therapeutic citizenship through participation in support groups and have portrayed such groups as spaces where domestic forms of citizenship are enacted and structured according to gender and social class (e.g., Igonya, 2017; Kalofonos, 2010; Lorway, 2017; Marsland, 2012; Le Marcis, 2012; Rhine, 2009; Reed, 2016). Furthermore, Paparini & Rhodes (2016) have questioned whether the notion of biosociality and biopolitics, and particularly therapeutic citizenship, have lost some of their analytical power due to the ready availability of HIV treatment; as the notion was originally developed by Vinh-Kim Nguyen (2007) at a time when ART was scarcely available in the public sector in Burkina Faso and the Ivory Coast.

Extending the body of work researching the evolution of support groups throughout different phases of the HIV epidemic, and the particular forms of (bio)sociality and belonging they may generate, I seek to explore the formation and attraction of support groups in times of HIV treatment as prevention (TasP). To understand what draws people together in collectives, I draw on the notion of the "chronicities of everyday life" (Manderson & Smith-Morris, 2010:11), to capture how people navigate and normalize HIV risk and the risk of other chronic illnesses in their daily life circumstances. Using this term, Manderson and Smith-Morris (2010) seek to accentuate the structural factors, referring to inequalities of all kinds, including gender, ethnicity, age, and class, which create and exacerbate conditions of vulnerability and shape responses to disease. The notion of "chronicities of everyday life" links closely to what Bourgois et al refer to as "structural vulnerability" (2017: 17), to explicate how everyday conditions of vulnerability, embedded in wider "socioeconomic, political and cultural/normative hierarchies", can place people at risk for negative health outcomes.

In medical anthropology scholarship the notion of structural vulnerability was originally proposed by Quesada et al. (2011: 346) to capture "the embodiment of discursive, symbolic and psychodynamic effects of power", besides and beyond the larger economic and political forces, highlighted more in the theorization of "structural violence", a central concept in the field of medical anthropology (Bourgois and Schepher-Hughes, 2004; Farmer, 2004). One particular dimension of structural vulnerability highlighted by anthropologists studying HIV in sub-Saharan African settings, is how local gendered norms have an impact upon HIV acquisition and transmission (Adams & Zamberia, 2017; Dlamini-Simelane & Moyer, 2017b; Kendall & Hill, 2010; Verheijen, 2013). In my analysis, I focus on how gendered vulnerability and social and economic inequalities shape people's experiences of HIV risk and lead to the normalization of anticipated chronic illness. The everyday chronicity of HIV risk, rather than narrow diagnostic identity, I argue has become a powerful motivation to join support groups, and a basis for shared identity, particularly for HIV-negative married women.

In the following sections, I first provide more context about the study's setting and methods. Subsequently, the discussion of findings is included in a section that describes the formation of support groups in eSwatini both at the national level and in my main fieldwork locality. Following this is a section that discusses the structural conditions of everyday life that motivate people to join support groups in times of TasP. I show that the increased attention and available funding for HIV TasP in eSwatini led to the revival of old HIV support groups and the formation of new groups. However, I found that whilst some people join the groups because of a shared biosocial identity, they appeared attractive to people with different kinds of chronic conditions besides HIV, but also for people without any specific diagnosis, because they catered to a need for social solidarity in the context of vulnerability to chronic illness in general. I suggest that, in situations where prevention of HIV infection is difficult due to structural vulnerabilities, a condition of "chronic awareness" is fostered in which people get accustomed to living with, and anticipating, HIV and other chronic illnesses.

Study setting

The Kingdom of eSwatini is a former British protectorate and considered Africa's "last absolute monarchy." It has a population of 1.1 million people and borders South Africa and Mozambique. Administratively, the country is divided into four regions which are themselves split into 55 *tinkhundla* [constituencies]. These *tinkhundla* are administrative subdivisions;

each is made up of a cluster of chiefdoms that together form the political structures through which eSwatini's governance is organized. Post-independence, eSwatini's Ministry of Health started decentralizing public health services to the point that approximately 80 percent of the population lives within eight kilometers of a health facility (Whiteside & Whalley, 2007). Tertiary care is provided through several government and mission hospitals, whilst secondary care is available in health centers with in-patient facilities. Primary care is provided through government, mission, and private-sector clinics, as well as through the more than 5,000 community health workers known as rural health motivators (RHMs) [*bagcugcuteli*], a role created in 1976 (Walker et al., 2020). Each chiefdom has several RHMs, who live in the chiefdom and visit about 30 households in their neighborhood each month, assess health problems, educate rural communities about illness prevention, and encourage people to seek (biomedical) care services when they are ill. The RHMs have been involved in HIV prevention efforts since the 1990s as providers of health education and home-based care for people living with HIV, and are often active participants in support groups, as will be further discussed.

Since the first HIV infection was diagnosed in 1986, eSwatini has experienced a steep rise in HIV infections and succumbed to a generalized epidemic affecting all age groups. It is commonly said to have the world's highest HIV prevalence: as high as 27 percent among 15- to 49-year-olds (GoSL 2019). HIV infection is five times as high among women compared to men (26 percent compared to 5 percent), with peaks among middle-aged men and women (54.2 percent among females aged 35–39 and 48.8 percent among males aged 45–49 (Bicego et al., 2013). Historical, political, and economic conditions thought to underlie the HIV epidemic include underdevelopment during colonial and post-colonial periods, economic dependence on migrant labor in the South African mining industries, the collapse of subsistence agriculture, and the effects of international trade agreements (Hickel, 2012). Other structural forces cited as having contributed to high transmission rates are deteriorating healthcare infrastructure, pressures for transactional sex, gender inequality and sexual violence, and the late arrival of ART (Hickel, 2012). ART became available free of charge in the public sector in November 2003, but was only provided in 14 percent of eSwatini's health facilities until 2006 (WHO 2008).

Anthropological research among adults and adolescents in eSwatini has revealed that, despite greater access to HIV testing and antiretroviral therapy, HIV stigma has persisted (Root, 2010; Shabalala et al., 2016). Due to the organization of kinship and marriage systems, women appeared to be at greater risk of losing their livelihood after HIV disclosure (Root, 2010). In traditional conceptualizations of kinship structures a Swazi family is patrilineal, patrilocal, and patriarchal (Kasenene, 1993), and marriage signifies the linking of two families rather than two individuals (Kuper 1986). Married women move in with their in-laws and, in case of a divorce (which is difficult under customary law), a woman would be expected to move back in with her own parents, leaving her children (who became the legal "property" of the patrilineage when their parents married) with her in-laws (Ibid). Ethnographic studies have however revealed that kinship ties, gender norms, and family structures can be challenged in response to the widespread loss experienced as a result of high mortality rates among those suffering from HIV, particularly during the period before ART was available (Golomski, 2014; Reis, 2008).

Methodology

The data presented in this article are part of a larger ethnography studying the design, rollout, and responses to HIV TasP in eSwatini. As well as conducting ethnographic research as part of my doctoral research, I worked as the social science coordinator within a multi-disciplinary consortium known as *Max*ART. The *Max*ART consortium conducted an implementation research project to evaluate the acceptability, outcomes, and scalability of TasP (also known as "early ART," "immediate ART," "Test and Treat" or "Treat-all"). Using "insider" ethnography, I studied the ways in which HIV TasP became contextualized and transformed at the policy levels, in the health system, and by community-based actors during the implementation of the *Max*ART project (between 2014 and 2017). Fieldwork occurred in several scattered localities throughout this period, including a study community in the northern Hhohho region, Ntfonjeni Inkhundla, where I spent 10 months. I started my first period of fieldwork a couple of months prior to the commencement of the *Max*ART project, which aided my ability to build up rapport within the community among, for example, support group members and clinical workers outside of my involvement with the *Max*ART project.

Ntfonjeni consists of seven chiefdoms. Each chiefdom had a support group. I visited each of these seven groups, but spent the most time with four groups, each of whom I visited four to six times. I visited 18 individual members of these four groups in their homes to learn more about their personal circumstances and support group membership. Through this self-selected sample, I interviewed 20 people during my home-visits (17 women and 3 men – one interview was with a couple and during another interview other female support group members spontaneously joined). The uneven ratio of women interviewed was illustrative of the wider female/male ratio in these support groups.

Whilst I did not ask support group members about their HIV status during the interviews, nearly all of them volunteered this information during our conversations. Of the 20 people interviewed, 12 mentioned they were HIV-positive and were taking antiretroviral treatment, seven said they were HIV-negative, and one person did not disclose her HIV status. Of the HIV-positive members, four women were co-founders of the four different support groups. Of the 20 people interviewed, nine were widow(er)s (five HIV-positive members, three HIV-negative members, and one member of unknown HIV status); eight were married (four HIV-positive members and four HIV-negative members); and three women, all HIV-positive, were neither married nor living with a partner. The majority of the support group members were either unemployed and depended on their husbands' income (two husbands worked in mines in South Africa and one in a factory) or were self-employed and engaged in small-scale business such as weaving and selling mats or foodstuffs. Only two (female) members interviewed were employed; both worked as rural health motivators.

The majority of the support group members were Swazi, with several members having grown up in South Africa, which borders the constituency. My siSwati language skills were sufficient to hold simple conversations with those in the support groups but too limited to conduct in-depth interviews, so I conducted interviews with the help of a female Swazi field assistant who provided direct translation, which enabled further probing. We usually brought small refreshments (fruit, buns, and juice) when visiting the groups. The interviews were transcribed verbatim and translated into English by a native speaker experienced in translating qualitative interviews.

I additionally conducted five key informant interviews. These key informants included two co-founders of the first HIV support group in eSwatini, two (former) Ministry of Health officials responsible for establishing public health and HIV laboratory services during the late 1980s, and a project manager of a humanitarian organization that funded support group activities. The key informant interviews were conducted in English, and all interviews were transcribed verbatim and coded using NVivo. The study received ethical clearance from the eSwatini Scientific and Ethics Committee and the University of Amsterdam. All participants verbally consented to being recorded. Names of the support groups and their members are pseudonyms except for the co-founders of the first established support group in eSwatini, who preferred not to be anonymous.

The formation of support groups in eSwatini

The first support group for people living with HIV in eSwatini was set up in 1989 by HIV counselors working in the AIDS Information and Support Centre in Manzini, supported by an international NGO and the UNAIDS. In the early days of the group, the goal was to address self-stigma by creating a safe space to discuss everyday struggles and lonelinessi-HIV . The *Pioneers* support group gradually developed into the first national organization of people living with HIV: the Swaziland AIDS Support Organization (SASO). SASO's members, under the leadership of Hannie Dlamini (regarded as the first person in eSwatini who publicly disclosed his status in 1995), started to do "community mobilization" – which entailed going to communities, schools, churches, and workplaces to share testimonies of living with HIV –with the aim of fighting discrimination and encouraging other people to get tested for HIV. Hannie Dlamini was not a *treatment* activist; on the contrary, he was known for not taking ART and instead promoting healthy living and a vegetarian diet. He and other SASO members referred to themselves as "community activists" instead. Dlamini only started taking ART in 2013, more than 20 years after his diagnosis. In 2004, SASO, together with the two other main community-based HIV organizations, Women Together and Swapol, formed an umbrella organization known as the Swaziland Network of People Living with HIV (SWANNEPHA). SWANNEPHA became financed by (inter)national government agencies including the eSwatini Ministry of Health, NERCHA (National Emergency Response Council on HIV and AIDS), and UNAIDS, and acted as a coordinating body through which international funding would be distributed to affiliated support groups. As of 2005, when HIV treatment scale-up became a primary focus of the eSwatini Ministry of Health, Dlamini's promotion of a vegetarian diet to stay healthy became controversial. He was increasingly shunned by HIV policymakers who desired "community activists" to endorse the scale-up of HIV treatment in Swaziland. He was fired from his position as an "expert client"[21] by the eSwatini government, a role he argued he had helped to establish, and ended his engagement with SASO and SWANNEPHA, which he argued had been "hijacked" by governmental actors. SWANNEPHA continued to exist and at the time of fieldwork there were around 300 support groups registered with the umbrella body (Personal communication SWANNEPHA 2017). The four support groups I visited regularly in Ntfonjeni were all registered with SWANNEPHA, but the formation of these support groups was shaped by a variety of other actors, as discussed below.

Eating pills for the rest of your life: local conceptualizations of support groups

The oldest support group in Ntfonjeni was *Asibambane* [coming together] support group. One of the oldest members of the group, Make[22] Gamedze, a sociable woman in her late 50s, had been working as an RHM for over 30 years. She explained that she had not succeeded in establishing support groups earlier in the epidemic because people feared public disclosure: "We are under the Health Ministry, who was preaching to us to build the support groups. It was hard… we were supposed to build the support groups but the sick ones didn't allow the situation." The work of RHMs entailed visiting about 10 households per day three days a week and earning a meager 350 emalangeni per month (roughly equivalent to 20 euro). They served to link the governmental clinics and the community; their job entailed encouraging people to seek biomedical healthcare when ill and reporting back information gathered during their household visits to the eSwatini Ministry of Health. The collection of information (including information about HIV and tuberculosis [TB] tests and treatment) by RHMs during household visits made some people view RHMs with ambivalence, which likely contributed to the challenge of forming support groups early on in the epidemic (before HIV treatment was available).

Asibambane support group was formed by an HIV-positive widow who was the first person to disclose her HIV status publicly during a chiefdom meeting in 2005. One of the earliest activities of *Asibambane* support group was advocating for the decentralization of ART through participation in protests in the capital city, Mbabane. Until this time, ART had been only available at the nearest district hospital in the town Piggs Peak, a 1.5 hours' drive from the support group's chiefdom. Except for *Asibambane* support group, none of the other groups mentioned whether their activities included advocating for antiretroviral therapy, likely related to the fact that the majority of the other support groups were formed after ART services were decentralized.

After HIV treatment became decentralized in the area in 2007, *Asibambane* group began organizing income-generating activities, such as producing Vaseline-based skin products,

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[21] In eSwatini, an expert client is "someone who is living with HIV and actively taking antiretroviral medications, who has demonstrated good adherence to treatment, encourages others living with HIV to seek treatment, and is willing to disclose his or her status and share the experience of living with HIV with other patients" (Dlamini-Simelane and Moyer 2017a: 3).

[22] In siSwati, a woman who is older than you is called by the title "Make" [mother] followed by their surname or clan name. Someone younger is typically called by their first name. In this article I follow these naming conventions, as I did in conversation with the support group members.

and received nutritional education and food gardening support from various organizations including SWANNEPHA, the Red Cross, and the US Peace Corps. As the profit made from the Vaseline products was disappointing, the group started falling apart but kept meeting infrequently. At the time of fieldwork, *Asibambane* support group was being "revived," which is how support group members referred to the renewed interest of SWANNEPHA and other actors in their group, discussed further below. This meant that the groups were working on (re)writing their constitution and membership criteria when I visited them, which provided insights into the bureaucratic procedures and the (in)significance of diagnosis.

During a visit in July 2014, the constitution – in which the membership criteria, duties, and activities of the group were stipulated – was being revisited. The group's overarching goal emphasized the dual importance of health education and care, which was articulated in the group's constitution as follows: "To meet, learn and teach each other on health and take care of each other since this is a group of people living with HIV and those affected." However, members were not required to disclose their illness, as the RHM Make Gamedze explained:

> A support group is an organization for people that are ill that are on treatment for the rest of their lives. It could be TB, HIV, BP [high blood pressure], and asthma. Also diabetes. We have not reached that far to disclose to someone next to me that I have this type of illness. We have not talked about that to be honest. We rural health motivators educate about health-related issues.

Besides Make Gamedze, there were two other RHMs in the *Asibambane* support group. The RHMs seemed to play an important role in shaping the composition of support groups, as many of the support group members I interviewed were approached by an RHM who invited them to join the group. Since RHMs pay monthly visits to people's homes, they tend to be aware of people's health, social, and economic circumstances and invite only people who they believe would benefit from being part of the group. Whilst engaging in everyday speech, community members referred to support groups as being for people who are "eating pills"[23]; however, the actual membership criteria of these groups were elusive. All four support groups I visited were regularly chaired by a person living with HIV, and usually someone on ART. However, only one of the support groups was exclusively open to people living with HIV. Most groups mentioned that "knowing your HIV status – positive or negative" was the sole health-related criterion for membership. Hence, rather than a focus on public disclosure and a shared biosocial status determined by a positive biomedical diagnosis, characteristic of the early national-level support groups, these support groups promoted self-awareness of one's HIV status as a primary prerequisite for membership. Besides *Asibambane* support group, two other groups were being "revived" and three others were newly forming in Ntfonjeni, encouraged by different actors involved with the rollout of TasP, as discussed in the following section.

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[23] "Eating pills" [*kudla emphilisi*] commonly refers to taking antiretroviral treatment, but not in all cases; it can also be used for any other kind of pill—for TB or high blood pressure, for example.

Health education and the biopolitical potential of support groups

Siyaphila [we are alive] was a new support group that had recently started convening at a run-down community center, a ten-minute walk from Ntfonjeni's clinic. When my field assistant and I visited the *Siyaphila* support group, the initiator of the group, Make Tsabedze, was busy moving soil using a wheelbarrow whilst grumbling to herself about the lateness of the other members and how she could have been using the time to earn money by sewing in her workplace. Make Tsabedze was a widow, a lively woman well into her sixties who could not remember when she had started ART: "I started before the patient booklets existed!" This was the second time *Siyaphila* support group was convening, and today a community expert client from the nearby clinic was visiting. The expert client was employed through World Vision and explained that she had attended a workshop coordinated by the eSwatini Ministry of Health about community ART adherence clubs a month ago. She had taken one of the support group members to be "workshopped" on the government and partners' interest in dispensing HIV treatment at the chiefdom level, and expert clients were expected to spread this message. She was therefore visiting all support groups in the constituency, after which she would report the number of groups to World Vision. The support groups, in return for giving their contact information, received health education from the expert client. After providing the support group members with information about the importance of eating a balanced diet, the expert client mentioned to the group:

> I don't know how you feel about it, but I feel that people who do not have HIV, diabetes, and TB should be allowed to join the group because I have seen that they can help. They help because they enable those who have not accepted their status to feel free to join because people will not know which illness they have. That person will eventually be able to disclose.

The expert client was thus also trying to shape the formation of those support groups not exclusively for people living with HIV. Membership criteria, she suggested, should be left unspoken so as to attract people living with HIV and help them come to terms with their HIV status. The purpose of this fluid membership model seemed to be to de-stigmatize HIV.

Whilst it appeared that the expert client was actively de-centering the focus on HIV in support groups with a longer-term goal of "accepting" one's HIV status, for other local actors shaping the support group's formation there was no particular importance given to any health-related criterion. In a subsequent visit, I observed the support group members working on their constitution, in which they did not mention any health-related conditions but instead stated that membership was related to one's relational and economic situation: "Someone who is not working and is unemployed; someone who is able to work; someone who is married from the area; someone who carries himself or herself with dignity."

The founder of *Siyaphila* group, Make Tsabedze, was also one of the first people to disclose her HIV status in her chiefdom (similar to the founder of *Asibambane* group). Since her disclosure, Make Tsabedze's motivation to form support groups was focused on supporting her fellow community members and improving their livelihoods. She argued:

> We started because it was a problem for some to secure food, some do not have money, they do not have ideas they can action to help themselves the savings and loans scheme helped them to get whatever they can to buy themselves food.

HIV-positive initiators of two other support groups stated in interviews that one of the additional reasons for forming a support group was to provide a space for emotional support, as "you cannot be too alone", as well as livelihood support (i.e. agricultural products). Yet, for international donors (including the US government's President's Emergency Plan for AIDS Relief [PEPFAR-CDC]) who financed the majority of the expert clients, a focus on livelihood support was found to be "against CDC rules," as the key informant from World Vision argued. Instead, the CDC wanted them to do "health education."

Health education in eSwatini featured as a constant activity sponsored by different (inter)national actors throughout the different phases of the HIV epidemic. During the rollout of HIV TasP through the *Max*ART project, SWANNEPHA, the national network of people living with HIV, was involved in facilitating health education for support groups, which included "human rights and responsibilities" training in relation to starting HIV treatment early. In addition, support group leaders were trained by the *Max*ART study team to perform community mobilization in order to "create demand" for study enrolment by informing people in their own communities about the importance of early treatment initiation. Demand creation was also noted to be an important, but failed, part of an earlier public health intervention focused on HIV prevention; a countrywide male circumcision campaign (Mkhwanazi, 2020). In the *Max*ART project, the demand creation activities generated (as a by-product) the formation and revival of support groups, who were hoping to receive more tangible livelihood support through their engagement with SWANNEPHA.

For HIV-positive members interviewed, the health lessons were part of the reason why they formed a support group. For example, the HIV-positive founder of *Asibambane* support group argued:

> Mostly what we like are lessons. We are taught about health, also how we should live because we are ill people. We want to develop in our illness to reach 2022 alive, all of us alive.

The support group member referred to the speech of King Mswati III during the opening of the parliament in 2016, during which he announced the goal of achieving an "AIDS-free generation" by 2022. Health education in support groups can be perceived as an expression of biopower, whereby through a process of "subjectivation" (Rabinow & Rose, 2006) support group members learn how to live as "ill people" and foster life-long learning in the context of being "good citizens" aware of their rights and responsibilities. This shows the biopolitical potential of support groups, and highlights health education as a primary mechanism through which global health discourses are transformed by local actors in the context of the chronicities of everyday life.

Gendered vulnerability and anticipation of HIV: Why people join support groups

Make Kunene came running down the hill from where she was selling ice blocks (a flavored frozen slushy solid) to the primary school children during their lunch hour upon seeing Selly (my field assistant) and I walking from the home of her neighbor, who was in the same support group. We had been to *Siyaphila* support group twice before we visited Make Kunene, a 39-year-old mother of seven, in her homestead in a mountainous area near the border with South Africa. After exchanging greetings, Make Kunene started lamenting about her husband, who had recently married a second wife with whom he was currently residing in Mbabane. Make Kunene was upset that her husband, a former pastor in the Zionist church who she had married through a Christian or "white" wedding (in which polygamous unions are not legally recognized), had married another woman via a "traditional" Swazi wedding. Her husband and his new wife had a child together, and besides feeling hurt by his infidelity, Make Kunene was worried about her inheritance and her husband's financial support to their children. When her husband made his occasional visits, he requested to sleep with her without a condom. She had been treated at the hospital for a sexually transmitted infection and was told that her husband should seek treatment as well, but he had refused. Make Kunene mentioned that condom use was difficult to negotiate in her marriage:

> I don't enjoy it [sex] because I feel like he is raping me and it hurts just because I don't enjoy it. If it was going according to my wish he would come and go back without us having sex, unless he can use a condom, because after that I become sick … There was one day when I asked him to use a condom, but he said, "Listen Macawe's mother, I'm not cheating with you, you are my wife. I will never sleep with you using a condom."

The day before we visited Make Kunene, she went to get an HIV test and tested negative. Whilst she was well aware that the situation with her husband put her at risk of acquiring HIV, divorce was not an option for her. She explained:

> I tested because you have to when you don't trust the man you are in love with … But I will stay in my marriage. I don't want go back in my life, I have told myself that I will stay in my marriage even if it's like this. I will go when death will do us part, with my husband; if he is still alive, never!

Make Kunene's decision to stay in her marriage shows that the social value of marriage is still highly regarded in eSwatini, particularly in rural areas (see Dlamini-Simelane & Moyer, 2017b). Furthermore, it appears that, beyond the economic security marriage provides, the status of being married has moral value, also apparent in the inclusion of *being married* as one of the membership criteria mentioned in the constitution of the *Siyaphila* support group. A life condition that shapes Make Kunene's vulnerability to HIV – that is, her relationship with her partner – was a motivation for her to join *Siyaphila* support group. When a neighbor told her about a support group for people "eating pills," she was interested enough to seek more insight and encouragement in case she ever tested HIV-positive: "I see that, one day, I will also … I will end up eating pills due to the life here at home."

Another example where gendered vulnerabilities shaped the anticipation of a possible HIV diagnosis was the situation of Make Mabuza, a 39-year-old married woman and mother of six children who had lived with her husband for 25 years. Make Mabuza had joined *Asibambane* support group nine months prior to the interview when a neighbor told her about the group. She was afraid of acquiring HIV through her husband, whom she suspected was HIV-positive because of the death of his second wife. She had tested several times but was still negative. She too was unable to use condoms with her husband:

> When coming to condoms, I don't want to lie: he has never used it. That's why I'm saying I'm being helped by the Grace of the Lord and with the fact that I told my blood, that listen my blood, you are my blood so you will be controlled by me, I don't want to be ruled by you but I want to rule you.

The anticipation of HIV was echoed in the other groups as well, for example in the *Asibe Munye* [let us be one] group. One of the founding members stated:

> We didn't start it for HIV-positive people only, it was for all ill people. Those with sugar diabetes and also those with TB. Even if you've checked and found you are negative you were allowed to join because you will go to the clinic in the coming month and find you are positive. Just to have the knowledge that no matter what happens in life, you'll be accepting because you've learned.

Rather than specifically referring to gendered vulnerability, the quotation above shows how the anticipation of HIV might be more generally related to the chronic risk of HIV infection in the context of eSwatini's generalized epidemic. As the majority of the four support group members were between 30 and 50 years old, the anticipated risk of infection might be seen as realistic given the reported prevalence rates of around 50 percent for some of these age categories (Bicego et al., 2013).

Make Mabuza and Make Kunene's gendered vulnerabilities put them at risk of acquiring HIV, but it seemed that the risk of possibly losing one's children and social status made HIV risk the lesser of two evils. For these married women, the risk of becoming HIV-positive may be understood as an embodiment of structural vulnerability, one which is particularly shaped by gendered norms and marital practices. Structural vulnerability in its original conceptualization by Quesada et al. (2011) has focused on structural forces that negatively impact health and well-being. Whilst women's lives are shaped by structural vulnerability, their decision to join a support group might be regarded as a form of women's agency within the structural constraints of marriage (for a similar example of how women make use of available social structures to improve their livelihoods, see Verheijen, 2013). The individual stories of these HIV-negative women depict the gendered contours of the chronicity of everyday life in eSwatini, in which it appears that prevention of HIV is difficult due to structural vulnerabilities. Instead, support groups foster a “chronic awareness” of and preparedness for anticipated illness as an alternative condition.

Social and economic vulnerabilities

Several community members joined support groups after RHMs encouraged them to do so. For example, Make Gama, a widow who explained she was diagnosed with asthma about 15 years ago, had recently joined *Asibambane* support group after one of the RHMs had invited her because of the “many illnesses that existed nowadays.” Make Gama was particularly appreciative of the “health lessons” provided by the RHMs in the support group, which could help her—and by extension her sister’s child who was living with her since her sister’s death—come to terms with different types of illnesses. Make Gama argued; “The RHMs explain well that if I get such an illness then I will do such and such, and how do you live and welcome an illness because sometimes it’s not that easy to welcome an illness.” Becoming part of a support group thus provided her with informational, social, and emotional resources that could assist her in the case of illness. In this sense support groups play a role in the management and expectation of (future) illnesses, and make up a particular kind of biosociality; one that is characterized by a shared anticipation of disease(s), rather than the disease(s) itself. The importance of health lessons for HIV negative members suggest that self-awareness is seen as holding particular value through encouraging preparation for potential future illness by teaching people how to handle different types of chronic illness.

I was also asked by one of the support groups to provide health lessons similar to those offered by the expert clients and RHMs. As I did not possess the medical expertise, I offered to take any questions they had to the nurses of the nearby clinic instead, and report their answers back. The topic that was of most interest to the group was diabetes. In my conversations with support group members, the severity of diabetes was often juxtaposed with HIV: for example, one HIV-positive member argued, “You live when you have HIV ... Some have lived for up to twenty years ... Diabetes can kill you faster and cancer too.” Interestingly, in one of the support groups, people with diabetes were expected to disclose their condition to the group so that if that person experienced low blood sugar (hypoglycemia) members would know what to do.

Another HIV-negative woman who had recently joined *Asibambane* support group was 31-year-old Philile, who had recently moved to Ntfonjeni area from an urban town to move in with her husband and their one-year-old son. Her husband was in a polygamous marriage and was working as a soldier, so was away often. Her primary reason for joining the support group after hearing about it from a neighbor was to have a social network to fall back on in case of an emergency: “So if I have got a problem, maybe even I have been knocked by a car, they can recognize me – ‘Ah, this is Make Dlamini, I know this person.’ I joined the support [group] for that.”

Lastly, another married woman, 30-year-old Thembi, joined *Siyaphila* support group primarily for economic reasons. Thembi had been living with her husband and their five children for the past eight years in a stick-and-mud structure. Her husband did piecework and they were struggling to make ends meet. Thembi and her husband had tested for HIV when she was pregnant and were both negative. The worries Thembi had related to her ability to feed her children were the main reasons motivating her to join *Siyaphila* support group: “Something that made me join the support group is to keep busy with the fact that I’m able to meet with people and not think a lot.” Thembi was also a member of four other savings groups in the area. Thembi’s membership of *Siyaphila* support group was thus not because of an anticipated HIV diagnosis but because it provided a welcome distraction and possible material assistance in her struggle for everyday survival. Thembi was not the only member we interviewed who cited economic reasons for joining their support group; several members, both HIV-positive and HIV-negative, were struggling to make ends meet.

The stories of these women illustrate that support groups cater to a need for social solidarity in the present as well as the future. Whilst the majority of support group members are HIV-positive, the members generally do not discuss their illness status and instead focus on equipping themselves with information on how to prepare for possible illnesses. As such, it appears that shared social and economic vulnerabilities bind support group members to a greater extent than shared diagnostic identity or pill-taking.

CONCLUSION

While HIV remains exceptional in terms of the availability of treatment and international funding, in most support groups HIV diagnosis no longer takes center stage. Nonetheless, current efforts to promote early ART initiation and adherence to HIV treatment in eSwatini ignore the shifting needs and changing memberships of support groups and instead continue to place HIV at the center of interventions implemented with the help of support groups. Ethnographic research can help better align the kinds of assistance support groups may need by providing insights into the structural vulnerabilities that draw people to support groups in the first place.

Whilst the first support groups in eSwatini focused on stigma reduction by means of disclosure and by fostering a specific identity based on a shared diagnosis, their ambiguous relationship with HIV treatment scale-up resembled what Lorway has called “begrudged biosociality,” referring to “friction embodied in their relationship to biomedicine” (2016: 37). Whilst support groups in eSwatini were locally seen as places for people who are “eating pills,” very limited time was spent discussing matters of HIV and ART during support group meetings and there was little interest amongst members to turning support groups into the so-called Community ART Adherence Clubs. The primary reason for this is that most members did not disclose any illnesses they might have and, as such, these clubs were never implemented through the *Max*ART program. The adherence clubs are, however, currently being mobilized in response to the COVID-19 pandemic, in an effort to limit contact moments in health facilities for HIV-positive people (Grimsrud & Wilkinson, 2021). Given the continuous attraction of support groups to public health interventions, it is pertinent to understand the local constellations of support groups and conceptualize them as social formations of people who share similar anticipations, anxieties, and social and economic conditions, rather than sharing a specific biomedical illness or diagnosis.

The revival and formation of new support groups during the rollout of TasP show that support groups are responsive to various international funders' agendas, which resemble insights from other ethnographic work about the evolution of support groups in other sub-Sahara African countries (e.g., Benton, 2015; Igonya, 2017; Kenworthy, 2017). But my findings indicate also that besides being responsive to donor priorities, local actors such as RMHs and expert clients are actively shaping the composition of support groups to be responsive to local chronicities of everyday life. The way support groups broaden the criteria for membership to anyone affected by structural vulnerabilities and chronic illness conditions that face eSwatini society, make up a particular kind of biosociality. In this phase of the epidemic in eSwatini, the binding 'bio' is not a shared diagnosis or illness condition, but more broadly a concern about anticipated chronic illness, and a desire to be prepared for future misfortune. Having a support group is seen to be key to live in conditions of precarity and under the perpetual threat of chronic illness in the present and future.

Of late public health studies have reported a decrease in new HIV infections in eSwatini that has been attributed to the substantial scale-up of HIV testing and HIV treatment (Minnery et al., 2020). In fact, eSwatini was recently announced to be the first African country to reach UNAIDS's global "95-95-95" target (95 percent people living with HIV diagnosed, 95 percent on treatment, and 95 percent virally suppressed) (The Global Fund 2020). However, recent successes of HIV treatment scale-up notwithstanding, I have shown that HIV-negative members of support groups seem to regard HIV infection as something that should be anticipated, rather than that it could be prevented. That the expectation of becoming HIV-positive appeared less frightening than becoming diagnosed with diabetes, might be interpreted as a sign of the normalization of HIV. But, as argued by Malambo & Erikson (2018), this widespread expectation also points to the scarcity of screening and treatments available for serious illnesses *besides* HIV. Furthermore, other ethnographic research conducted into TasP in eSwatini (Horter et al., 2019; Pell et al., 2019) has shown that stigma is pervasive during TasP and that health workers appropriated stigma to encourage early treatment initiation. I contribute to this body of literature by showing that in this phase of the HIV epidemic in eSwatini, it appears that it is the *risk* of acquiring HIV rather than HIV itself that is normalized.

Recent HIV prevention efforts in eSwatini are focusing on providing Pre-Exposure Profylaxis (PrEP) for HIV negative people, which initially targeted "high-risk" populations (sex workers, and men having sex with men), but was later broadened to include the general public (Bärnighausen et al., 2019). Whilst PrEP might be a suitable HIV prevention method for the HIV negative women in Ntfonjeni, such biomedical prevention technologies do not address the wider structural factors contributing to the gendered vulnerability shaping the risks and consequences of HIV. Hence, future HIV prevention interventions may direct efforts at HIV in conjunction with other chronic illnesses, as well as the conditions of everyday life shaping the ability to prevent and live with chronic illnesses.

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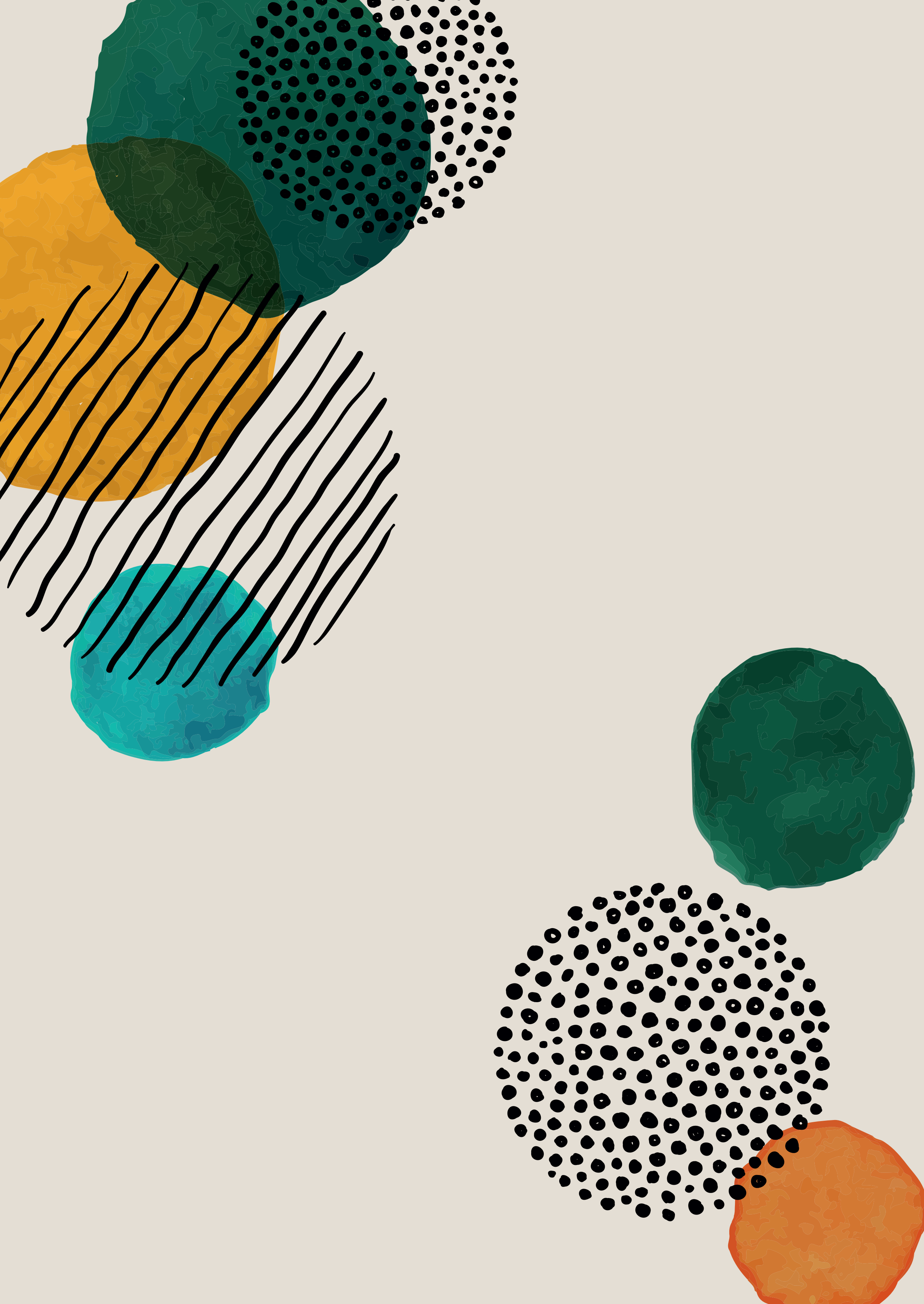

CHAPTER 6

Navigating multipositionality in ‘insider’ ethnography

Eva Vernooij

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ABSTRACT

In this article, I reflect on my experience of conducting “insider” ethnography in a multidisciplinary collaborative project that evaluates HIV treatment as prevention in Swaziland. Having worked as the project’s social science coordinator for over five years, I discuss balancing my role as an insider on the study team with studying the project as the object of my doctoral research. Drawing on field notes taken during the design and implementation of the project, I discuss how my proximity to the study team created certain expectations in my interactions with team members and clinic staff. In some instances, I distanced myself from the study by not participating or not supporting a consensus option; my doing so engendered a sense that I was being disloyal and sometimes created frustration among my colleagues. The multipositionality that I navigated was a product of social interactions and therefore inherently relational and intersubjective. This article aims to stimulate self-reflective and methodological discussions of how anthropologists engage in global health research and what kind of knowledge and subject positions such collaborations produce.

INTRODUCTION

Over the last 25 years, anthropologists have provided important critical insights into experimental HIV-related research. They have explicated hidden cultural transcripts and unintentional "social side effects" of HIV interventions (Taylor, 2007) raised ethical concerns about recruitment, consent, and confidentiality in cross-cultural contexts (Molyneux & Geissler, 2008; Reynolds et al., 2013); questioned the growing commercialization of experimental science, and highlighted the power relations embedded in HIV interventions that are carried out among economically and politically marginalized people (Biehl, 2007; Epstein, 1996; Farmer, 2001; Nguyen, 2010).

Reflecting on anthropologists' different modes of engagement with biomedicine during the AIDS epidemic, Hardon and Moyer (2014) differentiate between subaltern alignment, reflexive dialogue, and collaborative design (note these modes are not limited to HIV research, see also Hardon 2010). "Subaltern alignment", in which anthropologists reveal what is at stake for people who have little power to influence global health efforts, is arguably the most common and comfortable approach for anthropologists. Two more active forms of engagement are "reflexive dialogue", in which the anthropologist does not align solely with the subaltern but engages with different actors, and "collaborative design", in which the anthropologist does not only enter into dialogue but also participates in developing interventions with, for example, people affected by the HIV epidemic and/or biomedical practitioners (Hardon & Moyer, 2014).

Anthropologists' collaboration in experimental HIV research can take different forms, such as: executing preliminary qualitative explorations to inform interventions, instruments or designs of trials; conducting field studies and observational studies in parallel with trials in order to increase external validity, among other goals; and undertaking critical ethnographies of "trial communities" and investigating practices of knowledge production (Geissler, 2011; Le Marcis, 2015; Pool et al., 2010; Reynolds et al., 2016). Some have argued though that with the increased biomedicalization of HIV, much anthropological research has shifted toward applied qualitative health research and away from ethnographic fieldwork characterized by "deep hanging out" (Moyer, 2015). So far, there are few accounts from anthropologists (and other social scientists) working within intervention-oriented HIV research that critically reflect on what is going on in collaborative design and how it is done (Montgomery & Pool, 2011), and whether it can be mutually constructive for anthropologists and their collaborators (see Elliott and Thomas 2017, this issue, for a discussion on collaborative partnerships between anthropologists and epidemiologists). In this article, I draw upon my own experience of a collaborative research project in Swaziland to reflect on my attempts to simultaneously conduct "insider" ethnography as a doctoral student and applied qualitative research as the social science coordinator of the project I was studying.

Insider ethnography

"Insider" ethnography is often multipositioned as well as multisited (Marcus, 2008). This means that the anthropologist is not a detached observer, but rather participates as an active (and possibly paid) member of the institutional alliances and interventions under study. This may include being involved in the coproduction of research designs, tools, and interventions, and it necessitates that the anthropologist explores rather than conceals the personal connections and contributions one has as an actor in the social processes that are being analyzed (Mosse, 2005). Feminist scholars have long advocated for analyzing the positionality of the researcher and taking account of the situatedness of knowledge (Haraway, 1988). Such analysis posits that the power dynamic between the researcher and researched shapes how knowledge is created and encourages explicit documentation of the "micropolitics of research projects" (Conti & O'Neil, 2007).

Accounting for one's own subject position has received attention in various fields of ethnographic inquiry, most notably in science and technology studies and development studies, in which methodological challenges of "studying up" are discussed when studying (global) elite or powerful epistemic communities (Marcus, 1983; Nader, 1972; Ortner, 2010). In a personal reflection, Forsythe (2001) discusses the ethical and political dilemmas she experienced as an insider studying the world of artificial intelligence in the Unites States. Despite problems of data ownership and powerful informants who were able to contest how they were represented, Forsythe was largely successful in her attempt to demonstrate that ethnographic approaches can be usefully applied to analyze informatics. This, ironically, placed her in direct competition with her informants who became (more) successful at appropriating funds for doing "ethnography light", without any formal training or understanding of ethnographic theory (Forsythe 2001, 136).

From a methodological perspective, Erikson (2011, 27) remarks that when the anthropologist's attention goes "macro" – when studying government agencies and corporate boardrooms – people often go missing; scholars tend to employ fuzzy concepts, using "words like *flows*, *circulation* and *processes* to describe global phenomena", instead of providing rich ethnographic detail of social situations and the actors involved. When writing from an insider perspective in global health, this rich ethnographic detail becomes difficult to include because it tends to destabilize the interpretation of events, something that organizations are keen to control (Mosse, 2005). Besides directly censoring critical insider accounts by objecting to publications (see for example Mosse, 2006), insider ethnography can be influenced by more subtle forms of disciplinary power (Foucault, 1979) that structure behavior during fieldwork (and writing), such as when researchers internalize when to speak or when to remain quiet, without the coercion of others. Moreover, multiple and fluid alliances across different settings characterize complex global health projects and, therefore, when a project's boundaries are porous and ambiguous, insider ethnography is more contested. It may therefore be necessary to occupy different subject positions to be accepted into different field situations (for example health facilities, study investigator meetings, and community events).

In this article, I reflect on my multipositionality in the *Max*ART project. Having worked in the project over the last five years, I have familiarized myself with the public health discourse of CD4+ counts, retention-in-care, and stepped-wedge designs. In fact, I have become familiarized to such a degree that I sometimes struggle to write "anthropologically" about the project and must either forego discussing the technical details or frame them as discursive objects in the making. I also gained new managerial skills through my work as the social science coordinator of the overall project, such as producing standard operating procedures[24] and logistical frameworks. Additionally, I acquired a great deal of tacit knowledge about working in a public health project, having embodied part of its practices and language. As time passed, however, these gains made it difficult for me to distance myself because of the different loyalties that emerged. In the following sections, I describe my social interactions with study team members and health facility staff. I discuss how I balanced my role as an "insider" who was on the study team with my role as a doctoral student researching the team and facility staff. I demonstrate that this balancing act was not only an internal process but a relational and intersubjective practice. I show this by discussing three ways of "making space": 1) through writing a doctoral research protocol that provided the flexibility to study events as they were unfolding and to ask critical questions, 2) by variously aligning with and detaching from the study team to avoid being seen as one of the study's "implementers", and 3) by taking moral distance from certain decisions related to the study's design and implementation.

Changing protocols

In 2011, the *Max*ART project received 8.8 million euros from the Dutch Postcode Lottery Dream Fund to, as the project's original proposal states: 'Virtually Eliminate New HIV Infections in Southern Africa … by "breaking the back" of the epidemic in Southern Africa by using a tool the world already has at its fingertips: anti-retroviral therapy' (SAN! and CHAI, 2010, 3).

Swaziland, a small country of around 1.1 million people with a HIV prevalence estimated at 26% among 15- to 49-year-olds (MOH, 2012), was chosen as the test location for the project. Stop AIDS Now! (SAN!) and the Clinton Health Access Initiative (CHAI), who jointly wrote the proposal, argued that if they could "demonstrate that the epidemic can be halted in Swaziland, the impact would be felt and multiplied around the world" (SAN! and CHAI, 2010, 3). The project entailed two phases. In the first phase, the focus was on implementing several interventions to increase access to HIV testing and antiretroviral therapy (ART) throughout the four regions of the country under the current HIV-treatment guidelines.[25] The second phase was originally conceptualized as the HIV Treatment as Prevention "Proof

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[24] Standard operating procedures (SOP) are detailed written instructions intended to achieve uniformity across practices, commonly used, for example, by laboratory technicians to ensure that procedures are performed the same way by each person each time. In the *Max*ART study, every organisation was requested by the study's management – consisting of several people with PhDs in clinical biology – to write an SOP detailing their activities. After several unsuccessful attempts to convince the management that it was uncommon and unhelpful to make an SOP for the two social science research assistants I was working with because of our iterative approach to research, I gave in and made an SOP detailing every step from the moment of entering a field site and greeting participants to where to store informed consent forms. Whilst arguably useful for large research teams with highly standardised procedures, it was not useful for us since we tried to adapt to situations instead of standardising our actions beforehand.

[25] At the time, the guidelines by the Swaziland Ministry of Health were stipulating that people living with HIV start antiretroviral treatment when their CD4 count was below 350 cells/μl, or clinical stage 3 and 4 (MOH 2010b).

of Concept" Study, which would test the feasibility and estimate the impact of "early"[26] ART initiation on reducing new infections (SAN! and CHAI 2010, 32).

As the Treatment as Prevention study was designed, I conducted qualitative research to inform the team about the current state of HIV testing, counselling, and treatment in the facilities that would participate in the study. I designed this research with a local advisor from the Swaziland Network of People Living with HIV. We shared similar ideas about participatory ways of conducting research and involving people living with HIV in the design of interventions. Together, we trained four Swazi researchers and conducted three months of observations, interviews, and focus group discussions in eight different facilities and surrounding communities. We assessed the understanding of ART as prevention amongst health workers and people living with HIV, inquired about the key requirements they felt should be in place for the implementation of immediate ART initiation, and investigated the current state of HIV testing and counselling and ART service delivery.

In July 2013, we presented the preliminary findings at the biannual "Face-to-Face" meeting, when all eight organizations of the *Max*ART consortium convened in Swaziland, and we invited about 20 study participants (people living with HIV, health providers, and administrators) to attend the presentation. During the presentation, one of the hospital administrators asked the principal investigator why the planned study was called "Treatment as Prevention", which, in her opinion, was an ambiguous term and could lead to ART being seen as a substitute for condom use. The principal investigator, a medical doctor from the Swaziland Ministry of Health, responded by indicating that the ministry was also unhappy with the terminology, and arguing that the study should be called "Treatment for All" (for a more detailed discussion of this terminology see Vernooij et al., 2016). One of the conclusions the *Max*ART consortium drew from our presentation was that there was need for developing tailor-made health messages to explain the benefits of early ART for different groups: health providers, people living with HIV, and the general public. I became interested in studying the social processes of knowledge production and translation in relation to the project's focus and the evident concerns about correct "messaging". I therefore wrote a separate PhD proposal to study the interactions between different actors involved in the design and implementation of messages as an insider in the project.

At the same time, a public health expert from CHAI was taking the lead in writing the protocol for the Treatment as Prevention study, later renamed Early Access to ART for All (EAAA), and between December 2012 and September 2014, 29 versions of the protocol were developed. During this period, I received seven versions on which to provide feedback and to revise our social science sections, in line with the changing study design. My qualitative study with the Swaziland Network of People Living with HIV/AIDS had placed me in a more powerful position in the consortium because I had acquired experiential knowledge of the study facilities and relationships with the staff there, which were of particular interest to CHAI, and I was able to use that knowledge to try to influence parts of the study design.

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[26] "Early" ART (also called "immediate" ART) refers to starting HIV treatment immediately upon diagnosis, instead of basing the start date on disease progression and the status of the immune system (for which, in the past, CD4+ count has been used as the key marker).

When the EAAA study finally started in September 2014, it was no longer a proof-of-concept study to test the impact of early HIV treatment on reducing new infections. Instead, it was defined as an: "implementation study designed to answer critical implementation questions (i.e., acceptance and retention among patients initiated on ART at higher CD4+ thresholds) and determine the 'real world' potential of this new prevention intervention" (*Max*ART EAAA 2015, 14). In practice, this meant that the study team was tasked to implement the intervention in the 14 participating health facilities, not as a study, but rather as a new approach to HIV care. At the same time, the study had to produce usable and reliable data to inform the "scale-up" of early ART in the rest of the country and several standardization methods, such as including randomization and blinding to make the study more "robust".

Performing alignment and detachment

Adams (2016; 23) has recently described "research as intervention" as the key characteristic of global public health today, writing that interventions "must produce not just health but also statistically robust data that can be powered, subjected to chi-square or linear regressions, and then used for scaling up". The discrepancies between doing research and doing implementation created ethical dilemmas for members of the study team and shaped my interactions with the rest of the team, as the following field note excerpt illustrates.

> *22 August 2014*
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> It is a Friday afternoon in a government health clinic in northern Swaziland. Nine facility staff members, three study team trainers and I sit in the cramped tea room of the clinic for the training of the Standard Operating Procedures of the EAAA study which will commence next week. The room gets filled with the smell of Kentucky Fried Chicken, the customary lunch brought to health facilities whenever there are on-site trainings. When the trainer is explaining to the healthcare staff which steps to follow when enrolling people living with HIV into the study, another study team member, a representative from the Ministry of Health, corrects her and tells the staff they should not explain the project as a study to patients. "People don't like to be studied" she says. Rather she argues – as it is also written in the patient information guide – they should mention that the project is a new approach to HIV care. The trainer's supervisor, who oversees the clinical procedures of the study in the 14 participating facilities, questions whether this is ethical. She looks at me. Nobody responds.

At this point, I had been doing observations of HIV counselling and care practices in this clinic for four months before the study started. I was interested to learn how the study would affect HIV-prevention messages given to people living with HIV and how the staff would incorporate the study into their daily routines. I divided my time, location, and loyalties between my rural field site, where I shared a house with one of the staff members from the facility, and the CHAI office, a two-hour drive from my house, where I participated in weekly study team meetings. When the clinical study team came from Mbabane to the clinic for trainings, I tried to participate as an observer in the training to avoid being seen as one of the study's "implementers", because I feared my participation would affect the staff's perception of me and thereby their willingness to share their views. However, just a few weeks previously, during a lunch meeting with the clinical supervisor and a study team manager (both working for CHAI), I had tried to convince them to talk to the principal investigator of the Ministry of Health to change the procedures to inform people they were enrolling in a study about starting ART early, and to obtain their consent.

I remained quiet when the question about ethics came up during the training at the clinic, as I wanted to see how the health workers would react. However, I did not learn this by observing the training sessions, but rather by spending time with the clinic staff and hanging out in the clinic's dispensary. Because the dispensary is the only room in the clinic that has air-conditioning, the staff usually sit there on a hot day when there are no patients. It is also the place where I could make myself useful – helping to count pills and placing them into small plastic bags of pre-packed medications – whilst doing "participant observation". In the following two excerpts from my field notes, I describe how I negotiated my different subject positions in the field(s).

> *29 August 2014*
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> It is the day before the EAAA study starts. I am sitting in the dispensary with the nurse-in-charge, the lay counsellor, one of the expert clients, and one orderly. A study team member walks in to drop off the study enrolment stickers and forms, and the blood collection tubes for the additional viral load and resistance test to be done for study participants to generate evidence for one of the study's primary outcomes: viral suppression. She quickly explains the study enrolment procedures to the nurse-in-charge and leaves.
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> After the study team member left the staff starts discussing in siSwati how they should explain "viral load test" to patients, since the test is not routinely available in government facilities in Swaziland. Noticing that I am trying to follow their conversation, the nurse-in-charge turns to me and says in English; "we are talking about the consent now, I'm worried everyone will be consenting into the study." She explains that it is uncommon in these rural areas for a patient to refuse an offer from the health provider. Patients fear that this might damage the relationship with the provider. She asks me whether she understood correctly that they should not ask for consent for starting ART early, but just for the extra lab tests performed. I confirm this. Two other staff members walk in and we have a long discussion about their concerns about the study, which are mainly related to being understaffed and the fear that the study increases their workload without adding extra personnel. I ask why they did not mention any of these concerns to the study team during the training last week. One of the nurses explains that in such trainings there is not much room for discussion. The presence of the Ministry of Health during the training carries weight and since this is a government clinic they have to respect their authority. Furthermore, the study was going to start in

> a week, how much room for changes was there? I encourage them to share their concerns about the study with the clinical study team. One staff member gets enthused and makes a plea that if they want to change something, this is the time to act, not after the study has started.
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> *2 September 2014*
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> It is the first day of the study. I am in the CHAI boardroom for a study meeting. The clinical team is celebrating that thirteen people enrolled into the study today. The clinic in which I do fieldwork is a topic of concern, they have not enrolled anybody yet, and they have called today to ask for a meeting to discuss their concerns. I don't say anything but after the meeting I tell the clinical supervisor that I encouraged the staff to share their concerns. "Ah, so you are the culprit!", she says. A few days later the supervisor goes with a representative from the Ministry of Health to the clinic to discuss their concerns.

My attempts to disassociate myself from the study team at times, trying not to influence the situation at one moment but nonetheless stirring up debate in the next, illustrate my navigation between trying to be accepted in both field sites: the study team and clinic. I tried to be part-study-team-insider during investigator meetings and part-study-team-outsider when they visited the facility to train and oversee the study implementation. One reason for this was methodological: I did not want the clinic staff to perceive me as a representative of the study team, which could have influenced my rapport with the staff. Another reason was moral: I found it difficult to support certain aspects of the study, such as blinding the study team and participants to the timing of the intervention, which I had tried to argue against in previous meetings during the study design process. It was repeatedly argued during study team meetings that randomization and blinding would make the study more "robust". Since the 14 facilities were not randomly selected, but instead were selected to avoid overlap with another large implementation study going on, I questioned whether sequence randomization affected the robustness or power of the study. A final reason was epistemological, as I was concerned with the manner in which knowledge was being obtained. Instead of supporting efforts to control behavior by blinding, I argued in favor of a participatory approach that would involve healthcare providers and "community mobilizers" in discussions of why it was important that the intervention not be offered during the control phase of the study.

Moral entanglements

During the time the study was being (re)designed, I emailed one of my PhD supervisors (who was a co-investigator in the *Max*ART study) and described the proposal to blind participants (people living with HIV), healthcare providers and the study team about the intervention start date and which facilities would deliver it as "ridiculous". She advised that I take the proposition as seriously as I did traditional healers' stories about being trained in underwater worlds by creatures who were half-man and half-horse, which I had written about without normative undertones. Like many anthropologists, I was finding it more complicated to employ (cultural) relativism with “bureaucrats, politicians and corporate types” (Erikson 2011, 28). It was more challenging to suspend judgment when seeking to unravel the specific social context that produced particular scientific norms and values (such as blinding and standardization) than when trying to understand the life-worlds of traditional healers.

Part of this was linked to my stake in the project. Because of limited funding, we could only conduct our “applied” mixed-methods research in the facilities where I had previously conducted qualitative research with the Swaziland Network of People Living with HIV. Randomizing and blinding would make it impossible to select the facilities where we had worked before and plan data collection. Furthermore, several months before the discussions of randomization and blinding unfolded, I had started my fieldwork at one of the study sites. It was therefore decided that my field site could be taken out of the randomization so that I could continue my research there, the site was selected to offer the intervention first, and I was unblinded in order to be able to plan our data collection in advance. The rest of the facilities were randomized and the facility staff, community leaders, and (part of the) study team were blinded from knowing when the intervention started until six weeks before.

Although I was just as much part of the study team as, for example, the clinical supervisor was, I tried to align myself more with the study participants (healthcare providers and people living with HIV) than with the study team, as I had done previously with the Swaziland Network of People Living with HIV. However, this was not the type of alignment that was expected of an “insider”; in study team meetings, a collective sentiment was expressed that “we are all in this together” and that it was important that we all speak in one voice about the study to the outside world. From the start of the study, the two social science research assistants and I were expected to share information from our observations in order to improve the study’s implementation. Because we were dependent on the study team for access to conduct our observations and interviews, as time passed, I felt less able to openly critique several practices, for example, the informed consent procedure, because of these conflicting loyalties.

By the end of my fieldwork, in February 2015, it had become confusing for some that I was both the social science coordinator and simultaneously studying the study’s implementation. When I asked to be part of a training in the clinic where I had previously done fieldwork, the trainer first preferred not to have me present. She asked me: “Did you not say yourself that you wanted to be seen as separate from the clinical team?” It was important to her, and to the consortium at large, that we present a collective voice during the training sessions. During the training sessions, if I asked questions – instead of answering them – this would come across as if we were not on the same page. I explained that I wanted to participate as an observer and was allowed to do so. The conflicts between my roles followed me beyond the field sites, as this excerpt shows:

> *19 February 2015*
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> It's about 10 o'clock on a Thursday morning. My housemate, who works as an HIV counsellor in the clinic, asks me for help. Can I tell her how she should explain the "Early Access to ART for All" in the daily morning health education sessions? By this time the facility had "transitioned" to offering early ART as the new standard of care in the facility. I am hesitant to answer and ask her if the study's clinical mentoring team had not trained her how to explain this to patients. My housemate looks puzzled and says; "That training was only one day, you *work* in the project, why won't you tell me, what is the problem?"

I resisted telling my housemate how to explain the study (or new standard of care, as it was to be described to patients) for the same reason I did not want to speak out during the training: I did not agree with how the study's benefits were supposed to be explained to patients. At the same, I did not want (nor did I feel allowed) to assert my opinion about this to the healthcare providers or other "outsiders". My proximity to the study team thus created certain expectations when interacting with study team members and clinic staff. As the field note excerpts show, when I decided to distance myself, by not participating or not speaking in one collective voice, this sometimes produced frustration amongst the study team and clinic staff, and a sense that I was being disloyal.

CONCLUSION

Throughout my involvement in *Max*ART, I have been balancing active participation in a collaborative project with trying to maintain critical distance as an ethnographer. During my fieldwork, my position changed from that of a relative outsider, aligned with the Swaziland Network of People Living with HIV, to that of a study insider, concerned with maintaining access to multiple sites and occupying different subject positions in order to access them. By participating in study meetings, contributing to the design of consent forms, and attending messaging workshops, I became a coproducer of the study, which created expectations on the part of the study team and clinic staff. This involvement turned maintaining a degree of distance into a matter of disloyalty. During my time in *Max*ART, I shifted between the three modes of engagement (subaltern alignment, reflexive dialogue, and collaborative design) (Hardon & Moyer, 2014). Adopting these different forms of engagement within the same project, however, caused others to view me with ambivalence. At the end of my fieldwork, the dominant subject position allotted to me was that of social science coordinator working for *Max*ART. The tensions described in this article illustrate the distinctly performative mode of knowing implied in ethnographic fieldwork that links understanding to participation (Hastrup, 2004, 464).

I am still negotiating this multipositionality, albeit from a distance as I have returned home to the Netherlands. Although removed from the everyday intricacies of study implementation, I remain involved in weekly phone calls with research assistants, as well as email exchanges and conference calls with study managers to talk about data collection, preliminary findings, and report writing. Indeed, when conducting such insider research, it is often the social exit rather than the entry that produces a significant shift in relationships (Mosse, 2006). Moreover, it is often the act of writing and transforming of one's experience into public knowledge that can disturb and break fieldwork relations (see Hastrup cited in Mosse 2006, 951). This article is an effort to gain (more) distance from my concern with the study's implementation through the process of writing. However, my experience of insider research shows that, rather than being achieved post hoc through writing, the processes of alignment and detachment are a continual practice, navigated throughout the stages of ethnographic fieldwork as one's position shifts.

Balancing proximity and distance is a key effort in every anthropological encounter. But conducting ethnographic research in a highly political field, such as global health, highlights particular methodological and ethical challenges regarding how anthropologists relate to power (Marcus, 2008). Being part of a collaborative project requires the anthropologist to contribute during the project; "deep hanging out" is therefore unlikely to meet other participants' expectations and assumptions about the anthropologist's role in their interactions. In response, one can take up different roles in the project and contribute through more "applied" research that serves the agenda of the project (which may not necessarily be the agenda of the critical ethnographer). But, to grasp the social and political processes through which global health projects are made and transformed in practice, anthropologists must make space to produce critical ethnographies of global health.

Doing ethnography "of" global health, Pigg (2013, 132) argues, requires that the ethnographer "lingers on after the consultant's site visit" and "pay[s] attention to what falls out of view or falls between the cracks". For me, this "lingering on" – for example in the clinic after the study's trainings were finished – became increasingly difficult with time as the distinction between being the study team coordinator and a doctoral student started to fade. The three ways of "making space" were strategies to deal with the challenges of doing ethnography "of" and "in" global health simultaneously. Besides the methodological aspects of making space by having a separate PhD protocol and by aligning and detaching myself from the study team, I struggled with morally supporting certain aspects of the "research as intervention" strategy. My position as insider presented a challenge for ethnographic knowledge production based on principles of openness to and empathy for the "other" (Armbruster & Laerke, 2008), as I was creating distance rather than seeking closeness.

Doing insider ethnography may yield a specific kind of ethnographic knowledge. The results may be less theoretical and critical because of self-censoring, collaborators' objections, or insufficient time. Yet insider accounts that are more attuned to what is at stake for powerful collaborators may be powerful in their own terms too. Anthropologists have the ability to influence research projects in the making, but this depends on our presence in and the level of influence on the networks and institutions that create and implement health policy. The actual effect that the anthropologist might have on the project outcome is also related to the level of flexibility of the project and other people involved. Today, many anthropologists are involved in global health research, and more reflexive accounts of insider ethnography are needed to guide students and budding researchers on positioning oneself and dealing with expectations in collaborative research. Further exploration is needed about intersubjectivity in practice: How does the anthropologist engage in collaborations with differently positioned actors without (being perceived as) "taking sides"? Are the ethical principles of commitment and openness in anthropology being applied when "studying up" or doing a critical ethnography of global health? How does one combine moral engagement with (scientific) detachment?

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CHAPTER 7

Discussion and Conclusion

This dissertation has explored the contextualization of HIV treatment as prevention (TasP), a global health strategy that advocates the early initiation of antiretroviral therapy (ART) by HIV-positive people as soon as possible upon diagnosis so as to improve individual health outcomes and decrease HIV transmission in populations. In the previous chapters, I have examined how eSwatini-based actors interpret, adapt, and appropriate biomedical knowledge about HIV TasP and transform it into policy discourse and healthcare practices during the implementation of the Early Access to Art for All (EAAA) research project. In this final chapter, I bring to the discussion some of this study's main conclusions about how TasP becomes, through its implementation, shaped *in situ*, and place these insights into conversation with findings from other social science and public health research about the implementation of early ART in other settings, particularly sub-Saharan Africa.

To achieve my overall research objective of understanding how TasP was shaped and reshaped in context, I will revisit the locally constituted framings that eSwatini-based actors brought to the notion of HIV TasP across different levels (i.e., policy discourse, the health system, and study communities). One key insight that emerged from my analysis across these multiple levels is that values of responsibility, well-being, and solidarity come to underlie transformations in, and the reframing of, HIV treatment as prevention in eSwatini. Beyond local framings, which affected how early ART became contextualized in eSwatini, I also consider the wider organizational, political, and temporal dynamics that affect how global health research is utilized by differently positioned actors involved in the implementation of EAAA. The chapter ends with an outline of future research priorities and final reflections on doing critically applied anthropology within implementation science.

Contextualization across different levels

There are different disciplinary lenses through which context and contextualization can be conceptualized when analyzing the implementation of biomedical interventions within a specific locality. In the introduction of this dissertation, I discussed three approaches used in different research traditions (outlined by Brives et al., [2016]) to perceive of context(s) as *representational*, *interactional*, or *ontologically multiple*. Through my exploration of how the implementation of early antiretroviral therapy (ART) was shaped by eSwatini-based actors across various levels, I came to regard context as a powerful generative force that shapes interventions as a result of the interactions between different actors involved in implementation science, as well as the wider social and political influences on the implementation process. The lens through which I study context can thus most accurately be described as resembling an interactional approach. Rather than conceptualizing of context as a particular setting dissected into variables and "observable features," as is more common in representational approaches, an interactional approach focuses on analyzing the "relational features" of the way a particular setting operates, as suggested by Greenhalgh and Manzano (2021). Such relational features, they argue, are the "psychological, organization, economic, technical and so on relationships (forces) that interact and influence each other" (8). I find this conceptualization of context as a set of relational features useful because it focuses the analysis toward understanding what context *does* rather than what it *is*. In the following sections, I discuss how relational features shaped the contextualization of TasP in policymaking, the health system, and study communities in eSwatini. In doing so, I draw attention to temporal, political, and social forces, as well as organizational power dynamics within the health system and the Maximizing ART for Better Health and Zero New HIV Infections (*Max*ART) program, as relational features of context in eSwatini.

Contextualization in policy discourse: Governmental responsibility and ownership

A key aspect of the transformation of HIV treatment as prevention (TasP) in policy discourse in eSwatini was the careful conceptual reframing of TasP from a global HIV prevention strategy to one providing wider access to HIV treatment. This shift was part of a gradual change in global health policy discourse away from using the term TasP and toward a framing of early antiretroviral therapy (ART) initiation as a matter of providing universal access to HIV treatment, or universal test and treat (UTT).[27] But, as we have shown in chapter 2, the careful (re)framing of TasP in national policy discourse in eSwatini did not only reflect the global shifts in TasP discourse; it was also influenced by past experiences of failed HIV prevention campaigns, the widespread societal impact of HIV-related deaths, and the importance of portraying the government's responsibility to provide for the nation.

During the introduction of Early Access to Art for All (EAAA), much effort was put by the *Max*ART consortium into demonstrating the eSwatini government's responsibility and ownership of EAAA. This occurred through the organization of face-to-face dialogues between national-level political leaders and traditional authorities at the chiefdom level, as discussed in chapter 2. In so doing, the EAAA study recognized the country's dual governance structure and reached local leaders with information about the study prior to its commencement through traditionally recognized channels of communication. This approach was carefully prepared by the EAAA communication specialist, who worked across the different *Max*ART consortium organizations. The introduction of the EAAA study in study communities in northern eSwatini was arranged by local Swazi staff from the Southern Africa HIV and AIDS Information Dissemination Service (SafAIDS), who had ample experience engaging local structures at the chiefdom level in public health interventions. This bottom-up approach likely avoided some of the mistakes made by the *Soka Uncobe* [Circumcise and Conquer] male circumcision campaign, which executed a top-down communication strategy without effectively engaging local leaders[28] (Adams & Moyer 2015; Mkhwanazi 2020).

A similar approach was taken during the EAAA introduction trainings of health workers at participating study facilities whereby the leadership of the Ministry of Health was

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[27] Even one of the most vocal international advocates of (the term) TasP, biomedical scientist Julio Montaner (whose laboratory considered itself the owner of the term "TasP"), claimed, when challenged by an associate of the Global Network of People Living with HIV to prioritise public health over and above individual health and human rights during a discussion at the 2012 International AIDS Conference, that TasP was "not about preventing transmission" but rather about securing access to treatment (Kaiser Foundation 2012, 26).

[28] This is not to suggest that it was only the communication strategy which caused the failure of the male circumcision campaign, which, as Adams & Moyer (2015) and Mkhwanazi (2020) have explained, was also related to Swazi males' rational appraisal over the trade-off between the limited effectiveness of male circumcision to prevent the acquisition of HIV and its potential adverse health effects.

demonstrated through their participation in the training sessions, as discussed in chapter 6. According to several health workers I interacted with during my stay in my main fieldwork location, Ntfonjeni, the intertwinement of governance and kingship in eSwatini makes opposing an intervention led by the Ministry difficult. This was made particularly clear when one of the facility staff mentioned to me, "Saying no to the government is like saying no to the king"—it was, according to her, something that was simply not done. As such, the presence of government actors at the early ART training sessions, beyond showcasing national ownership of the intervention, also appeared to be a flexing of political power intended to bring local health workers on board. Such power dynamics, in addition to the lingering effects of previous health campaigns in eSwatini, affected how *Max*ART actors implemented EAAA. These phenomena are examples of the complex historical features and political dynamics that underlie the transformations of TasP in policy discourse in eSwatini.

The extent to which the government was actually responsible for the roll-out of EAAA was somewhat ambiguous; this was partially due to the fact that the EAAA study (including the antiretroviral drugs[29] involved) was financed by the *Max*ART program rather than the Swazi state. Whilst ambiguous in terms of its financial responsibility, the Swazi government's ownership of EAAA was consistently promoted in (inter)national public meetings and scientific conferences, not only by the Ministry, but also primarily by Clinton Health Access Initiative (CHAI), the coordinating organization. Portraying EAAA as a government-owned initiative in public discourse appeared important for CHAI, as it legitimized the organization's narrative that it was working "at the service of partner governments" and aligning strategies to their partner governments' "goals and priorities" (CHAI 2020, 9). The push by CHAI for government ownership was solidified in the organizational hierarchy of the EAAA study: the EAAA study's sole principal investigator (PI) was the director of the Swaziland National AIDS Programme (SNAP) at the Ministry of Health. This was unique among those TasP trials and implementation studies ongoing in the region, in which the PI position was often occupied by a scientist from a research institute in the US or Europe and sometimes shared with scientists from an Africa-based research institute (Yapa and Bärnighausen 2018). Other scholars have argued that the focus of global health organizations in highlighting country ownership (and accountability and sustainability) is part of a changing global narrative of international donors that serves as "prelude and justification" for the scale-down of donor support for HIV treatment since the 2007/2008 global financial crisis (Kenworthy et al., 2018, 962; Moyer 2015). In eSwatini, it appeared that a primary way through which the Swazi government was able to (continue to) receive international funding for HIV treatment was through implementation research. This makes up a second key

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[29] ART medication for the EAAA study was financed by a donation from the pharmaceutical company Mylan Laboratories Limited, currently known as Viatris. The main funders of the *Max*ART program were the Postcode Lottery (a Dutch charity) and the Dutch embassy in Mozambique. The ability of the Swazi government to finance the roll-out of early ART *outside* of the EAAA study was of particular concern to *Max*ART and the Swazi Ministry of Health, and the costing elements of the EAAA study were included to give insights about the costs of providing early ART across the entire country. The ART program has been partly funded in the past by the Ministry of Health, with significant support from PEPFAR, their main funder. In a recent PEPFAR report, it is stated that, in 2019, the Swazi government funded 58% of clinical care, including ART, while PEPFAR funded 31% and the Global Fund 11% (PEPFAR 2020).

aspect of the contextualization of TasP into the realm of policymaking in eSwatini, whereby early ART was introduced as a new approach to HIV *care* rather than as a research project.

Around the time Aidsfonds and CHAI reached out to SNAP with their proposal for *Max*ART, SNAP had recently taken over the financing of HIV treatment from the Global Fund, which had been covering the full costs of ART until 2010 (PEPFAR 2011). It was also during this period that eSwatini went through a fiscal crisis primarily caused by a collapse in transfers from the Southern African Customs Union (SACU). This affected the ability of the Swazi Ministry of Health to safeguard the funding for ART within the national budget (PEPFAR 2012). In 2011, the Swazi government requested the US President's Emergency Plan for AIDS Relief (PEPFAR) to finance a "buffer" stock of ART to augment drug shortages. Since then, a diverse range of international donors has become involved in financing ART for different population groups, often as part of implementation studies, by, for instance, offering ART early for children under two years of age and pregnant women (known as Option B+). The Swazi policymakers involved in the EAAA study who I interviewed indicated that these implementation studies helped them to "balance the budget" and incrementally scale up access to ART across the country.

During the EAAA study's three-year implementation period, eSwatini's national standard treatment guidelines changed twice: first in December 2015, when the guidelines switched to suggest initiating ART when CD4 ≤ 500, and subsequently in October 2016, when the national guideline instead promoted early initiation at any CD4 count, a transition financially supported by PEPFAR, SNAP's largest HIV-care donor at the time. As SNAP's director was also the PI of the *Max*ART study, the national policy changes were anticipated by *Max*ART and the stepped-wedge study design proved its value by not withholding an intervention that had become the national and international standard of care before the EAAA study was completed (and before the study's outcomes were known). This anticipation of early ART becoming the national standard of care affected EAAA study enrolment procedures whereby consent was only asked for additional laboratory tests performed within the EAAA study and not for the intervention itself: early ART. This decision appeared specific to the roll-out of the EAAA study by *Max*ART. In a similar EAAA[30] implementation study conducted by Médecins Sans Frontières (MSF) in southern eSwatini, participants were asked for informed consent for starting early ART in participating facilities at the insistence of MSF's own ethical board (Kerschberger 2015). This shows how organizational dynamics and ethical values may differently affect enrolment procedures and research practices, a point also made by Salla Sariola and Bob Simpson (2019) in their book *Research as Development*. Comparing the ways in which two different trials conducted in Sri Lanka were set up, financed, and managed, Sariola and Simpson argue that "specificity" (9) matters, not only in terms of country-level power dynamics but in relation to the particularities of

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[30] Both EAAA implementation studies conducted by MSF and *Max*ART carried the same name, "EAAA," at the insistence of the eSwatini Ministry of Health to convey unity. The two studies designed and pre-tested their communication strategy together. Both studies were both carried out in government health facilities (though in the case of MSF, health facility staff and services were financed partly by MSF) and implemented during roughly the same time period, with the MSF study starting only a few months before *Max*ART.

the trial network itself. Furthermore, they illustrate how Sri Lankan researchers involved in internationally sponsored clinical drug trials strategically seek out international scientific collaborations as a "tool and target" for personal, institutional, and societal development; research is used as a form of and means to development (7). In a similar vein, this dissertation has revealed how Swazi policymakers strategically make use of and shape biomedical interventions and research to be of use to *them*—not on a personal or institutional level, but on a national-level programmatic scale.

Beyond their participation in EAAA introductory meetings in health facilities and communities, national-level policymakers were not actively involved in the day-to-day implementation of the EAAA study. Nonetheless, they were updated every week about the progress and setbacks of the implementation process, as well as the intermediate study findings and implementation insights, which every consortium organization prepared in weekly PowerPoint presentations. Further, every *Max*ART organization presented its activities and preliminary findings (if available) in half-yearly face-to-face meetings. In this way, the EAAA study was useful to the national HIV program as it provided learning-by-doing insights, skills, and capacity generated through its implementation. Insights and skills that appeared particularly useful for programmatic purposes to the Ministry were those generated by the clinical team that oversaw implementation in health facilities and trained health workers and lab staff in new diagnostic technologies, such as viral load testing, which was not widely available in the public sector at the time, i.e. using research as a form of care[31]. However, regarding *Max*ART's capacity to oversee the implementation of the study, there was always a question about how far the study team could go to intervene, or improve, the existing health system services, since the overall research goal was to measure the effect of EAAA within a government-managed health system. These real-time implementation insights were particularly helpful to the Ministry, especially considering that the EAAA final study results were not yet known at the official end of the *Max*ART project (late 2017), in part due to differences of opinion between the economic scientists and biostatisticians involved in the analysis of the trial data collected.

Contextualization in health facilities: Well-being and readiness

In public health literature about the implementation of treatment as prevention across various settings, it is noted that moral and racialized fears of increased sexual risk-taking (also referred to as sexual "disinhibition") limited the sharing of information about the preventative benefits of antiretroviral therapy in clinical encounters in African countries as well as other settings (Bor et al., 2021; Legemate et al., 2017; Calabrese & Mayer 2020). Similar fears regarding an increase in condomless sex also existed among eSwatini-based policymakers and health workers as TasP implementation played out, and contributed to the camouflaging of the preventative aspects of HIV treatment during introductions in study

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[31] I do not wish to assert a value-laden framing of care here—i.e., that research is a "good" or "bad" form of care—but rather to direct attention at the way in which research provides care benefits to the national HIV programs through the provision of training and additional diagnostic tests, which are provided as part of HIV care in government-managed facilities.

communities and health facilities, as discussed in chapters 2 and 3. Other social scientists working alongside TasP trials in other African countries also mention the unfamiliarity of HIV-positive trial participants with the preventative potential of ART (e.g., Bond et al., 2016; Horter 2019; Mubekapi-Musadaidzwa et al., 2021; Viljoen et al., 2021). Writing about health workers framings of early ART in a large community-based TasP trial in Zambia and South Africa, Constance Mubekapi-Musadaidzwa and colleagues (2021) state that health workers did not mention the population or prevention benefits of early ART initiation, but rather emphasized the importance of early ART in keeping up body strength and feeling well. This suggest that health workers adapt their messages about the benefits of early ART to what they consider to be of priority for study participants. In the same trial, Lario Viljoen et al. (2021) concluded that TasP, and HIV prevention more broadly, did not feature in women's sexual decision-making processes. Rather, they noted that women idealized romantic sex and considered "risky sex" as something that belonged to "transgressive others" (2). The authors conclude that in order for interventions such as TasP to be taken up successfully, they should be framed in accordance with what people are motivated to uphold, which, for the women in their study, was about relational well-being rather than HIV prevention.

In our analysis of how biomedical knowledge about HIV TasP was transformed in ART initiation counseling messages (discussed in chapter 3), we found that health workers indeed attempted to frame the intervention of early ART in accordance with what they thought HIV-positive people would be motivated to uphold: that is, their physical and social well-being. These framings resulted from health workers' own understandings of the social realities of HIV, in particular the pervasiveness of HIV stigma in surrounding study communities, in which many of them resided. Whilst some providers included information about the possibility of ART to reduce HIV transmission in counseling sessions, they generally motivated people to start early treatment as a means to stay (visibly) healthy and avoid falling ill, thereby avoiding disclosure to and possible stigma from the wider community. Taking a substance to prevent falling ill or suffering some other misfortune is also a common practice in "traditional" forms of illness prevention and healing (Reis 1996), still practiced widely in eSwatini (Ndlovu 2018; Schausberger et al., 2021), whereby the body of a person is protected by making cuts in the skin and applying herbal medicine in the wounds. We did not observe, however, that facility-based nurses alluded to such traditional conceptualizations of prevention in their counseling messages, as was, for example, noted in earlier scholarship about the reframing of the workings of childhood immunizations by Swazi nurses when training traditional healers (Hoff and Shapiro 1986).

One important change in the practices of ART initiation during EAAA was a reduction from three "pre-ART" initiation counseling sessions to one, after which a person could start ART—technically on the same day as their diagnosis. However, many EAAA study participants had been diagnosed with HIV several years prior and were already registered in facilities as pre-ART clients and thus were considered to be "in care" (Molemans et al., 2019). Pre-ART clients received co-trimoxazole, a broad-spectrum antibiotic, to prevent and treat HIV-related opportunistic infections. In counseling sessions, expert clients or nurses taught people about the "dos and don'ts" of taking ART (e.g., *do* adopt a balanced diet, *do* disclose to your partner/family member, *do* continue using condoms to prevent reinfection and possible treatment resistance; *don't* use herbal medicine and *don't* share medicine with family members) (Vernooij & Mehlo 2013). The pre-ART counseling sessions we observed generally ended with what was referred to as a "readiness" assessment, during which the health worker questioned the HIV-positive person about lessons they'd learned and discussed their willingness to start ART.

Whilst health workers generally motivated people to start early ART as a means of taking responsibility for their own life rather than for the greater good, during pre-ART counseling we observed health workers tailoring their messages to the patients' psychological and social circumstances. When a person did not appear to have "accepted" their HIV-positive diagnosis and/or was not privy to a social support system, health providers were less inclined to promote immediate ART initiation and instead recommended disclosure to a partner or close relative first. A similar finding regarding the importance of patients' levels of readiness was reported by Shona Horter and colleagues (2020) in their analysis of how health workers balanced individual and public health interests during the implementation of early ART within the Médecins Sans Frontières (MSF) EAAA implementation study in southern eSwatini, where health providers feared that hasty initiation would lead to poor adherence (Horter et al., 2020). Rather than a prevention technology, Horter et al. (2020) argue, early ART was presented as a "technology of invisibilization" (Mattes 2014, 278) in ART initiation counseling, as has also been noted in earlier ethnographic work about the (partial) effects of HIV treatment on stigma and disclosure (ibid.; see also Moyer 2012). Yet, whilst we also found that health workers presented ART as a technology of invisibilization, at the same time, they stressed disclosure to one's partner or at least one close family member, rather than one's neighbor, in the pre-ART counseling sessions during the implementation of the EAAA study.

Another significant change in ART initiation counseling during EAAA was that health workers had to explain to patients why the CD4 count, or clinical staging in the absence of CD4 testing, was no longer used to determine ART initiation. In Ntfonjeni clinic, where I spent most of my time, health workers explained to their patients that the changes in policy resulted from the country's improved economic situation. They told patients that, since the Swazi government currently had "many foreign donors," it was now possible to start ART early. This shows how health workers, rather than replicating policy discourses about national ownership and governmental responsibility, used their own framings of TasP to explain the changes in facility guidelines. In an ethnographic study about how health workers respond to policy changes in HIV programs in Senegal, Alice Desclaux (2014) found that often health workers merely "implemented" a policy change without explaining the underlying rationale to patients. Our finding that local health workers made an effort to discuss and explain a given policy change to patients and adapted counseling messages to fit their social realities, reveal the particular institutional dynamics in which TasP became integrated. Such institutional dynamics might be considered another aspect of the relational features through which TasP became transformed in ART initiation practices in the public health system in eSwatini.

Besides the three EAAA study team "clinical mentors," who supervised study enrolment and assisted with ART initiation in the fourteen EAAA study facilities, the social science research team spent most of their research time in the EAAA study facilities whilst conducting mixed methods research. As we were expected to provide weekly updates about our progress and preliminary insights to the rest of the team, our insights sometimes led to additional visits by the clinical mentors or the Ministry of Health, to smooth out any disagreements with the potential to impact the uptake of early ART, as discussed in chapter 6. In this way, social science research shaped and enabled the implementation process. We thereby complied to a certain extent with the expectations associated with a representational contextual approach, whereby our facility-specific insights were used to support the uptake of early ART and motivate facility staff to comply with the study enrolment procedures.

Contextualization in study communities: Mobility, solidarity, and chronicity

As discussed in chapter 4, the first step leading to the discontinuation of HIV treatment under EAAA was mobility, whereby people often changed residency (temporarily) due to precarious employment circumstances and caring duties in other parts of the country. When looking at context through a representational lens, the high levels of mobility in eSwatini might be perceived as an observable feature of the eSwatini context that affects the implementation of EAAA. However, as we argued in chapter 4, it was not mobility as such that created a problem for HIV treatment continuation, but rather the inability of the health system, as well as the EAAA study, to cater to the mobile everyday living conditions of HIV-positive people. In this aspect, the EAAA study team did not manage to strategically make early antiretroviral therapy (ART) "fit" the local context of people's everyday circumstances. Besides the organizational aspects of the health system, which made it difficult for people to continue accessing ART when shifting localities, EAAA study participants also alluded to negative experiences and maltreatment by health workers themselves. Whilst the EAAA study organized "human rights and responsibility" training sessions for HIV support group members in study communities, these sessions were not organized for facility-based health workers. As such, the responsibility for sustained HIV treatment engagement was implicitly placed on the person living with HIV.

Similarly, on an organizational level within the *Max*ART consortium, the responsibility for representing and safeguarding the needs and rights of people living with HIV was attributed primarily to one organization: the Swaziland National Network of People Living with HIV (SWANNEPHA[32]). In the EAAA study, human rights were defined as ethical considerations concerned with voluntary participation, informed consent, and confidentiality. Besides through human rights training sessions offered to support group members, the mechanism through which HIV-positive human rights were supposed to be *monitored* in EAAA was the Community Advisory Board (CAB), which was coordinated by SWANNEPHA. In a training session I observed in my main fieldwork locality, local support group leaders

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[32] SWANNEPHA went through an unstable period during the *Max*ART program with leadership changes and lack of core funding to sustain its daily functioning. *Max*ART was one of its main funders and a short while after the end of the *Max*ART program the organization fell apart.

and CAB members motivated their fellow community members to take non-confrontational actions when they felt mistreated by health workers. This included calling a toll-free hotline managed by SWANNEPHA or switching facilities (the latter of which was not favorable to the outcomes of the EAAA study as it was not possible to follow up with study participants once they left EAAA study facilities). Even though it remained largely unclear how the insights from the CAB members were acted upon by the EAAA organizers, in a qualitative study about the experiences of CAB members in the EAAA study we learned that the CAB members, as well as the Ministry of Health, felt that the CAB was a highly valuable structure (Mlambo et al., 2019). It was valued because it provided CAB members with new knowledge and skills and provided the Swazi government with a regular feedback loop about the EAAA study's reception in communities. It thus appears that the *by-products* of the implementation of the CAB, rather than its ability to monitor human rights, were considered useful.

Within EAAA, discontinuation with early ART was not only related to a precarious medical landscape but also to patients' uncertain economic situations and the psychological impacts of broken relationships. Whilst same-day initiation reduced some of the health system-related logistical barriers (such as waiting for CD4 counts, which was found to delay ART initiation prior to the roll-out of EAAA [e.g., Dlamini-Simelane & Moyer 2017a]), structural barriers such as gender vulnerability and HIV-related stigma were unaffected by changing treatment enrolment criteria (Pell et al., 2018). One limitation of our qualitative research conducted with EAAA study participants was that it focused specifically on HIV-positive individuals who to a certain extent had been "failed" by EAAA. This group included those who had delayed the start of EAAA (see Pell et al., 2018), those who had discontinued HIV treatment (chapter 4), and people with unsuppressed viral loads (unpublished findings). In our mixed methods research, however, we focused on people who successfully initiated and sustained early HIV treatment. We found that, among the 233 HIV-positive people we interviewed who had enrolled in the EAAA study, the most-cited reason for starting ART early was "to avoid becoming sick" (Molemans et al., 2019, 6). Of those 233 people, only 21.5% reported feeling ill at the time of (early) ART initiation. Our limited ethnographic research into engagement with EAAA by HIV-positive people over time means we can offer few in-depth insights into the framings that HIV-positive individuals brought to early HIV treatment and how these affected their use of HIV treatment over time. Learning more about study participants' interpretation of the preventative potential of ART during EAAA was also difficult because this information was not pro-actively shared in policy discourses and counselling messages, and therefore largely unknown.

In her PhD thesis, based on longitudinal social science research with asymptomatic HIV-positive people who started early ART in the Médecins Sans Frontières (MSF) EAAA study in southern eSwatini, Shona Horter stipulates that the preventative benefits of early ART were relatively unknown by the MSF study's participants, and thus did not provide "the important frames for how people responded to early ART" (Horter 2019, 225). One of the important motivators for starting ART, according to Horter and colleagues (2019), was to prevent the development of physical symptoms, and thereby suffer inadvertent disclosure and anticipated stigma from family and/or community members, which is consistent with our findings. The authors conclude by suggesting that having enough time to come to terms with one's HIV status acceptance is an important facilitator of sustained HIV treatment under EAAA. They therefore caution against rushing ART initiation to prevent inadvertent disclosure without HIV-status acceptance, as it might undermine treatment adherence over time. The findings from Horter and colleagues, as well as our own findings, suggest that while many things stay the same under EAAA (e.g., people's social and economic living circumstances and the pervasiveness of HIV stigma), EAAA seems to affect people's relationship with ART; HIV treatment is increasingly taken to *prevent* one's body from revealing signs of HIV, rather than *because* of one's body revealing signs of HIV.

The fact that high levels of (anticipated) HIV stigma informed decisions about ART initiation could be noted as another example of an "observable feature" when taking a representational approach to the eSwatini context. At the same time, I have argued in chapter 5 (about support group transformations) that the risk of an HIV infection appears normalized by community members, particularly among the married women I came to know in my main fieldwork location in northern eSwatini. The social contract within the support groups (where people come together to support each other in dealing with chronic illness without explicitly talking about particular illnesses) reveals the social importance of respectful concealment in eSwatini as well as the ways in which stigmatization and normalization co-exist. I suggest that it is a value of solidarity —in the present and anticipated for the future— that underlies the transformations of support groups as a biosocial form, in which the binding "bio" is not a shared diagnostic identity but a broader concern with anticipated chronic illness and a desire to be prepared for future misfortune. When looking at these transformations as part of an interactional approach to context, the value of solidarity and the effects of chronic HIV risk on the management of social relationships appear to inform and transform support groups, and might be considered additional relational features of context in which eSwatini-based actors operate.

Future directions: Toward a critically applied anthropology of implementation science

The main findings concerning the ways in which early initiation of ART affected retention in care and viral load suppression (the two main study outcomes) were only published three years after the end of the EAAA study (Khan et al., 2020). These revealed that, at the 12-month mark, EAAA had improved the retention in care and viral suppression. In an analysis of the impact of early ART initiation on secondary endpoints, including mortality rates (a measure of individual-level health outcomes), no positive or negative effect was ascertained (Chao et al., 2020). The article states that there were more deaths reported among HIV-positive people who started ART early (3.6%, 49/1371) in comparison to individuals who underwent ART according to national HIV treatment guidelines at the time (1.8%, 36/2034), but limited statistical power prevented the authors from detecting a significant effect on mortality rates after one year of follow-up (Chao et al., 2020). Findings from the economic evaluation reported no impact of EAAA on the economic well-being of HIV-positive adults (measured as time spent to generate income, employment status, monthly household expenditures, and household living standards [Steinert et al., 2020]). Neither did the economists find an effect of EAAA on patients' satisfaction with healthcare services (Ogbuoji et al., 2019). They did, however, report a worsening of satisfaction in both the standard of care and intervention group over time. The economic evaluation study also found that EAAA significantly reduced patients' spending on private and traditional healthcare (Steinert et al., 2021). To my knowledge, there has not been a publication about the effect of EAAA on HIV incidence projections. All these quantitative analyses of the impact of EAAA were finalized after the EAAA study was completed and after the eSwatini government had already adopted early ART as the new national standard of care. Since the findings were no longer relevant to inform the further scale-up of early ART in government-managed settings in eSwatini, in these articles the authors suggested the findings were instead useful to "solidify" the decision to scale up early ART.

As I have shown in this dissertation, it was through the implementation, and the constant feedback loops within the EAAA study team — including the insights generated by the Community Advisory Board (CAB) — that learning occurred and research was made use of, not through the final study results. This shows that, rather than looking at the biomedical indicators of "success" as I have done above, eSwatini-based national and local actors appeared to take a care-driven approach to research, whereby it was the implementation itself that was considered successful, largely due to the real-time insights and useful by-products it generated. These insights contribute to a growing body of "critically applied" medical anthropology research conducted within and alongside implementation science that reflects on the ways evidence and notions of success are generated in (global) health research (Adams & Biehl 2016; Dodds 2021; Lazarus et al., 2019; Whitacre 2019). Reflecting on the implementation of a pre-exposure prophylaxis (PrEP) demonstration project in India, Lisa Lazarus and colleagues (2021) explain how the intervention in question was *made* a success by the additional efforts put in by community outreach workers to foster adherence to PrEP among study participants. However, while they had contributed to the success of the project in terms of its biomedical indicators, the local implementers felt ultimately failed by the research project, which did not result in continued access to PrEP beyond the time frame of the project. In other research about a PrEP implementation trial in the United Kingdom (UK), Catherine Dodds (2021) shows how the trial was used by governmental authorities as a way to grant continued access to antiretroviral medications during a political and financial impasse in the UK. The ambiguities of using implementation research as a way to accelerate and continue access to biomedical interventions is thus not specific to the eSwatini context, but possibly a general consequence of the decrease in the long-term financial commitments of donors (see also Kenworthy et al., 2018). Questions about the temporality and conceptualization of success (and failure) by differently positioned actors within implementation science demands further anthropological research in the field of global health.

Another future line of inquiry to which this dissertation contributes concerns the temporalities of national policy adoption and the role of implementation science in this process. The situation whereby the Swazi government adopted EAAA as their national standard of care before the EAAA study was finished is not unique to the *Max*ART study; it also occurred during the implementation studies offering early ART to pregnant women in 2014.[33] Whilst my research did not look into the influence of other international organizations, such as eSwatini's main funder of HIV care, the US President's Emergency Plan for AIDS Relief (PEPFAR), on the speed and timing of the adoption of early ART as the national standard of care, the notion that other international funders were advocating for a fast adoption of early ART as national policy was alluded to in EAAA study team meetings. Other social scientists researching the adoption of EAAA as national policy in Zimbabwe also observed that policymakers in Zimbabwe were motivated to accelerate the implementation of universal test and treat (UTT) as a national policy by being able to observe UTT working in practice, in their health facilities, as part of pilot projects (Moran et al., 2020). This dissertation has similarly shown how temporality affected the multi-level transformations of TasP, not only as a result of anticipated future (inter)national policy changes, but also as a result of past experiences of health campaigns as well as present implementation insights and practices.

Another topic that recently gained attention in public health and anthropology[34] is the rollout of HIV viral load testing in low-income settings. Prior to the EAAA study, viral load testing was not routinely available at government health facilities. During the implementation of EAAA, baseline viral load test results were given back to HIV-positive study participants *before* they were offered the opportunity to initiate early ART. This appeared specific to the *Max*ART EAAA study (that is, it was not done in MSF's EAAA study) and was informed by the notion that study participants were entitled to receive all their test results. In our qualitative research, we learned that the act of giving back baseline viral load results to pre-ART clients prompted requests to initiate ART, in order to decrease "the million copies" of HIV that were being detected. Future research may look into how viral load tests are integrated into government health care systems, outside of research contexts, and how the measurements of viral load and notions of (un)detectability become embodied in people's illness experiences, and may affect ART initiation and long-term treatment adherence.

Instead of reflecting on the design and implementation of global health research from a position of an outsider, in this dissertation I have drawn attention to the ways in which social science research is co-constructing global health as a field (see also McKay 2019; Montgomery et al., 2017). In their commentary on the role and use of social science research in several large HIV TasP trials conducted in various African countries, Carol Camlin and Janet Seeley (2018) note that in recent years social scientists are more likely to be part of the implementation/trial team than they are to work alongside of it. One of the consequences thereof is that social science research can help "not only to understand the *why* behind success or failure of interventions but also inform the adaptation of interventions that can facilitate their success" (Camlin & Seeley 2018, 55, emphasis in original). In *Max*ART, as a result of sharing (some of) our real-time insights during weekly study team

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[33] Early ART for pregnant women became national policy in eSwatini in 2014, at which point the implementation studies were still ongoing (Katirayi et al., 2016).

[34] See for example Gagliolo (2021) for anthropological research into the embodiment of viral load in Argentina and Rijneveld (2021) for discourses of (un)detectability during the implementation of TasP in India. For public health literature about the rollout of viral load monitoring in low-income settings, see, for example, Glass et al., (2019).

meetings, our qualitative research was regarded of particular value by the clinical team as it could be used to facilitate the implementation process. This was less the case for the more quantitative research conducted by the economic evaluation team, which surveyed over 3000 HIV-positive adults visiting EAAA study facilities (Steinert et al., 2020) yet only shared its first preliminary findings at the end of the *Max*ART project, after three years of data collection.

The request for social scientists to help explain the success or failure of biomedical interventions such as TasP in terms of their biomedical indicators prompts researchers to engage in a representational approach to context, which may itself have implications for the scale and methods used. In the large cluster randomized TasP trial conducted across 21 study communities in Zambia and South Africa, social scientists examined what kind of contextual differences between the 21 study sites may explain the differences in the uptake and outcomes of universal test and treat across the different study arms[35] (Bond et al., 2021). To do so, Virginia Bond and colleagues (2021) developed a meta-indicator framework for the comparative analysis of local community contexts based on observable features (such as housing, class profile, poverty, etc.) of the places in which social science researchers carried out their observations and interviews. The framework developed by Bond and colleagues will be of great use to future social science research studying how local contexts affect the outcomes of biomedical interventions. But, simultaneously, it is necessary to continue carving out space for social scientists (including anthropologists) to do small-scale in-depth ethnographic research within and alongside trials and implementation studies, not only to explicate the characteristics of a particular place, but to show what interventions become in interaction with that place. By examining the ways in which biomedical interventions are affected by temporal, social, and political dynamics within and outside of research/implementation teams, embedded ethnographic research is well-positioned to make "critically applied" contributions to medical anthropology scholarship of implementation science.

Concluding remarks

In this dissertation, I set out to explore how TasP is being constituted, shaped, and reframed in eSwatini. Instead of perceiving and understanding public health interventions as phenomena that travel across different contexts as stable entities, I have sought to understand how TasP is created and transformed *in context*. By studying the contextual shaping of TasP and associated interventions, I have illustrated how, through the framings they bring to HIV, biomedical knowledge and research, differently positioned actors are able to affect how interventions are used. Some of these actors were more powerfully positioned than others and were thus able to assert more influence over the transformations of interventions and to make them of use on a personal, institutional or societal level. I close this dissertation with a quotation gleaned from an interview I conducted with a *Max*ART colleague from the Swaziland Network of People Living with HIV (SWANNEPHA). It is illustrative of the frustration

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[35] The results of the HPTN 071 PoPART trial were "somewhat puzzling" in that the decrease in HIV incidence was found to be less pronounced in the intervention communities compared to the communities in which ART was commenced according to national HIV guidelines (Bond et al., 2021, 2).

of the organization, which was seen as responsible for shaping the implementation of TasP to “fit” the needs of people living with HIV in eSwatini, but which was often unable to do so due to the constraints placed on what was considered feasible in a government-managed health system;

“If government is learning, here is the opportunity for us to add some of these things; we can say, ‘For it to work you have to have this and this.’ Say, ‘If you can add treatment literacy, probably the uptake [of ART] will be more’—but in the current situation, we don’t have the evidence. Even if we are going to conclude to government it’s not working in the current government system, what option are we going to give government? ... It’s not different from just rolling out [HIV] treatment as prevention.”

(Interview EAAA study team member, December 2014)

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LIST OF PUBLICATIONS

Thesis-based publications

Authors’ abbreviations: Eva Vernooij (EV); Mandla Mehlo (MM); Anita Hardon (AH); Ria Reis (RR); Christopher Pell (CP); Njabuliso Dlamini (ND); Eileen Moyer (EM); Fortunate Shabalala (FS); Njabulo Simelane (NS); Nelisiwe Masilela (NM); Donna Spiegelman (DS); Boyang Chai (BC); Shaukat Khan (SK).

2022 **Vernooij, E**. HIV Support Groups and the Chronicities of Everyday Life in eSwatini. *Medical Anthropology*, *41*(3), 287-301. https://doi.org/10.1080/01459740.2022.2043306

2019 Pell C., Reis, R., Dlamini, N., Moyer, E., & **Vernooij, E.** “Then her neighbour will not know her status”: How health providers advocate antiretroviral therapy under universal test and treat. *International Health*, *11*(1), 36-41. https://doi.org/10.1093/inthealth/ihy058

Authors’ contributions

EV, RR and EM conceived the study; EV and RR designed the study protocol; ND conducted the interviews under the supervision of EV; CP conducted data analysis in consultation with EV and RR. CP drafted the manuscript; RR, EM and EV critically revised the manuscript for intellectual content. All authors read and approved the final manuscript.

2018 Shabalala, F. S*., **Vernooij, E***., Pell, C., Simelane, N., Masilela, N., Spiegelman, D., Chai, B., Khan, S. & R. Reis. Understanding reasons for discontinued antiretroviral treatment among clients in test and treat: a qualitative study in Swaziland. *Journal of the International AIDS Society*, *21*(S4), 53-59. https://doi.org/10.1002/jia2.25120

Authors’ contributions

EV and RR conceived of the sub-study; FS and SK designed the sub-study protocol with input from EV and CP; NS and NM conducted the interviews under the supervision of FS and SK; FS conducted data analysis in consultation with EV and RR. FS, EV and RR drafted the manuscript; CP, NS, NM, DS, BC, and SK critically revised the manuscript for intellectual content. *FS and EV are joint first authors, EV is corresponding author.

2017 **Vernooij, E.** Navigating multipositionality in ‘insider’ ethnography. *Medicine Anthropology Theory*, *4*(2), 34–49. https://doi.org/10.17157/mat.4.2.496

2016 **Vernooij,** E., Mehlo, M., Hardon, A., & Reis, R. Access for all: contextualising HIV treatment as prevention in Swaziland. *AIDS Care*, *28*, 7–13. https://doi.org/10.1080/09540121.2016.1178954

Authors’ contributions

EV, AH and RR conceived the study. EV, MM, AH and RR designed the study protocol. EV and MM carried out data collection. EV conducted data analysis in consultation with MM and RR. EV drafted the manuscript; MM, AH and RR critically revised the manuscript for intellectual content.

Other publications (peer-reviewed)

- 2021 **Vernooij, E.,** Koker, F., and A. Street. Responsibility, repair and care in Sierra Leone's health system**.** *Social Science and Medicine*, *300:* 114260. https://doi.org/10.1016/j.socscimed.2021.114260
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SUMMARY

The Kingdom of eSwatini, formerly known as Swaziland, has the world's highest HIV prevalence rate, estimated at 27% among 15-49 year olds. In the past decade, it has been a key site for global public health interventions aiming to control the epidemic. One such intervention is HIV treatment as Prevention (TasP): the topic of this dissertation. TasP refers to the promotion of starting antiretroviral treatment (ART) for HIV-positive individuals, not only to improve individual health outcomes by lowering the HIV viral load, but also because of its preventative potential to decrease HIV transmission in the population. This approach is also referred to as "Early" ART, because it entails starting HIV treatment as soon as possible upon diagnosis, instead of on the basis of disease progression and the status of the immune system, which had been the (inter)national HIV standard of care in the past. As one of the anthropological researchers working within a multidisciplinary research study evaluating the implementation of "Early ART" in the Kingdom of eSwatini between 2012 and 2018, I examined the transformation processes through which a global health intervention became shaped and reshaped to "fit" the local context.

This dissertation is based on five empirical chapters, published as articles in both medical anthropological and public-health-oriented journals, which reflects the dual positioning of this thesis. The five empirical chapters discuss transformations of TasP at three different levels: in policy-making (chapters 2 and 6), in the public health system (chapter 3) and within study communities (chapters 4 and 5). Together, they seek to answer the following research questions: What kind of political dynamics and temporal circumstances shaped the introduction of TasP in eSwatini? How do local health workers frame and integrate early ART initiation in counselling messages? How does the implementation of early ART initiation affect (dis)engagement by HIV-positive people with HIV treatment and support group transformations in study communities? Following a critically applied medical anthropology approach, the empirical chapters bring to the fore the local framings of biomedical knowledge by national-level policymakers, local health workers and community-based actors (people living with HIV and support group members), and explore how these framings shape and reshape what a global public health intervention comes to be. In so doing, this dissertation sheds light not only the ways in which people respond to interventions, but also how public health interventions are actively shaped by political, temporal and organizational dynamics of the implementation process.

In **chapter 1**, the introduction, I explore the emergence of HIV TasP as a global public health strategy. I discuss the biological, epidemiological and geopolitical rationales that lie behind the global push towards expanding HIV treatment, not only to benefit HIV-positive individuals, but also as a preventative technology to limit HIV transmission at a population level. Furthermore, this chapter introduces the *Max*ART (Maximizing ART for Better Health and Zero New HIV Infections) implementation research study, which set out to examine the "real world" impact of the early initiation of ART for All (EAAA) through its implementation in a government-managed health system in eSwatini. Additionally, I discuss the historical context regarding the HIV epidemic in eSwatini and outline three different disciplinary approaches to studying the contextualization of biomedical interventions: the representational, interactional, or ontologically multiple approach. Informed primarily by an *interactional* approach to studying context and contextualization, I explore how TasP is made meaningful to different actors at different levels, and what kind of transformations such a process entailed. Qualitative data collection took place in three different phases prior and during the roll-out of the TasP implementation study, and included observations at health facilities, research team meetings, in study communities, as well as focus groups discussions and semi-structured individual interviews with national-level policy makers, health workers, HIV-positive individuals enrolled in the implementation study and support group members.

Chapter 2 describes the findings from a qualitative situational analysis I undertook together with the Swaziland Network of People Living with HIV (SWANNEPHA). The objective thereof was to understand how eSwatini-based policy makers, as well as people living with HIV, understood and perceived of the notion of HIV Treatment as Prevention, *prior* to the start of the intervention study. Data collection consisted of eight focus group discussions with HIV-positive members of support groups and 14 key informant interviews. Our data showed that policy makers actively resisted the TasP terminology by framing it as (earlier) access to HIV treatment for all rather than HIV prevention. This was influenced by fresh memories of failed HIV prevention campaigns, the widespread societal impact of HIV-related deaths, and the importance of portraying the government's responsibility to provide for the nation. Rather than TasP being conceptualized in terms of individual or societal *benefits*, which was characteristic of international public health debates at the time about TasP, our analysis reveals that people living with HIV conceived of the notion of TasP in relation to taking responsibility for one's own health and others, previous biomedical knowledge about drug resistance, and relational dynamics.

Chapter 3 assesses the reframing of TasP at the level of the health system. In our interviews with twenty-five health workers from eight different facilities we found that health workers attempted to frame the intervention of early ART in accordance with what they thought HIV-positive people would be motivated to uphold: that is, their physical and social well-being. These framings resulted from health workers' own understandings of the social realities of HIV, in particular the pervasiveness of HIV stigma in surrounding study communities, in which many of them resided. Whilst some providers included information about the possibility of ART to reduce HIV transmission in counseling sessions, they generally motivated people to start early treatment as a means to stay (visibly) healthy and avoid falling ill, thereby avoiding disclosure to and possible stigma from the wider community. Reframing their messages about TasP in this way, health providers drew on their familiarity with the local *social* implications of HIV. This highlights how health providers are intertwined with the context in which they work.

Chapter 4 provides a qualitative analysis of the complex reasons why HIV-positive people stop using (early) HIV treatment, and disengage from taking part in the Early Access to ART for All implementation study. It therefore provides insights into the limitations of the possibility of making TasP "fit" the lives of HIV-positive individuals in eSwatini. The narrative analysis of interview transcripts revealed that people's reasons for discontinuing ART, for more than 3 months at the time of the interview, are a complex, inextricably interwoven chain of events rather than a single occurrence. Mobility – temporary or permanent relocation far from the health facility where HIV treatment was obtained – was often the first step leading to eventual discontinuation of ART. Mobility resulted from complex individual navigations of precarious and specific life circumstances and was often triggered by critical life-events: the death of one's spouse, a brother's serious illness, the marriage break-up of a migrant laborer, or the lack of freedom to refuse mobile employment or a job far from home. Yet, we argue that mobility becomes a problem in relation to the continuation of ART because the health system poorly catered to the reality of people's mobile lives, making it difficult for people to temporarily refill treatment prescriptions at different health facilities. Our findings suggest that policy interventions to prevent loss to follow-up should be comprehensive, multifaceted, and address the organization of healthcare by improving the referral systems and inter-facility communications, as well as be tailored to the situations and needs of the individual person.

In **chapter 5**, I discuss the transformations of HIV support groups during the implementation of the Early Access to Art for All study in Ntfonjeni, a community in northern eSwatini. Building on 10 months of ethnographic fieldwork in this locality, during which I visited four supports regularly, participated in their activities and interviewed 20 members, I explored what attracted both HIV-positive and HIV-negative women to form and join these groups. I show that the increased attention and available funding for TasP led to the revival of old HIV support groups and the formation of new groups. However, I found that whilst some people join the groups because of a shared biosocial identity, they appeared attractive to people with different kinds of chronic conditions besides HIV, but also for people without any specific diagnosis, because they catered to a need for social solidarity in the context of vulnerability to chronic illness in general. Several HIV-negative married women joined support groups because they anticipated a future HIV infection, but were unable to negotiate condom use in their marriage. These findings suggest that, in situations where prevention of HIV infection is difficult due to structural vulnerabilities, a condition of "chronic awareness" is fostered in which people get accustomed to living with, and anticipating, HIV and other chronic illnesses.

Chapter 6 is a methodological reflection on my experience balancing active participation in the implementation of the Early ART research project as the social science coordinator, with trying to maintain critical distance as an ethnographer. Drawing on fieldnotes taken during the design and implementation of the EAAA study, I discuss how I balanced proximity and distance within the study team and study sites, and the kinds of tensions and consequences this produced. I demonstrate that this balancing act was not only an internal process but a relational and intersubjective practice.

In the conclusion, **chapter 7**, of this thesis, I discuss my key insights related to how TasP, as a public health intervention, was shaped and reshaped in context at different levels: in policymaking; in the health system; and by its users living in study communities, people living with HIV, and support group members. One key insight that emerged from my analysis across these multiple levels is that values of responsibility, well-being, and solidarity come to underlie transformations in, and the reframing of, HIV treatment as prevention in eSwatini. Another key insight this dissertation revealed is that Swazi policymakers strategically make use of and shape biomedical interventions and research to be of use to *them*—not on a personal or institutional level, but on a national-level programmatic scale. Research was made use, not through its final study results, but because it provided learning-by-doing insights, skills and capacity generated *through* its implementation. The contextual shaping of a research project is therefore a valuable undertaking, and underlies the successful implementation of a global health intervention.

SAMENVATTING

Swaziland heeft ‘s werelds hoogste humaan immunodeficiëntievirus (hiv) prevalentie, geschat op 27% onder de bevolkingsgroep van 15 tot 49 jaar. In de afgelopen tien jaar zijn er in Swaziland verschillende volksgezondheidsstrategieën geïmplementeerd om de hiv-epidemie onder controle te krijgen. Eén zo'n strategie is “Treatment as Prevention” (TasP): het onderwerp van dit proefschrift. TasP verwijst naar het gebruik van antiretrovirale therapie (ART), ook bekend als hiv-remmers, voor hiv-positieve individuen, niet alleen om hun eigen gezondheid te verbeteren, maar ook vanwege het preventieve potentieel om hiv-transmissie te verminderen in een populatie. Deze aanpak wordt ook wel de “vroege behandeling” (*early ART*) genoemd omdat er op een eerder moment wordt gestart met antiretrovirale middelen, namelijk zo snel mogelijk na de diagnose. Dit is een verschil met voormalige (inter)nationale richtlijnen waarbij het tijdstip van de start van hiv-remmers werd gebaseerd op de progressie van de infectie en de status van het immuunsysteem. Als één van de antropologische onderzoekers werkzaam in een multidisciplinair onderzoeksproject waarin de implementatie van “Early ART” in Swaziland tussen 2012 en 2018 werd geëvalueerd, onderzocht ik de sociale en politieke processen waardoor een mondiale gezondheidsstrategie (TasP) werd omgevormd door, en aangepast aan, de lokale context.

Dit proefschrift is gebaseerd op vijf empirische hoofdstukken, gepubliceerd in zowel medisch antropologische als publieke gezondheidszorg georiënteerde tijdschriften. De vijf empirische hoofdstukken bespreken transformaties van TasP op drie verschillende niveaus: in beleidsvorming (hoofdstuk 2 en 6), in het publieke gezondheidssysteem (hoofdstuk 3) en binnen lokale gemeenschappen (hoofdstuk 4 en 5). Tezamen trachten zij de volgende onderzoeksvragen te beantwoorden: Op welke manier hebben politieke dynamieken en temporale omstandigheden de introductie van TasP in Swaziland beïnvloed? Hoe integreren lokale zorgverleners vroege hiv-behandeling in hun counseling praktijken? Hoe beïnvloedt de implementatie van vroege hiv-behandeling het gebruik van hiv-medicatie, en de vorming van patiëntenverenigingen in de lokale studie gemeenschappen? Op basis van een “kritisch toegepaste” medisch antropologische benadering verken ik in dit proefschrift hoe een mondiale volksgezondheid strategie wordt omgezet in nationaal gezondheidszorgbeleid en lokale gezondheidszorg praktijken. Op deze manier geeft dit proefschrift niet alleen inzicht in hoe nationale en lokale actoren *reageren* op een mondiale gezondheidsstrategie, maar ook hoe een interventie wordt gevormd door de politieke, temporele en sociale dynamieken van het implementatieproces.

In **hoofdstuk 1**, de inleiding, verken ik de opkomst van TasP als een mondiale volksgezondheidsstrategie en bespreek de biologische, epidemiologische en geopolitieke grondslagen ervan. Verder introduceer ik het *Max*ART project (Maximizing ART for Better Health and Zero New HIV Infections) en de multidisciplinaire implementatiestudie genaamd “Early Access to ART for All” (EAAA). De EAAA studie had als doel om de impact van “Early ART” te onderzoeken in de bestaande publieke gezondheidszorgstructuur in Swaziland. Daarnaast bespreek ik de historische context van de hiv-epidemie in Swaziland evenals drie verschillende disciplinaire benaderingen om de contextualisering van biomedische interventies te bestuderen: de representatieve, de interactionele, of de ontologisch meervoudige benadering. Gebaseerd op een interactionele benadering van het bestuderen van context en contextualisering, onderzoek ik hoe TasP betekenis krijgt voor verschillende actoren op verschillende niveaus, en wat voor transformaties zo'n contextualisatie proces met zich meebrengt. De kwalitatieve dataverzameling vond plaats in verschillende fasen, zowel voorafgaande aan, als tijdens de implementatie van de EAAA studie en bestaat voornamelijk uit (participerende) observaties en interviews. Observaties vonden plaats in gezondheidsklinieken, onderzoeksteam vergaderingen en trainingen, en in patiëntenverenigingen in lokale gemeenschappen waar de EAAA studie werd geïmplementeerd. Daarnaast heb ik, ook in samenwerking met een lokaal onderzoeksteam, focusgroep discussies en semigestructureerde individuele interviews uitgevoerd met onder andere nationale hiv-beleidsmakers, lokale zorgverleners, hiv-positieve personen die deelnamen aan de implementatiestudie en leden van patiëntenverenigingen.

Hoofdstuk 2 beschrijft de bevindingen van een kwalitatieve situatie analyse die ik heb uitgevoerd in samenwerking met Swaziland's nationale hiv-netwerk (SWANNEPHA). Het doel hiervan was om te begrijpen hoe hiv-positieve mensen, activisten en beleidsmakers in Swaziland tegen het concept van TasP aankeken, voordat de implementatie studie van start ging. De dataverzameling bestond uit acht focusgroep discussies met hiv-positieve leden van patiëntenverenigingen en individuele interviews met 14 sleutelinformanten (*key informant interviews*). Onze analyse laat zien dat beleidsmakers zich actief verzetten tegen de TasP-terminologie door het te *framen* als (eerdere) toegang tot hiv-medicatie in plaats van een vorm van hiv-preventie. Deze *reframing* werd beïnvloed door recente ervaringen met mislukte hiv-preventie campagnes, de maatschappelijke impact van hiv-gerelateerde sterfte, en het uitdragen van de verantwoordelijkheid van de Swazi overheid voor de gezondheid van de bevolking. In plaats van TasP te conceptualiseren in termen van individuele óf maatschappelijke baten, wat kenmerkend was voor de internationale debatten over TasP in die tijd, laat onze analyse zien dat hiv-positieve mensen het begrip TasP opvatten in relatie tot het nemen van verantwoordelijkheid voor zowel hun eigen gezondheid als die van anderen. Verder vormden eerdere biomedische kennis over de mogelijke gevaren van medicatie-resistentie, evenals specifieke familie- en liefdesrelatie dynamieken, belangrijke thema's in de lokale interpretaties van TasP.

Hoofdstuk 3 beschrijft de manier waarop TasP werd geïntegreerd in hiv-counseling praktijken in het publieke gezondheidssysteem, op basis van individuele interviews met 25 zorgverleners van acht verschillende gezondheidszorgklinieken. We ontdekten dat zorgverleners de interventie van het vroegtijdig beginnen met hiv-medicatie (her)formuleerden op een manier die overeenkwam met wat zij dachten dat belangrijk was voor hiv-positieve mensen: het behouden van hun fysieke en sociale welzijn. Deze herformuleringen kwamen voort uit hun eigen begrip van de sociale realiteit van hiv, en het wijdverspreide stigma wat de infectie met zich meedraagt, binnen de lokale gemeenschappen waarvan de zorgverleners zelf ook onderdeel zijn. Zorgverleners verstrekten daarbij amper informatie over het mogelijke preventieve effect van hiv-remmers op het verminderen van het overdragen van een hiv-besmetting. Als belangrijkste motivatie voor het eerder beginnen met hiv-remmers prijsde zorgverleners de interventie aan als een middel om te voorkomen dat je ziek (gezien) wordt, om zodoende mogelijke stigmatisering door de gemeenschap te vermijden. In hun herformuleringen van TasP in hiv-counseling praktijken bouwden zorgverleners dus voort op hun kennis van de lokale *sociale* implicaties van hiv en aids. Dit laat zien hoe zorgverleners verweven zijn met de context waarin ze werken.

Hoofdstuk 4 omvat een kwalitatieve analyse van de complexe redenen waarom hiv-positieve mensen stoppen met hun (vroegtijdige) HIV-medicatie, en daarmee ook hun deelname aan de EAAA implementatiestudie. De narratieve analyse van de interview transcripten onthulde dat de redenen van mensen om (langer dan 3 maanden) te stoppen met hiv-remmers een complex proces is van met elkaar verweven gebeurtenissen in plaats van het gevolg van een losstaand incident. Mobiliteit - tijdelijke of permanente verhuizing ver van de gezondheidsinstelling waar de hiv-medicatie is gestart - was vaak de eerste stap in het proces wat uiteindelijk leidde tot het stoppen met hiv-medicatie. Mobiliteit was het resultaat van complexe precaire levensomstandigheden en vaak veroorzaakt door kritieke levensgebeurtenissen: de dood van iemands echtgenoot, de ernstige ziekte van een broer, het uiteenvallen van het huwelijk, of het gebrek aan (economische) vrijheid om een baan ver van huis te weigeren. Wij beargumenteren echter dat mobiliteit alleen een probleem vormt voor het continueren van hiv-remmers omdat het gezondheidssysteem niet is toegespitst op de realiteit van het mobiele leven van mensen. Hierdoor is het vaak niet mogelijk om een herhaal recept van de medicatie te krijgen in een andere gezondheidszorginstelling. Onze bevindingen suggereren dat beleidsinterventies zich moeten richten op de organisatie van de gezondheidszorg om de verwijzingssystemen en de communicatie tussen de instellingen te verbeteren. Daarnaast zou het trainen van zorgverleners in het herkennen en beperken van risicofactoren voor het stoppen met hiv-remmers kunnen bijdragen om mensen met hiv te steunen bij het langdurig gebruik van hiv-remmers.

In **hoofdstuk 5** bespreek ik de transformaties van HIV patiëntenverenigingen (*support groups*) tijdens de implementatie van de EAAA studie in Ntfonjeni, een lokale gemeenschap in het noorden van Swaziland. Voortbouwend op 10 maanden etnografisch veldwerk in deze plek, gedurende welke ik vier patiëntenverenigingen regelmatig bezocht, deelnam aan hun activiteiten en 20 leden interviewde, onderzocht ik wat hiv-positieve alsmede hiv-negatieve vrouwen aantrok om zich bij deze groepen te voegen. Ik laat zien dat de toegenomen aandacht en beschikbare financiering voor TasP geleid heeft tot de heropleving van oude HIV patiëntenverenigingen en de vorming van nieuwe groepen. Ik ontdekte echter dat, hoewel sommige mensen zich bij de groepen aansloten vanwege een gedeelde biosociale identiteit (hiv), ze ook aantrekkelijk bleken voor mensen met verschillende andere soorten chronische aandoeningen naast hiv, maar ook voor mensen zonder een specifieke diagnose. Dit kwam omdat deze groepen mensen voorzagen in een behoefte aan sociale solidariteit in een situatie waarin zij zich kwetsbaar achtten voor het ontwikkelen van verschillende chronische ziektes in de toekomst. Een aantal hiv-negatieve getrouwde vrouwen sloten zich aan bij deze groepen omdat ze een hiv-infectie anticipeerden, mede omdat hun partners weigerden om een condoom te gebruiken binnen het huwelijk. Deze bevindingen laten zien dat in situaties waar hiv-preventie bemoeilijkt is door structurele kwetsbaarheden, een toestand van “chronisch bewustzijn” wordt gecreëerd waarin mensen gewend raken aan het leven met, en anticiperen op, hiv en andere chronische ziekten.

Hoofdstuk 6 is een methodologische reflectie met betrekking tot het vinden van de balans tussen actieve deelname aan de EAAA implementatiestudie als de coördinator van sociaalwetenschappelijk onderzoek, en het bewaren van kritische afstand om de interventie te bestuderen als etnografisch object. Aan de hand van veldnotities die ik tijdens de ontwikkeling en de uitvoering van de EAAA-studie heb gemaakt, bespreek ik hoe ik deze balans binnen het studieteam en de onderzoekslocaties heb getracht in evenwicht te houden, en welke spanningen en gevolgen dit heeft opgeleverd, voor mijzelf en voor anderen. Ik laat hierbij zien dat het zoeken van deze balans niet alleen een intern proces was, maar ook een relationele en intersubjectieve praktijk.

In de conclusie, **hoofdstuk 7**, van dit proefschrift bespreek ik mijn belangrijkste inzichten met betrekking tot hoe TasP, als mondiale gezondheidsstrategie, werd omgevormd en aangepast aan de Swazi context op verschillende niveaus: in de beleidsvorming; in het gezondheidssysteem; en in de studie gemeenschappen door mensen met hiv en leden van patiëntenverenigingen. Een belangrijk inzicht dat uit mijn analyse over deze verschillende niveaus naar voren kwam, is dat sociale waarden als verantwoordelijkheid, sociaal welzijn en solidariteit ten grondslag liggen aan transformaties in, en de herformulering van, TasP in Swaziland. Een ander belangrijk inzicht is dat Swazi beleidsmakers biomedische interventies en onderzoek strategisch gebruiken en vormgeven zodat ze voor hen van nut zijn - niet op persoonlijk of institutioneel niveau, maar op een nationaal hiv programma niveau. De EAAA studie was nuttig, niet vanwege de uiteindelijke studieresultaten, maar omdat het inzichten, vaardigheden en capaciteit opleverde die tijdens de implementatie werden gegenereerd. De lokale contextuele aanpassingen van een onderzoeksproject lagen daarmee ten grondslag aan de succesvolle implementatie van een mondiale volksgezondheidsinterventie.

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Eva Vernooij, Haarlem, July 2022.