EXPLORING THE POSITIVE HEALTH, DIGNITY AND PREVENTION NEEDS OF FEMALE SEX WORKERS, MEN WHO HAVE SEX WITH MEN AND TRANSGENDER WOMEN IN THE DOMINICAN REPUBLIC AND SWAZILAND
Exploring the Positive Health, Dignity and Prevention Needs of Female Sex Workers, Men Who Have Sex with Men and Transgender Women in the Dominican Republic and Swaziland

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EXECUTIVE SUMMARY

Background and aims
Female sex workers (FSW), men who have sex with men (MSM) and transgender women (TW) are key populations (KP) that are disproportionately affected by HIV around the world. While these populations are frequently the focus of HIV-related surveillance and primary prevention efforts, little is known about the prevention and care experiences of individuals from these KP who are living with HIV, particularly as they relate to the Positive Health, Dignity and Prevention (PHDP) framework. Kennedy et al. (2010) outline four goals of PHDP efforts: (1) physical health; (2) mental health; (3) prevention of further transmission of HIV; and (4) active involvement of people living with HIV (PLHIV) in prevention activities, leadership and advocacy. This study explored the prevention, care and treatment needs of FSW, MSM, and TW living with HIV in the Dominican Republic (DR) and Swaziland in order to better tailor PHDP programs and messages to meet their specific needs.

The specific aims of the study were to

1. Describe the social and structural context of FSW, MSM, and TW in the DR and Swaziland, particularly as it relates to stigma and discrimination among individuals living with HIV;
2. Examine the specific PHDP needs of FSW, MSM and TW who are living with HIV, including challenges to accessing ongoing prevention, treatment, care and support services;
3. Describe existing PHDP interventions and services and how these interventions and services do and do not meet the ongoing needs of KP within both countries; and
4. Identify ways in which PHDP interventions and services can be tailored to meet the needs of FSW, MSM, and TW, including specific program models and communication messages.

Swaziland and the DR differ on a number of important factors related to KP. Swaziland has a generalized HIV epidemic. The DR, in contrast, is an example of a concentrated epidemic with much lower population-level HIV prevalence but a disproportionate HIV burden among key populations. The legal, socio-cultural, and economic contexts surrounding FSW, MSM, and TW also differ across the two countries, resulting in differences in the organization of sex work and levels of acceptance of these populations. In Swaziland, both sex work and same-sex practices are explicitly illegal. While the legal environment is less repressive in the DR, ongoing stigma and discrimination experienced by these populations is still significant. Such differences allow the two countries to serve as comparative case studies of the HIV-related experiences of KP across epidemic typologies and social contexts.

Methods
Across both countries, a qualitative approach was used to address the study aims. Methods included (a) key informant interviews (n=47) with HIV program planners, policy makers, clinicians, and community leaders from the FSW, MSM and TW communities; (b) in-depth interviews with FSW (n=41), MSM (n=36) and TW (n=5), all of whom were living with HIV; and (c) focus groups with FSW (3 groups, n=43) and MSM (3 groups, n=45), including both individuals who were living with HIV as well as those who were not. In-depth interview participants were interviewed twice to enhance rapport and to gain more depth
and understanding of the study topics. Topics covered in interviews and focus groups included KP experiences, existing HIV-related services for KP, and suggestions for tailoring of services. In Swaziland, all interviews were conducted in SiSwati or English and, if needed, simultaneously translated and transcribed in English. In the DR, all interviews were conducted and transcribed in Spanish.

Data were analyzed using narrative analysis and coding methods to capture participants’ stories surrounding HIV and to identify recurrent patterns. This process included data analysis and interpretation workshops in both settings with key stakeholders to identify emerging themes and discuss implications of findings. Both study teams developed codebooks based on both a priori and emergent themes, and all transcripts were systematically coded using the computer software package Atlas.ti.©

Ethical review and approval for this study were received from the following Institutional Review Boards (IRBs): the National Research Council of Swaziland, the Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz in the DR, and the Johns Hopkins Bloomberg School of Public Health in the United States.

Results

Social, structural, and economic context of key populations

Participants in both settings described a social context characterized by multiple layers of stigma and discrimination related to gender, sexual orientation, professional identity, poverty and their identities as people living with HIV (PLHIV). In Swaziland, violence was a common experience for both FSW and MSM as both populations are criminalized and constantly fear being caught. In the DR, participants described significant barriers to economic productivity, especially their limited ability to secure formal work due to illegal hiring and firing practices by employers.

In both settings, participants described living in situations of extreme social and economic deprivation. FSW experienced a cycle of economic need, sex work, and HIV that inhibited their opportunities to find other work as well as to prevent further transmission of HIV. This underscores the effect that broader economic and legal structures have on KP. FSW cited their own need or that of their children as the impetus to begin sex work, and as a primary force in continuing to sell sex following their HIV diagnosis. MSM also reported struggling with poverty and lack of socio-economic opportunities, fueled by their own multi-layered experiences of stigma.

PHDP needs of key populations

Care and treatment: protecting physical health

In both countries, participants reported perceived and experienced stigma related to their sexual and professional identities in health care settings, contributing to low levels of care seeking. Participants in Swaziland described facing discrimination and embarrassment in health services because of their sexual practices. Additionally, both FSW and MSM in Swaziland reported perceived and experienced stigma against PLHIV from families and partners, contributing to low levels of HIV serostatus disclosure. Lack of
disclosure translated into lack of social support, which led to challenges with HIV treatment access and ART adherence. In the DR, participants noted considerable systemic challenges in engaging with the public health care system including lack of pre-HIV test counseling, delayed diagnosis, involuntary disclosure of HIV status by clinic staff, and poor quality services in clinics. Participants also described considerable care-related expenses, including the high costs of transportation to get to appointments as well as prescribed medicines and treatments (beyond ART).

**Psychosocial support: protecting mental well-being**

In both settings and populations, the primary threat to mental health was living with the multi-layered stigma related to their HIV status and their gender, sexual, or professional identity. The high prevalence of HIV in Swaziland, in some cases, seemed to help mitigate this stigma. Participants in Swaziland reported receiving emotional support from a variety of sources such as pastors; yet, only one Swazi MSM mentioned going to formal counseling services. FSW more commonly discussed the emotional support they received from participating in formal support groups, although they also mentioned receiving support from friends, female relatives and religion. Dominican participants accessed informal support from partners, family, friends and faith communities who gave them strength and helped them deal with stigma. Participants felt that this informal support was invaluable in helping them to cope with HIV. Unfortunately, participants who had not disclosed were unable to access this support, while those who did often faced discrimination from their own family and friends. Participants in the DR also described interactions with formal psychosocial support services such as psychologists, peer educators, and support groups. Most of these interactions, however, were isolated events rather than ongoing processes of support. One barrier to seeking ongoing psychosocial support was the stigma associated with mental illness and the perceived sense that seeking such support meant you were “crazy,” an additional negative label and form of stigma that participants reportedly did not want to chance.

**Preventing ongoing HIV transmission**

In both settings, participants were very aware of the need to prevent HIV transmission to sexual partners. Many had changed their behavior after being diagnosed with HIV in order to reduce transmission risk to others by using condoms\(^1\) and reducing the number of partners. They did, however, continue to face barriers to prevention. In Swaziland, clinical providers’ questions about HIV prevention often assumed heterosexuality and monogamy, limiting opportunities for safe sex conversations. Due to fear of stigma, FSW/MSM often just answered the question asked rather than discussing their true risk behaviors. Some FSW also described being offered more money for sex without condoms, which some accepted due to financial need. In the DR, many participants mentioned that they would like to have an HIV-infected partner so that they would not have to worry about infecting someone if the condom broke. Dominican participants faced some resistance to condom use from their partners and, as in Swaziland, some FSW received offers of more money from men to have sex without condoms. A few FSW also mentioned that sexual partners had tried to force them to have sex without condoms.

\(^1\) Participants generally did not distinguish between male and female condoms, so when condom use is discussed, this can be assumed to refer to male condom use.
Comprehensive services
In both countries, participants disagreed about whether they would prefer separate services dedicated to the needs of KP, or whether they would prefer integrated services with providers and staff who were trained to address the specific needs of KP and provide respectful care. Regardless, our findings indicate that KP require services that consider their specific needs in a holistic fashion, and PHDP program planners should consider this in comprehensive programs.

Increasing agency and involvement
The recurring theme of multiple layers of stigma among FSW, MSM and TW living with HIV also impacted participants’ involvement in HIV-related programs, advocacy and policy making. Participants from Swaziland indicated that people from their communities are often unwilling to disclose their status publically to represent these groups in HIV-related activities. Despite similar barriers, many participants in the DR were actively involved in HIV education and support activities to prevent the further spread of HIV in their communities. They indicated that participation in these activities made them feel better, gave them a sense of purpose and improved their own mental health.

Recommendations
Despite the contextual differences, there were many similarities in the experiences and needs of key populations living with HIV in Swaziland and the DR. Comparison of these populations highlights some considerations and recommendations that may be universal to KP and some aspects which may differ by setting.

Need to address the double burden of stigma and discrimination
Key populations in both settings experienced substantial multi-layered stigma related to their HIV-status and their sexual practices and/or gender identities. Being stigmatized or discriminated against affected participants’ physical and mental health, complicated their efforts to reduce the spread of HIV, and limited their participation in mobilization, leadership, and advocacy activities. These findings highlight the need for nuanced approaches to reduce stigma that account for the broader historical and social context of KP. Community mobilization—led by grassroots FSW, MSM and TW groups—is one such approach that can empower KP to address stigma within and against their communities. Another recommendation based on these findings is to train health care providers and staff in HIV clinics to improve their sensitivity to working with key populations in the context of HIV care services.

Navigating costly, disjointed systems of care and treatment
Participants in both countries described numerous barriers to meeting their care and treatment needs including long lines, high costs of clinic attendance, transportation costs, drug stock-outs and little continuity of care. While these barriers affect all PLHIV in Swaziland and the DR, FSW, MSM and TW may be more affected due to their socio-economic vulnerability. One approach to address some of these barriers would be to train a cadre of peer navigators or “expert clients.” These expert clients could accompany individuals to appointments, identify social service programs and provide social support through the processes of diagnosis, acceptance and disclosure. They could also assist with treatment adherence and ongoing prevention. Participants did not all agree as to whether there should be special
clinics or services for FSW, MSM and TW living with HIV. Some worried that these targeted services would reinforce stigma; therefore, careful analysis regarding the structure of the HIV care system is needed on a country-by-country basis. At a policy level, there is a need for greater advocacy to address the sustainability of access to treatment in both countries for KP as well as programs to provide nutritional and economic support to facilitate optimal engagement with health services.

A clear need for more psychosocial support
While participants in both countries described very similar psychosocial support needs, especially following diagnosis, the availability of services varied substantially. Key populations in the DR described many more formal mental health services than those in Swaziland. There were, however, financial and cultural barriers to attending these services, in particular fear of adding another burden of stigma related to mental health. Participants in both settings highlighted the need for more peer educators who were from KP. There is also a clear need for existing HIV clinics to integrate psychosocial counseling and support into the services provided. Additionally, identifying appropriate ways to develop discreet, safe support groups and socio-economic opportunities for KP could help to address the gaps in social support as well as barriers to employment and economic stability.

Ongoing prevention
A clear similarity in the DR and Swaziland is that participants expressed a strong desire to prevent transmission of HIV to their partners, though participants in Swaziland emphasized an unmet need for HIV prevention services and distribution of condoms and lubricants. In both countries, participants emphasized that they tried to use condoms with every partner, although economic necessity made condom use more difficult for some FSW whose clients offered more money in exchange for sex without condoms. Another challenge was condom use with regular partners, paying or non-paying, with whom participants may have more longstanding and intimate relationships. There is a clear need for further outreach and education with these partners to safely address HIV protective behaviors, such as condom use, that require agreement from both members of the couple.

Leadership and advocacy for key populations living with HIV
Finally, there were clear differences in the level of engagement of participants in HIV prevention activities, leadership and advocacy across settings. Key populations in the DR are highly involved in these activities and reported considerable benefits of participation. Participants in Swaziland, however, reported more challenges in becoming involved due to stigma and their hidden identities. Yet, activities in Swaziland suggest if approached in the right way, MSM and FSW would be interested in participating in HIV prevention and care efforts in their communities.

Conclusion
This study highlights the need to consider combination HIV prevention, care and treatment programs, integrating biomedical, behavioral, structural interventions for KP. There are additional needs for strengthening community mobilization efforts and health sector interventions/trainings to combat stigma and discrimination and to more effectively meet the PHDP needs of FSW, MSM and TW.
INTRODUCTION

HIV in Swaziland and the Dominican Republic
HIV prevalence in reproductive-age adults in Swaziland is among the highest in the world at 26.1% (Mngadi et al., 2009). The epidemic seems to have stabilized since 2001 when the overall prevalence was estimated at 26.3% (Mngadi et al., 2009). Heterosexual transmission currently accounts for the majority of HIV infections in the country. The 2009 Swaziland Modes of Transmission study found that important drivers of HIV incidence included multiple concurrent partnerships before and during marriage as well as low levels of male circumcision (Mngadi et al., 2009). Surveillance suggests that Swaziland has an epidemic with differential risk by gender, with significantly higher risk among younger women; estimated HIV prevalence among 15- to 24-year-old women is 22.6%, compared to 5.9% among age-matched men (Mngadi et al., 2009).

The Dominican Republic (DR), in contrast, has a much lower HIV prevalence of 0.8% among adults aged 15-49 (Macro International, 2007). HIV prevalence in the DR has generally declined since the mid-1990s, a trend that has been attributed to behavioral changes significant in the population level (Halperin, de Moya, Perez-Then, Pappas, & Garcia Calleja, 2009). There is, however, regional diversity in HIV prevalence and higher risk within certain key populations (Halperin et al., 2009). The epidemic has been described as largely heterosexual, but with a noted significance of men who have sex with men (MSM) (Halperin et al., 2009). The epidemic in the DR does not differ by gender, as HIV prevalence is 0.8% for both women and men. Prevalence has, however, been reported to be slightly higher in rural compared to urban areas (1.0% vs. 0.7%) (Macro International, 2007).

Key populations in Swaziland and the DR
Key populations (KP) are those that are at heightened risk of for HIV infection and transmission and typically include sex workers, men who have sex with men (MSM), and transgender women (TW). MSM is a term that was coined in 1994 to reduce stigma against homosexual, bisexual, gay-identified, and non-gay-identified MSM by describing behavior rather than using potentially stigmatizing labels (Young & Meyer, 2005). As such, MSM is a broad term that encompasses a wide range of sexual identities and behaviors. The term sex workers can include male, female, and transgender individuals, although female sex workers (FSW) have been most extensively studied. The nature and structure of sex work varies considerably, but for the purposes of this study, we focus specifically on female commercial sex work, i.e., the explicit exchange of sex for money, not transactional sex more broadly defined. TW are individuals who were biological males at birth, but who identify themselves as women. While these KP are frequently the target of HIV-related surveillance and primary prevention efforts, little is known about the prevention and care experiences of individuals from these key populations who are living with HIV, particularly as they relate to Positive Health, Dignity and Prevention (PHDP).

UNAIDS characterizes HIV epidemics as low level, concentrated, or generalized. Swaziland is an example of a generalized epidemic, where HIV prevalence is consistently over one percent in pregnant women nation-wide. The Dominican Republic, in contrast, is considered a concentrated epidemic, with HIV prevalence consistently over five percent in at least one defined sub-population but below one percent.
in pregnant women in urban areas. Historically, HIV prevention, care and treatment services have focused on the general population in generalized epidemics, while focusing on KP in concentrated epidemics. However, recent evidence suggests that key populations should not be ignored even in generalized epidemics. Research from a number of countries with generalized epidemics has revealed the heightened risk of MSM and FSW even in these settings (Baral et al., 2009; Baral et al., 2012). Because both MSM and FSW are connected to broader sexual networks through their partners, the heightened prevalence of HIV within these groups is a public health concern not only for these specific populations, but also for the country as a whole. Additionally, HIV interventions targeted to the general population may overlook the specific needs of KP and thus dilute their overall effectiveness. Accordingly, it becomes an essential public health task to gain a better understanding of HIV among KP even in generalized epidemic settings such as Swaziland (Baral & Phaswana-Mafuya, 2012).

In Swaziland, both sex work and MSM practices are illegal. This is one reason why, until recently, there were no known HIV prevalence estimates for either FSW or MSM in the country. Among FSW, HIV prevalence estimates in other countries in the region range from 24% in Rwanda and 37% in Uganda to over 70% in Malawi (Braunstein et al., 2011; Vandepitte et al., 2011; Malawi NACo, 2007; Baral et al., 2012). Two rapid assessments of FSW in Swaziland were conducted in 2002 and 2007; however, both had small samples and only cursorily examined the dynamics and practices of sex work in Swaziland (Swaziland. Ministry of Health & Social Welfare, 2002; Swaziland. Ministry of Health & Social Welfare, 2007). In 2011, a respondent-driven sampling (RDS) survey of KP was conducted by the Swazi Ministry of Health, PSI, and the Johns Hopkins Bloomberg School of Public Health in conjunction with this research (Baral et al., 2013). This survey of 325 FSW found an RDS-adjusted HIV prevalence of 60.5%. Additionally, the survey revealed condom use as higher with new clients than with regular partners and recorded frequent experiences of violence and human rights abuses. Most sex work in Swaziland is concentrated in hot spots such as specific bars and nightclubs, traffic circles and intersections, and border crossings (Swaziland MHSW, 2007).

Until recently, there were also no systematic data on HIV prevalence and risk behaviors among MSM and TW in Swaziland. However, RDS studies of MSM in the nearby countries of Malawi, Namibia, and Botswana revealed an overall HIV prevalence of 17.4% (95% CI: 14.4-20.8) (Baral et al., 2009). The 2011 RDS survey with key populations provided the first data on HIV prevalence and associated risk behaviors among MSM in Swaziland (Baral et al., 2013). Among 328 MSM surveyed, RDS-adjusted HIV prevalence was 12.6%. Over one-third reported sex with both men and women in the past 12 months. Additionally, many participants reported stigma, discrimination and human rights abuses.

The HIV epidemic in the DR is characterized by the disproportionately high burden of disease among FSWs, MSM, and individuals who use drugs (Halperin et al., 2009). Despite its relatively small overall population size, the DR has a large female sex work industry, with tens of thousands of Dominican FSW both within the country and abroad (Vuylsteke & Jana, 2001). Sex work among persons over the age of 18 is not illegal in the DR. Estimates of HIV prevalence among FSW indicate variability across cities and regions; the most recent data from the 2008 COPRESIDA-Presidential AIDS commission study among
vulnerable groups show that HIV prevalence among FSW is 4.8% overall, with a range of 3.3% to 8.4% across regions (COPRESIDA, 2008).

The majority of female sex work in the DR is establishment-based, although most establishments are “indirect,” such as bars and discos, where women earn money from waitressing, dancing and other activities besides sex work. These differ from “direct” establishments, such as brothels, where women are mainly paid directly for sex work (Kerrigan et al., 2003). Past studies among Dominican sex workers have shown that although condom use is high with new and casual paying partners, most FSW have regular paying partners with whom condom use is lower (Kerrigan et al., 2003). The strongest predictor of consistent condom among FSW use is perceived relationship intimacy (Murray et al., 2007). Male sex work also exists in the DR, particularly in tourist settings, although male sex workers are highly stigmatized and are less likely to be targeted by HIV prevention programs (Padilla et al., 2008; de Moya & Garcia, 1998; Thanel et al., 2009). To date, very little research has been conducted with TW in the DR, a population that is heavily involved in sex work.

The HIV epidemic in the DR has been hypothesized to have “an important MSM and bisexual component” because of the high ratio of male to female cases of HIV and AIDS, as compared to heterosexual HIV epidemics elsewhere (Halperin et al., 2009, p. S52). Since MSM behaviors are highly stigmatized in the DR it is hypothesized that many cases of HIV among MSMs are reported as heterosexual transmission (Halperin et al., 2009). Recent data from COPRESIDA (2008) show that HIV prevalence among MSM ranges from 5.1-7.6% in the eastern tourist area of the country and is 5.9% in the capital of Santo Domingo. While there are no HIV prevalence estimates specifically for TW in the DR, anecdotal evidence suggests that this population has also been greatly affected by HIV, as well as violence and drug use (Thanel et al., 2009). Several grassroots NGOs exist that address MSM and transgender rights and issues, including HIV. As previously mentioned, however, MSM and TW are highly stigmatized and the response to HIV among these groups has been much less extensive than the response among FSW.

**Positive Health, Dignity and Prevention (PHDP)**

In the early years of the HIV epidemic, HIV testing and counseling was not widely available in low- and middle-income countries. Consequently, few people living with HIV (PLHIV) were aware of their HIV status. HIV prevention programs, therefore, relied on messages for the general population that implicitly assumed that all individuals were in the same situation, i.e., uninfected or untested. Program planners were also hesitant to target prevention messages toward PLHIV due to fear of blaming the HIV-infected individual and adding to their already heavy burden of stigma (Auerbach, 1994).

In recent years however, the situation has improved. HIV testing and counseling and associated care and treatment services have been scaled up dramatically, and many more people in low- and middle-income countries have been tested for HIV and know their HIV serostatus. In turn, program planners have realized that a continued reliance on general HIV prevention messages may limit the effectiveness and sophistication of HIV prevention strategies (Global HIV Prevention Working Group, 2004). In light of recent studies showing the importance of HIV treatment in the prevention of ongoing transmission
prevention activities are increasingly focusing on individuals who know they are HIV-infected (Janssen & Valdiserri, 2004). This strategy was originally known as positive prevention, although it has also been called prevention by, for, or with positives (Auerbach, 2004; CDC, 2003a; CDC, 2003b; Collins et al., 2000; International HIV/AIDS Alliance, 2003), and, most recently, positive health, dignity and prevention (PHDP) (GNP+, 2009). We use the term PHDP here as it is most accepted by PLHIV groups, and it has been agreed upon as the preferred terminology at the world AIDS conference in Vienna, Austria, 18-23 July, 2010, validating the overall well-being and human rights of those living with HIV.

Kennedy et al. (2010) outlined a framework for PHDP (which they refer to as positive prevention) that includes activities centered on four main goals: (1) keeping PLHIV physically healthy; (2) keeping PLHIV mentally healthy; (3) preventing further transmission of HIV; and (4) involving PLHIV in prevention activities, leadership and advocacy. Interventions include both biomedical (e.g., antiretroviral therapy (ART), prevention of opportunistic infections, prevention of mother-to-child transmission programs, and sexually transmitted infection (STI) diagnosis and treatment) and behavioral interventions (e.g., psychosocial counseling and support programs, adherence counseling and support, prevention counseling, mass media, training in advocacy methods). The ultimate goal of these interventions is to reduce morbidity and mortality related to HIV/AIDS, reduce HIV incidence, and reduce HIV-related stigma and discrimination.
PHDP conceptual framework

Figure 1: Conceptual framework for PHDP developed by Kennedy and colleagues (2010)

PHDP and key populations

PHDP interventions and programs are being rolled out globally in association with the scale-up of antiretroviral treatment and associated care services for PLHIV. However, to date, these programs are generally targeted toward heterosexual populations. Key populations, including FSW, MSM, and TW, may have specific and unique needs that should be addressed by targeted services, including PHDP programs, but little research has been conducted on the PHDP needs of these groups.

Objective and specific aims

To address these gaps, this study sought to explore the prevention and care needs of HIV-infected KP in Swaziland and the DR to better tailor PHDP programs and messages. These two countries differ on a number of important factors related to KP and PHDP. HIV prevalence differs, as does the nature of the HIV epidemic: Swaziland is an example of a high prevalence, generalized HIV epidemic while the DR is an example of a relatively low prevalence, concentrated epidemic. The legal, socio-cultural and economic contexts surrounding sex work, MSM and TW behaviors differ across the countries, resulting in
differences in the organization of sex work and levels of acceptance of FSW, MSM, and TW. Such differences allow the two countries to serve as comparative case studies of PHDP among key populations in different epidemic and social contexts.

The specific aims of the study were to

1. Describe the social and structural context of FSW, MSM, and TW in the DR and Swaziland, particularly as it relates to stigma and discrimination among individuals living with HIV;
2. Examine the specific PHDP needs of FSW, MSM and TW who are living with HIV, including challenges to accessing ongoing prevention, treatment, care and support services;
3. Describe existing PHDP interventions and services and how these interventions and services do and do not meet the ongoing needs of KP within both countries; and
4. Identify ways in which PHDP interventions and services can be tailored to meet the needs of FSW, MSM, and TW, including specific program models and communication messages.
METHODS

Across both countries, a qualitative approach was used to address the study aims. Methods consisted of (a) key informant interviews (n=47) with HIV program planners, policy makers, clinicians, and community leaders from the FSW, MSM and TW communities; (b) in-depth interviews with FSW (n=41), MSM (n=36), and TW (n=5), all of whom were living with HIV; and (c) focus groups with FSW (n=43), MSM (n=41), and TW (n=4), including both individuals living with HIV and those who were not, to confirm preliminary findings and provide member checking (Crabtree & Miller, 1999). Study participants are summarized in Table 1.

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*All in-depth interview participants were interviewed on two occasions
**Focus groups in Swaziland included participants who were living with HIV as well as participants who were not

Key informant interviews

We conducted one-on-one, semi-structured interviews with a variety of key informants who had important knowledge regarding the FSW, MSM, and TW communities and PHDP services in these settings, specifically, HIV program planners, policy makers, clinicians, and community leaders. Individuals from each of these groups were identified and recruited through community partner organizations and through snowball sampling from initial participants. We interviewed 16 key informants in Swaziland and 31 key informants in the DR.

Eligible participants were invited to participate in an interview at a time and location of their convenience. Before the start of the interview, interviewers explained the study and obtained verbal informed consent. All interviews took place in a private setting of the participant’s choice in his or her preferred language (English or SiSwati in Swaziland, Spanish in the DR). Key informant interviews lasted approximately one hour.

A field guide was developed to guide the discussion and stimulate probing on topics of interest. Participants were asked to describe the situation of FSW, MSM and TW in their communities, their knowledge of existing PHDP services as well as services specifically targeted towards FSW, MSM and TW, and their thoughts for how services could be improved to better meet the needs of KP. All interviews were semi-structured, whereby the interviewer used a guide to ensure that all topics were covered, but a certain amount of flexibility was allowed to permit discussion of unanticipated but interesting issues that may have arisen.
In-depth interviews with FSW, MSM and TW living with HIV

In addition to the key informant interviews, we conducted in-depth interviews with FSW, MSM and TW who were living with HIV. In Swaziland, we interviewed 21 FSW and 20 MSM. In the DR, we interviewed 20 FSW, 16 MSM and 5 TW.

Recruitment was conducted through a variety of settings and organizations to facilitate diversity of participants. These settings included HIV clinics, networks of people living with HIV, community organizations for FSW, MSM and TW, and HIV prevention, care and treatment activities. Individuals were identified through existing relationships, inputs from key informants and participant referral. This purposeful sampling, also known as criterion-based selection, was deliberately intended to broaden the number of response categories to explore the experience of individuals from a variety of perspectives (Maxwell, 1996). Eligible participants were invited to participate in an interview at a time and location of their convenience. As with key informants, interviewers explained the study and obtained verbal informed consent prior to the start of each interview. All interviews took place in a private setting of the respondent’s choice and in his or her preferred language. Interviews lasted approximately one to two hours each.

Interviews were semi-structured and interviewers employed a field guide to direct the conversation and stimulate probing. Each participant was interviewed twice to enhance rapport and to gain more depth and understanding on the aforementioned topics. Participants were asked about the general experiences of FSW, MSM and TW in their communities, the organization and networks of these populations, their personal and community experiences with HIV prevention, care, and treatment services, their experiences with stigma and discrimination, and their suggestions for how services, interventions, and messages could be better tailored to meet the needs of their population.

Focus groups with SW, MSM and TW

To gather a broader community perspective on the topics of this study, including from FSW and MSM who were not infected with HIV, we conducted additional focus group discussions in each country. In Swaziland, 3 focus groups were conducted with 19 FSW total (8, 4, 7 participants, respectively, in each group) and 3 focus groups were conducted with 26 MSM (4, 13, and 9 participants, respectively, in each group). In the DR, 3 focus groups were conducted with 24 FSW total (8, 7, and 9 participants, respectively, in each group) and 3 focus groups were conducted with 15 MSM and 4 TW (9, 6, and 4 participants, respectively, in each group). Focus group participants were asked to discuss similar topics as covered in in-depth interviews, including programmatic models, approaches, and messages to address PHDP that would be acceptable and appropriate for their communities. In the DR, all participants were living with HIV where long-standing NGOs and relationships facilitated access to these groups; however in Swaziland, HIV status was not a criterion for focus group participation due to the criminalized and more sensitive nature of these populations in that setting.

Qualitative data analysis

In Swaziland, all interviews and focus groups were recorded, transcribed, and translated into English. Debriefing notes were taken immediately following each interview to capture the interview context, a
theoretical memo, a methodological memo, and topics for follow-up. Weekly meetings were held with all interviewers to debrief on topics covered and issues for further exploration to ensure an effective iterative process.

Analysis of qualitative data was conducted through identification of recurrent patterns and themes following Crabtree and Miller’s five steps in qualitative data analysis, or what they call the “interpretive process” (Crabtree & Miller, 1999). These steps are (1) Describing, (2) Organizing, (3) Connecting, (4) Corroborating, and (5) Representing. These steps form part of an iterative process that is better seen as cyclical or spiral rather than linear. They start by re-examining the goals of the research and considering questions of reflexivity, then move towards ways of highlighting, arranging, and reducing texts to make connections through the identification of recurrent patterns and themes.

After all data were collected, a full-day data analysis workshop was attended by representatives from MSM and FSW groups, Ministry of Health (MOH) and National Emergency Response Council on HIV and AIDS (NERCHA) staff, interviewers and members of the research team, clinicians, and others. This workshop devoted individual time to read de-identified transcripts to identify themes, and group time to categorize and discuss emerging themes and implications. Following the workshop, a codebook was developed by four members of the study team working together until agreement on a set of codes was reached. Codes were selected based on a priori topics of interest (research questions), themes identified during the data analysis workshop, and additional emergent themes from transcripts. Codes were then applied to all transcripts using the computer software package Atlas.ti © qualitative analysis software (version 5.2, Scientific Software Development GmbH, Eden Prairie, MN). The coded text was read to identify further themes or patterns and memos were created for key themes, which were then further developed into the findings presented here.

In the DR, interviews and focus groups were recorded and transcribed in Spanish, but not translated into English; all analyses were conducted using the original Spanish text, and select quotes were translated into English for the final write-up. Structured debriefing notes were taken immediately following each interview to capture the interview context, methodological memos and interviewer reflections. Through periodic analysis meetings, the team identified emergent themes that were used to guide subsequent interviews and inform early analysis. An interpretation meeting was held following the completion of data collection to discuss these themes and overall impressions of the data with the interviewers.

Interview and focus group discussion transcripts were analyzed using narrative and thematic coding procedures to preserve the holistic nature of participants’ HIV stories while also identifying topical information related to study aims (Maxwell & Miller, 2008). The study team first developed a narrative analytic summary of the main story of each interview (Sandelowski, 1995; Lieblich et al., 1998). These summaries also include content-driven sections to summarize key findings related to the domains of interest in the study (e.g., participant experiences in HIV diagnosis and accessing HIV services). Following the development of these summaries, the researchers reviewed the codebook developed for the Swaziland analysis and adapted it for use in the DR context, based on emergent themes from the interviews. All interviews were then coded using Atlas.ti (version 6.2). Finally, the coded text was read to
identify additional themes or patterns. The key themes were then further developed into the findings presented here.

**Ethical Considerations**
All participants provided informed consent prior to participation, and referrals to clinical and counseling services were provided, as needed. Study staff members were trained on FSW, MSM and TW-friendly approaches to interacting with participants. Ethical review and approval for this study was received from the following Institutional Review Boards (IRBs): the National Research Council of Swaziland, the Instituto Dermatológica y Cirugía de Piel Dr. Huberto Bogaert Díaz in the DR, and the Johns Hopkins Bloomberg School of Public Health in the United States. A study advisory board, including representation from the community, implementing partners, and national partners in each country, reviewed the study protocol and interview guides and provided ongoing advice on the management and execution of the study.
RESULTS

Social, structural and economic context of FSW, MSM and TW

Social context
Participants in both settings described a social context surrounding FSW, MSM and TW that is characterized by multiple layers of stigma and discrimination due to HIV and their gender, sexual, and/or professional identity. One FSW in the DR explained, “Today people discriminate against one for being a sex worker and also for being infected with HIV.” Experiences with and fear of stigma and discrimination led to a lack of disclosure of these identities. Sometimes, participants said it was easier to disclose one identity than another to different people. For example, among family, participants in Swaziland said they may disclose HIV status but not MSM/FSW/TW status; while among sexual partners, they may disclose MSM/FSW/TW status but not HIV status. Transgender participants felt they were particularly vulnerable because of the high visibility of their lifestyle. A TW explained, “Yes, there is discrimination [for MSM] because you have relations with another man, but it is not as visible as with us in the trans community”.

In Swaziland, violence was a common experience in the social context of both FSW and MSM. FSW reported violence from clients and police. Some clients became violent when asked to use condoms. Others would refuse to pay after sex and become violent. Sex workers also described police round-ups, demand for sex, and violence. MSM reported violence from a range of individuals, including sex partners, families, the general public, and police. Both groups felt they had no recourse to bring incidents of discrimination or violence to the authorities.

In addition to discrimination related to sexual and gender identities, Dominican participants confronted considerable stigma related to their HIV status within their communities and at medical facilities. Nearly every participant experienced some form of discrimination, as reflected in the experience of this MSM participant:

I have gone through a lot and I am suffering from a lot of discrimination where I live; how the society looks at me, I am afraid to provide a meal to a person because I might offend someone. (MSM, DR)

Some of this HIV-related discrimination was a result of misinformation in the community on how HIV is transmitted. A Dominican TW participant stated, “People think that HIV is an illness that is spread in the air, that, even with brushing up against someone, they think that they are going to be infected.” As a result, some participants were isolated and no longer permitted to share food or utensils with their families. A few participants were also left by their sexual partners when they told them their HIV status. Discrimination against individuals living with HIV also existed inside both private and public health services in the DR. Although a few participants described overall positive experiences with general health services, the vast majority had at least some negative and stigmatizing experiences. Discrimination in health services ranged from the perceived negative tones of health workers’ voices to outright refusal to perform medical services and involuntary disclosure of HIV status.
**Structural and economic context**

In Swaziland, the structural and economic context surrounding both FSW and MSM is similarly challenging. Both populations are criminalized and constantly fear being caught. One FSW described it this way:

> You know that everything you do is illegal. It would be better if it was legal, then it wouldn’t be a problem. Because then you could walk during the day and get called by somebody [for sex]. As it is, people are ashamed during the day. You think, eesh! I’ll try and get close then be seen by people. When it’s dark, I’m at ease, because even if they look at me they won’t see who I am because I can just disappear. They won’t even know where I went. (FSW, Swaziland)

Economic opportunities also significantly shaped the context of participants in both settings. FSW in Swaziland and the DR described a cycle of poverty, which led to sex work, which sometimes led to HIV infection (Figure 2). HIV, in turn, drove an increased need for healthy foods, while sex work sometimes led to alienation from social networks that offer material and emotional support against hunger and poverty. FSW cited their own food security or that of their children as the impetus to begin sex work, and as a primary force in continuing to sell sex. A common request in both settings was for food-related services (parcels, grants, or education) when asked about desired programming. Good nutrition and the ability to eat “healthy” or “balanced” foods were seen as important means of controlling HIV disease progression. Participants described challenges adhering to ART when faced with taking pills on an empty stomach. Finally, food security and food sharing were seen as important expressions of social networks, which many FSW felt they had trouble accessing as a result of their profession. MSM also reported struggling with poverty and lack of economic opportunities and some engaged in sex work.

**Figure 2: Cycle of hunger/poverty, sex work, and HIV described by participating FSW**
In the DR, the most frequently described economic barrier for study participants was the use of HIV testing by employers in the hiring process. While it is technically illegal in the DR to screen work applicants for HIV, almost every participant described personal experiences in which they or people they knew were required to undergo medical examinations, including HIV tests, when they applied for work. They were generally informed that they were being tested for drugs or for other reasons, but participants felt—and sometimes knew—that the medical screening also included HIV testing. Participants stated that they were never informed of the results of the screening, but that they were rejected from jobs because of their HIV status and because the companies “believe that working with a person with HIV is risky for them, for their institution, for their company” [MSM]. As a result, some participants became frustrated and stopped applying for work in the formal sector. Others reported that they were fired from jobs because they were either suspected of being, or confirmed to be, HIV-infected. This inability to find formal employment resulted in food insecurity, and an inability to leave sex work for many participants.

**PHDP needs of FSW, MSM, and TW living with HIV**

*Care and treatment: protecting physical health*

In both countries, participants reported perceived and experienced stigma against their sexual and professional identities in HIV health care settings, leading to a lack of care-seeking behavior. Participants in Swaziland described the following experiences in formal health services:

> When they say “bring your partner,” and then you bring the same-sex partner, they are like, “yah, this is why you are having this [HIV], this is why,” and they will be throwing words at you [... ] so then you get embarrassed, sometimes you’ll decide to leave without being treated, and where are you taking that sickness to? (MSM, Swaziland)

> A health care worker comes and says, ‘you have an STI so bring your partner.’ And if the sex worker says, ‘I do not have a specific partner, I have lots of partners, I sleep with different men in exchange for a living,’ then the health care worker’s face suddenly changes and becomes unfriendly and she will say, ‘ah, you are a sex worker. You are doing a dirty job.’ [...sometimes they don’t have to say anything, it’s just] the facial expression [...] It scares them [FSW] away. They leave and they don’t come back. They are afraid to come back and decide to go...to the pharmacy, rather than going to the hospital or clinic, where they won’t be questioned. (FSW, Swaziland)

Key informants did, however, emphasize that they personally treated all people in the same way. They stated that, regardless of their personal belief, they had an ethical responsibility to provide “non-discriminatory services to all the members of the population.” One key informant explained:

> Even though I don’t approve of what they are doing [...] as a public health officer, I have to make sure that they have access to health services. I don’t have to judge them. I don’t have to give my views on what they are doing. But my duty is to make sure that they
have access to services [...] whatever their sexual orientation is, they are human beings, they are Swazi. (Key Informant, Swaziland)

Additionally, both FSW and MSM in Swaziland reported perceived and experienced stigma against PLHIV from families and partners, leading to a lack of disclosure. This lack of disclosure led to challenges with ART adherence, hiding medications, and a lack of social support for treatment access and adherence. MSM participants in Swaziland also described challenges adhering to ART, and challenges getting to clinic due to poverty and hunger.

In the DR, participants noted considerable barriers to engaging with the formal health care system. Some of these challenges included lack of pre-HIV test counseling, delayed diagnosis, involuntary disclosure of HIV status by clinic staff, economic and social circumstances, and poor services in the clinics. One FSW explained that at one clinic, “They treat you poorly. They talk to you harshly.” Other frequently mentioned challenges with the Dominican health services were long waits for HIV services, insufficient information about treatment and personal health, and a lack of continuity of care. One FSW participant previously received medical attention at the clinic, but she became disillusioned with the services and stopped going because of the many lines and visits that were required. Another FSW explained:

I want to go to a site where if they are going to help me, they help me, but they do not make me have to fight. It is difficult because one comes from very far; it is difficult and anyone becomes disenchanted and does not return. I became disappointed and did not return again. (FSW, DR)

Additionally, numerous participants and medical providers described instances when medicines were not available for extended periods of time.

Another frequent barrier to using HIV services in the DR was the cost associated with care, treatment, and laboratory testing. In the current system, patients are generally required to do their laboratory tests at different locations from where they receive their HIV services and have to attend many different appointments. This expensive and time-consuming system resulted in poor adherence by some of our participants. Participants also described considerable expenses, including vitamins, injections, and transportation to appointments. These expenses varied because different clinics provided different services for free. A FSW stated that she was not able to quit sex work because she needed clients’ money to pay for her transportation to go and collect her treatment. Many patients lacked the economic resources to pay for these items and were, therefore, unable to follow their doctors’ orders. Additionally, some participants felt that the government was apathetic towards the situation of individuals living with HIV, as stated by an MSM participant:

[The government does] not care about us as sixty or seventy thousand people that are living with HIV and the Dominican state, the Dominican government does not care about us at all [...] They do not understand that a healthy person with HIV is much cheaper than a person with HIV who is sick with HIV. (MSM, DR)
Psychosocial support: protecting mental well-being
In both settings, the primary challenge for participants staying mentally healthy was living with the dual stigma against their HIV status and their gender, sexual or professional identity. This stigma led to feelings of depression as well as internalized self-stigma and shame.

In Swaziland, participants explained that the initial receipt of an HIV-positive diagnosis was emotionally devastating. “At first I was devastated, such that I even lost weight,” said one FSW. She continued,

I was even afraid to leave the house in fear that maybe I’ll be sitting with a person, and that person would just know my status. I was ashamed and at some point I told myself that the test was wrong. So I decided to go test again. I went back again and I was told the same thing. I became more ashamed and stayed in the house the whole week without coming out. (FSW, Swaziland)

Many participants in Swaziland said that, although the initial period following their diagnosis was difficult, over time, they came to accept their status. However, for some FSW especially, the risk cycle described above led them to not be particularly surprised or upset when they were diagnosed with HIV. They were aware that they had engaged in behaviors that put them at risk, as described by this Swazi woman:

I think that person [FSW] knows what they have been doing. It’s something they have done to themselves. It may happen that they have the virus because you cannot sow beans and reap cabbages. (FSW, Swaziland)

This acceptance of their diagnosis, however, was often still intimately tied in with feelings of shame. Some MSM in Swaziland said feelings of self-stigma led them to drink alcohol as a coping mechanism. Participants also linked drinking to sexual risk behavior. As one MSM put it, “Most of the time we have sex without a condom it is when we are drunk.” However, in some case, the high HIV prevalence in Swaziland seemed to help mitigate some of the impact of diagnosis. Many participants talked about friends and neighbors who were also living with HIV. As one FSW put it, “[I] am still free [emotionally at ease] because a lot [of people] are living with HIV.”

Participants in Swaziland reported receiving emotional support from a variety of sources. One MSM said he went to his pastor for support, while another derived comfort from religion but had not disclosed or discussed his lifestyle with his church. Only one Swazi MSM mentioned going to formal counseling services, saying he and his partner saw a private counselor who knew they were gay. FSW more commonly talked about the emotional support they received from participating in formal support groups, although they also mentioned receiving support from friends—sometimes other FSW—as well as female relatives and religion.

In the DR, participants had diverse psychosocial support needs and experiences. They described an acute need for psychosocial support immediately following diagnosis because many were initially very depressed and some were in denial. Many participants expressed a desire to die when they were diagnosed and multiple participants attempted to commit suicide.
For many patients, diagnosis was a major transition from a perceived healthy life to feeling that they could die from HIV. One FSW explained:

My life changed a lot [...] On the one hand, it has changed a lot because it lowers the self-esteem, apart from the discrimination that is not the same when a person is healthy as when a person is sick; it is not the same. It closes many doors for us in work, family and also the community. (FSW, DR)

Dominican participants accessed a broad range of formal and informal forms of psychosocial support that helped them surmount these feelings. Some informal support came from partners, family and friends who gave them strength and helped them deal with stigma.

I am ready to face anything that appears before me because, thank God, I have people that are close to me and that have been able to appreciate me for who I am, they have made me grow as a person. (MSM, DR)

Participants felt that this informal support was invaluable in helping them to deal with HIV as these informal supports provided information, motivated participants to receive medical attention and helped to pay for their medical care. Like in Swaziland, Dominican participants drew comfort from religion and put their faith in God. Though the majority of respondent had disclosed their HIV status, some had not, limiting their ability to access psychosocial support. Some participants also faced discrimination from their own family and friends, particularly when they lacked information on modes of HIV transmission.

Additionally, participants in the Dominican Republic described interactions with formal psychosocial support services such as psychologists, peer educators, and support groups. Many participants had met with psychologists a few times, especially immediately following their diagnosis. Participants reported that they also really liked the support from peer counselors and health messengers because they treat them well and teach them about treatment, HIV and protecting themselves. One FSW explained that the messenger was "like a nurse, like a friend, like a mother." A barrier to seeking ongoing psychosocial support, however, was the stigma associated with mental illness and the concern that seeking such support meant you were “crazy.” Participants worried that the negative associations with mental illness would cause them to be further labeled and stigmatized.

Finally, most participants in the DR had at least some interaction with charlas (health talks) and support groups. These groups were integral for some participants in coming to terms with their diagnosis and for the provision of psychosocial support. There were diverse support groups including one exclusively for MSM, and participants often described the support group members as their families. One MSM FGD participant explained:

I never had guidance when I learned my condition and sometimes because no one in my family knows and none of my friends know, sometimes I felt the necessity to express myself to someone who has my same condition, but I didn’t know anyone [...] Here in the group I have found more knowledge, they have helped me to learn new things that I did not know and to express myself. I feel free. (MSM, DR)
Another man in the same focus group responded that the support group “is the best thing that has happened to me since I have had HIV.” While many of the FSW participants had attended a support group at some point, most did not describe ongoing participation. One challenge they acknowledged was finding a group where they felt welcome and a sense of belonging. There were also some concerns about support groups, including allegations of fraud and breach of confidentiality.

Prevention: preventing ongoing HIV transmission
In both countries, participants were very aware of the need to prevent HIV transmission to sexual partners. Many discussed how they had changed their behavior after being diagnosed with HIV in order to reduce transmission risk to others. These changes included condom use and reductions in their number of sexual partners. They did, however, continue to face barriers to prevention.

In Swaziland, some MSM felt that the clandestine nature of MSM relationships in Swaziland may lead to greater numbers and more casual types of partnerships. MSM described many of their partners as bisexual or having female partners/wives, possibly to hide MSM behavior or to fulfill cultural expectations. Further, MSM said that their relationships are often kept secret and therefore families do not play a role in relationship counseling and peacekeeping in the way that they might for heterosexual couples. An MSM participant from Swaziland reflected on this situation in the following way:

> Usually in our community we have short-term relationships. These relationships are caused by the fact that there is nothing bonding those people. And maybe the community, the parents or relatives are not involved in our relationships. And then if I have got a problem with my boyfriend, if I say it’s over, it’s over [...] you are not able to go tell your parents or relatives [...] if people are informed either way about such people [MSM] in the community, if there is a relationship going on with his parent, the parent will be able to intervene either way, and those relationships will sustain. (MSM, Swaziland)

FSW, MSM, and key informants in Swaziland noted that in clinical services, such as HIV testing and treatment, providers’ questions about HIV prevention often assume heterosexuality and monogamy. Due to fear of stigma, FSW/MSM often just answer the question asked rather than discuss their true risk behaviors. For example, if asked about condom use with a steady partner, a FSW might just say “I don’t have a steady partner” and not discuss her casual partners.

In the DR, participants explicitly stated that they did not want to spread HIV and employed diverse techniques to protect others. Almost every participant stated that he or she used condoms when engaging in sexual activity. A FSW FGD participant explained, “I do not want to infect my partner. I cannot. I cannot have a relation without a condom, me no, because I have to take care [of him].” One TW participant stated that she does not have sex with anyone other than her HIV-positive partner because she is afraid that the condom will break and that she will infect someone. Possibly as a result of this desire to prevent the spread of HIV, many participants mentioned that they would like to have an HIV-infected partner so that they would not have to worry about infecting someone if the condom broke.
Dominican participants did, however, face some resistance to condom use from their partners and some FSW reported that they received offers of more money from men to have sex without condoms. A few also mentioned that partners had tried to force sex without condoms. Despite this resistance, most stated that they would refuse to have sex without a condom. An FSW from the DR reported how she prayed to God to protect her partners “because I do not want to be guilty of anyone getting HIV from me.” Similarly, some Swazi FSWs reported being offered more money from men to have sex without condoms, which some accepted due to financial need.

FSWs in the DR employed several different strategies to enforce condom use with clients. Many explained to clients that they did not know about one another’s health status and that they had to take care of themselves. Some sex workers refused to have sex if the client would not wear a condom and one participant even told clients that they did not have to pay her if they did not like sex with the condom and reported that there were only two times when they had paid her less. FSW also very commonly used oral sex as a way to discreetly put a condom on men with their mouths to “motivate them and sometimes they do not even realize that they have on a condom,” according to a FSW in a focus group discussion.

**Rights/involvement: increasing agency and involvement**

The main impediment to increasing involvement of FSW, MSM and TW living with HIV in HIV-related programs and policy-making was the dual stigma and their hidden identities. Participants indicated that people from their communities were often unwilling to disclose their status publically to represent these groups in HIV-related activities. Further, both MSM/FSW in Swaziland have difficulty trusting outsiders until they get to know particular individuals over time.

Despite these barriers, many participants in the DR were actively involved in HIV education and support activities to prevent the further spread of HIV in their communities. Participants involved in these activities expressed a desire to help prevent ongoing HIV transmission. One MSM explained his work in his community:

> I am going to the street because I want to give talks to the young people that are growing up and give them education [...] talks about HIV, you understand, so that they have, so they have sex with a condom if they have sex with a woman so they are not infected. (MSM, DR)

Participants in the DR indicated that participation in these activities made them feel better, gave them a sense of purpose and improved their own mental health. One FSW explained, “I feel good doing my work. Previously, when I started, I wanted to hide, but now I am not ashamed of the condoms.” The work gave them pride and, for some, was also a mechanism for economic opportunities. Condom promotion was an important service provided by participants and one TW focus group discussion participant explained, “After I discovered my health condition I had to have at least two hundred condoms in my house because besides having my own condoms, young men come to me to look for condoms.”
Tailoring existing PHDP interventions and services for FSW, MSM and TW

Care and treatment interventions
Participants held a variety of opinions on how best to tailor existing PHDP interventions and services for FSW, MSM and TW. Participants in both countries highlighted the need for additional training for health care workers on issues related to KP, particularly on how to work with HIV-infected patients in an appropriate and respectful manner. One participant in Swaziland explained:

I would train health care workers. Even their procedures manuals should have information on how to handle KP [...] Also let’s make educational materials that also speak of KP. (Key Informant, Swaziland)

A TW in the DR emphasized the need to train the entire clinic staff on how to work with TW because “the health system is not sensitized to the trans community” and maltreatment is the norm. Many participants suggested structural and staffing changes for HIV services for KP. For example, one suggestion was to have more staff members living with HIV or “expert clients” to help individuals navigate services.

Participants did not all agree as to whether there should be special clinics or services for FSW, MSM and TW living with HIV. Some in the DR worried that targeted services would reinforce stigma because people would know that they were living with HIV and that they were FSW, MSM, or TW when seen walking into or out of the clinics. Swazi participants emphasized the success of specific FSW-friendly services, including Family Life Association of Swaziland (FLAS) and other clinics. Several mentioned that FSW using these services have a system to avoid having to disclose that they are FSW by saying they are from the “support group,” as explained below:

For instance, Piggs Peak and Lobamba, they come and say, ‘I’ve come to see So-and-so ...’ and the health care worker will know it’s from the support group so it means she is a sex worker. Same with Lobamba, they meet and she can say, ‘I’m from the support group,’ oh, then she will know she is a sex worker without announcing. (Key Informant, Swaziland)

Several participants suggested that this approach of using code words for sex work could be expanded to other clinics and services.

Additionally, in the DR, participants suggested changes in the structuring of HIV-related health services. One MSM suggested that nurses be given the authority to authorize medicine when a doctor has many patients in order to make treatment provision more efficient. They also highlighted the need for consistent provision of medication. An MSM FGD participant described the stress of inconsistent availability of medication:

[…] this [delays in medicine] makes someone stressed first because I know that I need to take my medications daily at their hour and when I see that I am lacking a treatment I become very stressed. I become very nervous and it is extremely bad and this is not only
the [physical] damage that it is doing to one in not taking it but also the stress, the psychological damage. (MSM, DR)

Participants in the DR felt that there were a number of potential solutions to the barriers related to the disjointed HIV care system which requires substantial expenditures on transportation and tests. One MSM participant suggested that the clinics “take the sample and send it and the unit has staff that collects [the results] and brings them.” Focus group participants also highlighted the need for clinics to have all of the medication and tools necessary for treating PLHIV available within the clinics where they attend services, instead of continually being required to attend different sites.

Finally, participants in both settings described the need for nutritional and economic support in order to facilitate optimal engagement with health services. Participants faced economic insecurity and mentioned that some patients do not have enough food to eat a few meals a day. The lack of food led people to discontinue treatment, as was the experience of one FSW in the DR who explained, “I stopped taking treatment because I did not have sufficient food so that I could take the treatment and it was very strong.” Some clinics previously provided protein supplements in the DR and participants felt strongly that this service should be brought back.

**Psychosocial support interventions**

Participants in Swaziland said less about psychosocial support. A handful of FSW and MSM said providing counselors would be helpful:

> I think that the government needs to provide counselors per region [proportional to the number of PLHIV], who will counsel these people when they are faced with problems.

(MSM, Swaziland)

Otherwise, participants did not put forward other suggestions to improve mental health and well-being of HIV-infected FSW and MSM.

Despite the diverse support mechanisms, participants in the DR described some unmet educational and emotional support needs. Many expressed a desire to have emotional support from people who were like them: One MSM explained that “90% of the people who work with HIV positive people are not positive, do not have the condition,” which limits the work opportunities for people living with HIV. One key informant felt that support from FSW living with HIV could be very beneficial because “they have empathy and a closeness that is not with a doctor, nor with a peer educator nor with anyone.” Others felt that there was a need for training and microcredit funds within the support groups to address their barriers to employment and economic instability.

**Prevention interventions**

Sex workers in both settings appreciated the existing prevention interventions provided to FSW, particularly HIV educational sessions and condom distribution programs. Participants also highlighted additional needs including need for specific HIV prevention services targeted to MSM in Swaziland. Many MSM suggested a “training of trainers” model, whereby trusted MSM community members could be trained in HIV prevention messages particularly relevant for MSM and could then share those
messages with others in their community. Also, FSW and MSM in Swaziland suggested continued or expanded distribution of condoms and particularly lubricant to prevent condom breakage.

Some participants in the DR felt that they had everything that they needed in order to prevent the further spread of HIV: awareness and condoms. Many received condoms and health information from their clinics. When asked about what is needed to avoid infecting others, one MSM from the DR responded, “I think that we already have the methods to in order to not transmit HIV to a person... if one has the knowledge... he/she does not need anything, nothing more than a condom.” Participants did, however, describe various experiences with condoms breaking, reflecting the potential for ongoing opportunities for transmission.

**Human rights and increased involvement**

Both MSM and FSW said that societal acceptance and stigma reduction would be the most important mechanisms to increase their involvement in prevention activities, leadership and advocacy. As one MSM in Swaziland said:

> If we can be recognized and they can know that there are people who are living this kind of life and they can know how they can reach us in terms of programs and services. (MSM, Swaziland)

Participants in the DR also reported that there was a need for community outreach to reduce stigma and discrimination. One TW emphasized that people needed to “become more aware of the disease, that people who have this condition [HIV] are human beings and have the right to life; to enjoy the same privileges of healthy people; to share sociably in all of the material environments.” One focus group discussion with MSM highlighted the need for more information to be provided on television, radio and in schools, because:

> [...] here in the DR they do now have awareness and information on what is HIV and how it is spread and how a person lives with it. What they should understand is that [a person with HIV] is a human being and that he/she needs to continue to living, needs to continue working, needs all of the support that others can provide. (MSM, DR)

Additionally, participants highlighted the need for action to improve the economic opportunities for PLHIV in the DR. This included a call for enforcement of the law preventing HIV testing; training of business owners and human resource managers about HIV; and development of a mechanism for applicants to report companies that require HIV tests. They also felt that there is a need for more awareness of the law and of their rights among PLHIV and for more clinics to offer employment opportunities to people living with HIV.
**DISCUSSION**

**Interpretation of findings and recommendations**

Despite the contextual differences, there were many similarities in the experiences and needs of KP living with HIV in Swaziland and the DR. Comparison of these populations highlights some considerations that may be universal to KP and some aspects which may differ by setting.

**Need to address multi-layered stigma and discrimination**

In both settings, participants described social and structural contexts characterized by economic deprivation. Many FSW experienced a cycle of hunger and sex work, further exacerbated by HIV, which inhibited their ability to live positively and prevent further transmission of HIV. MSM also reported struggling with poverty and lack of economic opportunities. Food support may be an appropriate mechanism to break the cycle and to enhance the health of KP in both settings. For some FSW, this cycle also included experiences of violence. FSW participants in Swaziland were particularly at risk, given the illegal nature of their activities. This underscores the effect that broader economic and legal structures have upon KP.

KP in both settings experienced substantial multi-layered stigma related to their HIV-status and their sexual practices and/or gender identities, in addition to poverty in both settings and race/ethnicity in the case of the DR. Participants described experiencing stigma and discrimination in their homes, work environments and within health services. Being stigmatized or discriminated against affected participants’ physical and mental health, complicated efforts to reduce the spread of HIV, and limited participation in mobilization, leadership, and advocacy activities. TW felt that they were particularly affected, given the high visibility of their identities and lifestyles. These experiences were described as a barrier to achieving each of the four goals of PHDP: (1) keeping PLHIV physically healthy; (2) keeping PLHIV mentally healthy; (3) preventing further transmission of HIV; and (4) involving PLHIV in prevention activities, leadership and advocacy (Kennedy et al., 2010).

The various forms of stigma described by participants reflects Parker and Aggleton’s framework for HIV-related stigma, which highlights how KP experience multiple, overlapping forms of stigma (2003). In this framework, Parker and Aggleton position stigma as a social mechanism for reinforcing differences that, “feeds upon, strengthens and reproduces existing inequalities of race, gender and sexuality” (Parker & Aggleton, 2003, p. 13). Given the marginalized roles and limited power of FSW, MSM and TW in both Swaziland and the DR, it is unsurprising that these identities compounded the stigma that they faced as PLHIV.

These findings highlight a need for nuanced approaches to addressing stigma that account for the broader history and social mechanisms that allow stigma to flourish. Efforts to reduce stigma need to be tailored to meet the unique needs of KP within Swaziland and the DR. Community mobilization, led by grassroots FSW, MSM and TW groups, is one such approach that can empower KP to address stigma within and against their communities. Another recommendation based on these findings is to train health care providers and staff in HIV clinics to improve their sensitivity in working with KP.
Navigating costly, disjointed systems of care and treatment

Participants in both countries described numerous barriers to meeting their care and treatment needs including long lines, high costs of clinic attendance, transportation costs, drug stock-outs and little continuity of care. While these barriers affect all PLHIV in Swaziland and the DR, FSW, MSM and TW are economically vulnerable and may be more affected. One approach to address some of these barriers would be to train a cadre of peer navigators or “expert clients.” These expert clients could accompany individuals to appointments, identify social service programs and provide social support through the processes of diagnosis, acceptance and disclosure. They could also assist with treatment adherence and ongoing prevention. Such models have shown promising results in other settings (Bradford et al., 2007; Van Tam et al., 2012). Within the clinic setting, participants suggested having “expert clients,” who would be PLHIV, to provide additional support—though this model would need to be thoughtfully designed (Kyakuwa et al., 2012; Hallum-Montes et al., 2013; Higa et al., 2012). Participants did not all agree as to whether there should be special clinics or services for KP living with HIV. Some worried that these targeted services would reinforce stigma; therefore, careful analysis regarding the structure of the HIV care system is needed on a country-by-country basis with active involvement of KP in the design of such services. At a policy level in both countries, there is a need for greater advocacy to address the sustainability of access to treatment for KP as well as providing nutritional and economic support to facilitate optimal engagement with health services.

A clear need for more support

Participants in both countries described very similar psychosocial support needs, especially following diagnosis; the availability of services, however, varied substantially. KP may have particular counseling needs due to histories of trauma and abuse or may be living in unstable and highly vulnerable situations that create psychological stress above and beyond HIV (Machtinger et al., 2012). KP in the DR described using many more formal mental health services than those in Swaziland. There were, however, financial and cultural barriers to attending these services—in particular, fear of adding another burden of stigma related to mental health. Participants in both settings highlighted the need for more peer educators from KP as sources of psychosocial support. There is also a clear need to work with existing HIV clinics to identify opportunities to integrate psychosocial counseling and support into the services provided; currently, most HIV-related services have minimal time available for psychological services, although some support is offered through HIV testing and counseling and ongoing clinical care. Additionally, identifying appropriate ways to develop discreet, safe support groups for key populations could help to address the gaps in psychosocial support as well as barriers to employment and economic stability. Comprehensive PHDP interventions for KP should consider how to incorporate strong psychosocial support components.

Ongoing Prevention

A clear similarity in the DR and Swaziland is that participants expressed a strong desire to prevent transmission of HIV to their partners, though participants in Swaziland placed a greater emphasis on an unmet need for HIV prevention services and expanded distribution of condoms and lubricants. In both countries, participants emphasized that they tried to use condoms with every partner, although economic necessity made condom use more difficult for some FSW whose clients offered more money
in exchange for sex without condoms. Another reported challenge was condom use with regular partners, paying or non-paying, with whom participants may have more longstanding and intimate relationships. Interventions with FSW, including in the DR, have been effective in increasing condom use with casual paying clients (Kerrigan et al., 2003, 2006), but condom use with non-commercial partners remains quite low (Luchters et al., 2008; Morris, Morris & Ferguson, 2009). There are numerous barriers to condom use between FSW and regular partners, including the strong association between factors such as trust and intimacy and inconsistent condom use (Kerrigan et al., 2003; Murray et al., 2007; Ngugi et al., 2012). Findings support the need for innovative approaches to promote consistent condom use among KP living with HIV. There is also a clear need for further outreach and education with the regular partners of FSW, MSM and TW to promote HIV protective behaviors, such as condom use, that require agreement from both members of the couple.

Comprehensive services
In both countries, participants disagreed about whether they would prefer separate services dedicated to the needs of KP, or whether they would prefer integrated services with providers and staff who were trained to address the specific needs of KP and provide respectful care. Regardless, our findings indicate that KP require services that consider their specific needs and address these needs in a holistic fashion. Program planning for comprehensive HIV prevention, treatment and care services for people living with HIV should give specific consideration to how best to meet the needs of KP.

Leadership and advocacy for key populations living with HIV
Finally, there were clear differences in the level of engagement of participants in HIV prevention activities, leadership and advocacy across settings. KP in the DR were highly involved in these activities and reported considerable benefits of participation. Participants in Swaziland, however, reported more challenges in becoming involved due to stigma and their hidden identities. For some individuals, this stigma means that they are not yet ready to participate openly in the HIV response. However, ongoing activities in Swaziland and findings from this research suggest if approached in the right way, many MSM and FSW, including those living with HIV, are interested in participating in HIV prevention, care and treatment decisions for their communities.

Strengths and limitations
This study is one of the first to examine PHDP needs of KP globally, and it is among the first studies to explore issues related to MSM in Swaziland in particular. Our design had several strengths. By interviewing individuals from KP as well as key informants, we obtained diverse perspectives. Our use of multiple interviews with the same participant enhanced rapport and the depth of responses. Additionally, conducting focus groups after the individual interviews allowed us to confirm emerging themes and discuss possible responses in a group setting. Despite these strengths, since our data were collected largely from MSM, FSW and TW in urban centers in both Swaziland and the DR due to reliance on existing networks, there may be limited transferability of the findings to other groups of FSW and sexual minorities in these countries, as well as to other countries and settings. Despite these limitations,
this study clearly highlights important commonalities and differences in PHDP experiences of key populations across settings.

**Conclusions**

This study highlights the need to develop combination HIV prevention, care and treatment programs, supporting biomedical, behavioral, social and structural interventions for key populations. There are additional needs for community mobilization strengthening, safe work spaces, and health sector interventions and capacity building. Current implementation models favor a streamlined, integrated approach to service delivery. However, our findings indicate the importance of complementary efforts to develop KP-specific PHDP services to address the holistic needs of these groups in a given context. Areas for future research include further exploration of the multi-layered stigma faced by key populations, and the development and evaluation of tailored PHDP policies and programs for key populations in diverse social and epidemiologic settings.
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