



Research Paper

Generating trust: Programmatic strategies to reach women who inject drugs with harm reduction services in Dar es Salaam, Tanzania



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ABSTRACT

Background: Strong evidence supports the effectiveness of methadone-assisted therapy (MAT) to treat opioid dependence, reduce the risk of HIV transmission, and improve HIV related health outcomes among people who inject drugs (PWID). HIV prevalence reaches 71% in women who inject drugs (WWID) in Dar es Salaam, Tanzania; creating an urgent need for access to MAT. Despite the availability and potential benefits of treatment, few women have enrolled in services. This formative research sought to identify programmatic strategies to increase women's participation in outreach and their subsequent enrollment in MAT.

Methods: We conducted twenty-five, in-depth interviews with patients and their providers at a MAT clinic. Open-ended interviews explored enrollment experiences, with a focus on contextual barriers and facilitators unique to women. Ethnographic observations of harm reduction education at outreach sites and the MAT clinic enriched interview data. *Trust/mistrust* emerged as an overarching theme cross cutting patient and provider accounts of the connective process to enroll PWID in the methadone program. We explore *trust* and *mistrust* in relationship to the interrelated themes of *family loss*, *social isolation*, *vehement discrimination* and *motivation for treatment*.

Results: Narratives delineated both the generation of *mistrust* against PWID and the generation of *mistrust* in PWID against outsiders and medical institutions. In order to enroll PWID in treatment, community base organizations engaged outreach strategies to overcome *mistrust* and connect eligible patients to care, which varied in their success at recruiting women and men. Greater discrimination against WWID pushed them into hiding, away from outreach teams that focus on outdoor areas where men who inject drugs congregate. Building trust through multiple encounters and making a personal connection facilitated entry into care for women. Only PWID were eligible for MAT, due to resource constraints and the higher risk associated with injection drug use. Many women smoke heroin, yet still face high risk of HIV, resulting from low condom use during sex work to fund drug use.

Conclusion: Expanding outreach times and locations, by women peers, could increase women's enrollment in treatment. Allowing women who smoke heroin to enter the program could prevent onward transmission via sex work and reduce the chance of progressing from the lower risk smoking or sniffing to injection drug use.

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Background and significance

Injecting drug use has emerged as a critical concern in the HIV epidemic in Tanzania. While HIV transmission continues to occur primarily through heterosexual intercourse, transmission via shared injecting equipment carries much higher risk per exposure,

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making it imperative to reach people who inject drugs (PWID) with prevention and treatment services (Metzger & Zhang, 2010; Sullivan, Metzger, Fudala, & Fiellin, 2005). Port cities along the coast of East Africa have been involved in heroin trade routes between countries that supply in the Middle East and consumer markets in Europe and North America since at least the mid-1980s (Ross, McCurdy, Kilonzo, Williams, & Leshabari, 2008). However, a recent surge in the availability of strong, cheap heroin to urban populations has contributed to growth in injecting drug use in Dar es Salaam (McCurdy, Williams, Kilonzo, Ross, & Leshabari, 2005; McCurdy, Ross, Kilonzo, Leshabari, & Williams, 2006; UNODC, 2013). Easy access to heroin combined with myriad social and economic forces, such as rapid urban migration, lack of employment for youth, and limited mental health care, have further contributed to a rise in injecting drug use (Acuda, Othieno, Obondo, & Crome, 2011; McCurdy et al., 2005). The Tanzania Drug Control Commission estimates that 50,000 people inject drugs nationally (TDCC, 2010). Women's participation in sex work to fund drug use raises the chance of PWID to act as a bridge population, potentially reversing downward trends in HIV incidence and fueling new infections (Bruce, 2010).

In Dar es Salaam, HIV prevalence in PWID has reached crisis proportions. Research estimates that 42% to 50% of PWID in Dar es Salaam are living with HIV (Ross et al., 2008; Williams et al., 2007, 2009), compared to an estimated 6.9% prevalence in the general urban population (Tanzania Commission for AIDS (TACAIDS), Zanzibar AIDS Commission (ZAC), National Bureau of Statistics (NBS), Office of the Chief Government Statistician, ICF International (ICF), 2013). Economic and social inequities create heightened vulnerability in women who inject drugs (WWID), who are more likely to be homeless and experience abuse than their male counterparts (McCurdy, Ross, Williams, Kilonzo, & Lesabari, 2010; Williams et al., 2007). Gendered risk-taking behavior, such as sex work and sharing equipment with other women in communal settings, contributes to a higher burden of HIV disease among women (McCurdy et al., 2010; Williams et al., 2007). In WWID in Dar es Salaam, HIV prevalence is estimated at 71% (Nyandindi et al., 2013).

In response to this crisis in PWID, in 2009 the government of Tanzania established a national strategy to prevent and treat HIV among people who use and inject drugs, including methadone-assisted therapy (MAT) for heroin dependence (TDCC, 2010). Extensive research from a range of settings supports methadone as a long-term, life-saving medical intervention (Bruce, 2010). MAT reduces the morbidity, mortality, and illegal income-generating activities associated with heroin dependence (Ball, Ross, & Dole, 1991). Among people with opioid dependence and HIV infection co-morbidity, MAT can play a critical role in reducing onward transmission and improving health outcomes, in part by enhancing the linkage and adherence to antiretroviral therapy (ART) (Connock et al., 2007; Gibson, Flynn, & McCarth, 1999; Lawrinson et al., 2008; Metzger et al., 1993; Palepu et al., 2006; Uhlmann, Milloy, & Kerr, 2010; Wood et al., 2005). While opiate replacement therapy is recommended as standard of care for people with heroin dependence, the majority of people worldwide who could benefit from treatment remain without access (Sullivan et al., 2005). The leadership from Tanzania's government to address HIV in PWID is critical to improving health outcomes among this marginalized population.

Despite the availability and potential benefits of treatment, few women access harm reduction services in Dar es Salaam. Program evaluation research demonstrated that only about 10% of clients who use harm reduction services, including MAT, in Dar es Salaam are women (Lambdin et al., 2013). Yet weighted survey estimates suggest women comprise up to 30% of those eligible for services (Lambdin et al., 2013). Given the high prevalence of HIV in WWID,

engaging them in outreach and treatment services is crucial to achieving the objectives of the national strategy (TDCC, 2010). Currently prospective MAT patients must first receive a referral to the clinic via one of four support four community-based organizations (CBOs) before entering care. Similar to the "poverty of drug treatment opportunity" described by Rhodes and colleagues in Kenya, there is a paucity of treatment in Tanzania compared to the potential need (Rhodes, Ndimbii, Guise, Cullen, & Ayon, 2015.) Thus the MAT program enrolls clients who first have demonstrated commitment to treatment. In order to enroll, patients must complete a multi-step process, beginning with referral to a series of orientation and educational sessions. Outreach becomes the entry way into this process, thus it is critical to increase women's participation in outreach to increase their enrollment in the treatment program.

To our knowledge, no research has been conducted to date around programmatic strategies to address gender inequities in drug treatment in developing country contexts. Yet evidence highlights gender disparities in access to treatment. While MAT has only recently been available in Africa and Asia, early studies from India, Malaysia, China and Vietnam suggest that women enroll in disproportionately lower numbers than men (Armstrong, Kermodé, Sharma, Langkham, & Crosts, 2010; Gu et al., 2012; Mohammad, Abu Bakar, Musa, Talib, & Ismaili, 2010; Nguyen, Nguyen, Pham, Vu, & Mulvey, 2012). Challenges recruiting and retaining women in drug treatment are not unique to resource limited settings. In a review of the literature on women and substance misuse treatment entry, retention and outcomes, drawing primarily on studies conducted in North America and Europe, Greenfield et al. concluded that women are less likely than men to enter treatment; and those that do, present with more severe addiction and mental health disorders (Greenfield et al., 2007). Socially gendered experiences, such as family roles, domestic responsibilities, economic opportunities, greater stigma, and greater prevalence of sexual violence history, disadvantage women in their fight for recovery (Eiroa-Orosa et al., 2010; Greenfield et al., 2007). Despite documented gender differences in treatment enrollment and retention, literature has rarely addressed barriers and facilitators to treatment entry that are specific to women (Peterson et al., 2010; Wolde, Carrieri, & Shepard, 2010).

To address this critical gap, our formative study employed qualitative methods to identify barriers and facilitators to engaging women in outreach. We selected outreach as a focal point since the treatment program requires a referral to enroll in care and methadone is new in Tanzania, thus disseminating information on available services is crucial to increasing demand for MAT. We approached the study with the intention of identifying strategies to adapt outreach to better engage women that would require minimal additional resource investment. Based on key findings, we delineated evidence-based recommendations to adapt outreach strategies and enrollment policies to increase women's participation in care. Conclusions have implications for MAT program development in Tanzania and neighboring countries with similar epidemiologic and cultural contexts.

Methods

Study setting

This study was conducted at the first publically funded MAT clinic on mainland sub-Saharan Africa, located at Muhimbili National Hospital in Dar es Salaam, Tanzania. With leadership from the Ministry of Health and Social Welfare (MoHSW) and the Drug Control Commission (DCC) and support from the U.S. Centers for Disease Control and Prevention (CDC) and Pangaea Global AIDS, the government of Tanzania established the clinic in February

2011. The MAT program has been described in detail previously (Lambdin et al., 2013). In brief, four CBOs located in different storefronts in densely populated urban shantytowns throughout the city, recruited participants for the treatment program through harm reduction outreach at hot spots where PWID congregated. The four CBOs, Kimara Peer Educators, Blue Cross of Tanzania, Center for Human Rights Promotion (CHRP) and Youth Volunteers Against Risky Behavior (YOVARIBE), all had distinct missions and organizational structures, while sharing a commitment to increase access to prevention and care for populations most affected by HIV.

To be eligible for MAT enrollment, patients must have been: (1) referred through one of the four supporting CBOs; (2) present with opioid dependence; (3) demonstrate evidence of current injection drug use; and (4) test positive to a urinalysis for opioids. Before entering treatment, participants completed a series of education courses at the CBO that recruited them. Education courses covered transmission and treatment of HIV and other sexually transmitted infections and the benefits of medication adherence. After enrolling in the program, patients presented daily for directly observed oral methadone at the MAT clinic. The MAT clinic offered a range of integrated health services, including HIV counseling and testing. Patients who tested positive for HIV were referred to care at Muhimbili National Hospital. The linkage to care program has been described in detail elsewhere (Tran et al., 2015). The four CBOs provided psychosocial support services to MAT patients at their storefront locations, such as 12-step programs, family counseling, individual counseling, and safer sex education.

Study population and sampling approach

The study population included men and women enrolled in the MAT program and their service providers, with the intention of triangulating perspectives on women's access to treatment. All patients enrolled in MAT at the time of data collection were eligible to participate. We designed our purposive sampling strategy to recruit a group of patient and provider participants that varied in ways research indicated might shape their understanding of women's enrollment and retention in care. For both male and female MAT patients, we selected participants with varying severity in heroin dependence at enrollment, varying responses to treatment (i.e. people who dropped out and re-enrolled, people who were struggling, people who were thriving in treatment) and varying length of drug use history. For providers, we selected participants who had a range of interactions with MAT patients and varied in their experience, roles and responsibilities in service provision.

We used snowball-sampling methods to recruit patient participants (Biernacki & Waldorph, 1981; Kaplan, Korf, & Sterk, 1987), with the intention of oversampling women patients, whose perspectives were essential to the research goals and who were underrepresented among the study population. Snowballs were initially started via an announcement about the research study using a standard script, made to the general patient population waiting at the MAT clinic for their methadone dose in a large, open air seating area. Patients who were interested in learning more about the research were instructed to assemble outside a private counseling room at the clinic to speak with researchers. We selected our first interview participants from this group and initiated a referral chain among patients at the clinic. Key informant service providers further helped us identify participants in line with our theoretical sampling approach.

Key informants from the MAT clinic and the four CBOs that conduct recruitment and provide supportive care, were purposively sampled to capture a range of experiences with the MAT patient population. We selected providers in various positions at the five sites, including two nurses, one program coordinator, one

social worker and two outreach supervisors. Key informants differed in their background experience, roles and responsibilities, and level of patient interaction. Key informants were invited to participate using a standard script. In addition to formal interviews with key informants, casual conversations during direct observation of service delivery provided additional data and were recorded in field notes.

Participant sample description

The general patient population at the MAT clinic has been described previously (Lambdin et al., 2013) and differed in a few key ways from the sample of 19 patients (13 women and 6 men) that participated in interviews. In regards to their age and education background, patient participants were similar to the general patient population, with most between the ages of 26 and 35 with a primary school education. A few had completed secondary school and one had some college education. A majority of patient participants (13 out of 19) were women, while women made up only 7% of the general patient population. Over half of patient participants were married, compared to only 13% of the general patient population. Marriage was more common among female patient participants (8 out of 13) compared to men (3 out of 6). A majority of patient participants had at least one child (13 out of 19), while only 31% of the general population had children. All but four female participants had children, and of the remaining four, two shared that they had reproductive concerns that prevented childbearing. Most female participants (10 out of 13) described surviving sexual and physical violence when they were using heroin, compared with only one male participant. All but one of the female participants described former sex work. Six of the female participants voluntarily noted that they were HIV-positive, while none of the men disclosed their status. The prevalence disclosed by female interview participants is similar to the general patient population, where female patients had an HIV prevalence of 67% (95% CI: 50–80%) and male patients had an HIV prevalence of 35% (31–40%).

The six key informants selected for study participation from the MAT clinic and CBOs ranged in their roles and responsibilities. Key informants included two outreach supervisors with extensive experience in their current positions and previous experience in service delivery for PWID. One outreach supervisor had been conducting similar work since the 1990s. Each supervisor led teams of outreach workers at two different CBOs, managing outreach times and locations, and ensuring outreach workers were well trained in harm reduction education and supplied with adequate informational materials, condoms and safer injecting kits. Two nurses who worked at the methadone were interviewed. These nurses provided a range of medical services to patients, including monitoring their methadone dose. One of three social workers serving the patient population and the program coordinator who leads a program focusing on working with WWID were also interviewed.

Data collection

This study used multiple sources of primary and secondary qualitative data. Data collection occurred from November 2012 to April 2013. Primary data sources included in-depth interviews with patients and providers, ethnographic observations of service delivery at the five sites (MAT clinic and four CBOs) and outreach locations. Secondary data included programmatic reports, outreach materials, program advertisements, and education curriculum and training materials for the pre-enrollment sessions.

Direct observation of outreach activities took place at 12 outreach sites. Community outreach workers and peer outreach

workers from Blue Cross, Kimara Peers, YOVARIBE and CHRП conducted the outreach. S. Zamudio-Haas accompanied outreach workers during their neighborhood rounds, lasting anywhere from two to four hours. At each site, the senior outreach worker from the CBO conducting service delivery and a peer community outreach worker acted as key informants and interpreters. Observational data were documented via note taking on the setting, individual behavior, group dynamics, number of people present, and logistics. Notes included a sketch of the service delivery settings and key comments from informal conversations.

A majority of interviews took place at the MAT clinic or the nearby Tanzania AIDS Prevention Program building, located at Muhimbili University of Health and Allied Sciences (MUHAS). Most patients preferred to interview in a counseling room at the MAT clinic, while most service providers preferred an office at MUHAS. All interviews were audio recorded, translated from Swahili into English, and transcribed. Interviews ranged in length from 45 min to 105 min, with a majority lasting about an hour.

Interview approaches differed between male and female patients and providers. Open-ended interviews with female patients broadly explored drug use history, sources of family and social support, and experience with health services, focusing on their decision-making process around treatment entry and identifying any unmet health needs. Interviews with male patients explored similar areas; however, the focus was on complementing, contrasting, and augmenting the information female patients provided. Open-ended interviews with providers looked at their work background, typical day-to-day experience with patients in the MAT program, and ideas about how to improve service delivery to increase women's participation in treatment. Data collection was carried out over a number of months, to allow for simultaneous analysis. Our understanding of emerging concepts and categorical relationships informed subsequent data collection and participant sample selection.

Data analysis

Coauthors collaborated throughout the thematic analysis process to identify and understand emerging themes, key concepts and their interrelationships. Initial open, line-by-line coding used gerund verbs such as “getting hooked,” “isolating socially” and “motivating for treatment” to capture the action in sentence and stay close to the data (Charmaz, 2006). These initial codes were revised and reduced to capture larger segments of data under concept codes, such as “social isolation” and “treatment motivation.” In this second stage of coding, we added deductive codes such as “enrollment experiences,” “outreach strategies,” and “service expansion to reach WWID” that were central to our analysis goals. We developed a structured codebook to facilitate similar coding across transcripts (MacQueen, McLellan, Kay, & Milstein, 1998). Coded excerpts were organized into word documents under three main analytic categories: “A junkie gets no love” which included themes describing life before MAT; ‘Service Provision and Utilization’ which included themes on programmatic experiences, and “Standing at a crossroads” which captured themes around issues in treatment and ideas for improving services. Further analysis tabled particularly salient coded excerpts with patient and provider characteristics (i.e. women, married, 2 children, 8 months in MAT) to facilitate comparative analysis across informants. Memos, email correspondence and meetings helped to develop our understanding of thematic concepts and their interrelationships.

At the last stage in analysis, *trust* emerged as a central overarching theme linking analytic categories and other prevalent themes. Here we describe and discuss results around the generation of *trust/mistrust* and explore interrelationships among

the following themes: *family loss*, *social isolation*, *vehement discrimination* and *motivation for treatment*. Results are organized according to the three analytic categories, which roughly follow chronological experiences from pre-MAT, through enrollment, ending with suggestions to improve service delivery from the perspectives of patients in treatment and their providers.

Ethical protections

All individuals who participated in interviews offered informed verbal consent and received a copy of the consent form. We obtained oral rather than written consent to protect interview participants who might disclose illegal activity. The organizations that participated in the research offered letters of support for the research. Ethical approval was received from the Committee for the Protection of Human Subjects at the University of California, Berkeley and from the Research and Publications Committee at MUHAS.

Key findings

Understanding women's MAT enrollment experiences, with an eye to contextual and programmatic barriers and facilitators to accessing care, served as our primary focus during data collection and analysis. A high HIV prevalence in PWID and limited availability of newly introduced methadone stood out as defining characteristics of the larger service delivery context for the treatment program. *Trust/mistrust* emerged as an overarching theme cross cutting patient and provider accounts of the connective process to enroll PWID in the methadone program. We explore *trust* and *mistrust* in relationship to the interrelated themes of *family loss*, *social isolation*, *vehement discrimination* and *motivation for treatment*. Before entering MAT, patient narratives described their lives as *teja* (“junkies”), living on the margins of society, where heroin became their sole focus at the expense of family relationships and self-care. Narratives delineated both the generation of *mistrust* against PWID and the generation of *mistrust* in PWID against outsiders and medical institutions. In order to enroll PWID in treatment, CBO's engaged outreach strategies to overcome *mistrust* and connect eligible patients to care, which varied in their success at recruiting women and men. Regaining *trust* from their families and rebuilding relationships with loved ones proved a major *motivation for treatment* for patients to enroll in the MAT program. We close by discussing how expanding enrollment policies to include women who smoke heroin could increase their participation in the treatment cascade.

“A junkie gets no love:” The generation of ‘mistrust’ against PWID

Patient accounts of life before treatment describe an ongoing struggle to survive that created alternate, *teja* identities. Looking back on their time before MAT, patient narratives paint an existence centered on the cyclic urge of heroin dependence. Patients described this time in their lives in dehumanized terms. “You become a pariah,” noted one participant, “you are in complete default of society's norms.” Another notes, “I lost my value as a human being.” One woman summarized; “being a junkie causes you to lose all dignity.” Most patients recounted stealing from family or neighbors to quell the sickness of heroin withdrawal. In one narrative, a patient laments how she had “done them wrong,” describing how she had stolen clothes from her family home. Another patient tells how he held a knife to his wife's throat, threatening to hurt her if his uncle would not give him money for heroin. Patients told their pre-MAT accounts with distant expressions, as though describing the actions of another person, a pre-treatment self.

At the same time, patients' narratives link their desperate actions to the *generation of mistrust* in PWID by families and communities: "They did not trust us because we were using drugs. They looked at us like thieves even if we were not;" "My whole family cast me out. They would close the doors, 'she will just steal' they would say;" "People did not trust me even in small things, because I created an environment that was not trustworthy;" "The first thing I lost was trust- my society stopped trusting me because they knew I was a drug addict and a thief." Patients acknowledged that their actions in many cases fueled their families' *mistrust*, yet they also described how familial and community rejection contributed to an unbearable sense of *loss* and *social isolation*. "My friends... I lost them... some of them tried to help me and some of them rejected me," noted one woman. Patient accounts described a similar downward spiral, with heroin becoming their prime focus at the expense of self-care, family and social relationships.

The *dago* and *vijiwe* (drug hang outs) became the places that PWID could congregate without judgment. In these hang outs, located in the heart of dense urban slums or on the edges of the city near the ports, people might live for weeks or months on end. Outreach workers described that all camps have a leader that minimally regulates who stays at the camp, who has access to the space, and who can sell drugs to inhabitants. Men in particular gravitated towards the outdoor *dago* to meet other PWID and use: "I lost my job, my wife, so I had to stay in the *dago*." A provider explained, "It's because they are isolated from their families, so the only place that they remain with is the *dago*, so the majority of them are in the *dago*." During outreach visits to *dago* and *vijiwe* located throughout the city, we observed men high/getting high, with only the occasional woman. The few women who were observed at *dago* presented as masculine in appearance.

'Vehement Discrimination' and the generation of 'Mistrust' in PWID

Mistrust combined with stigma to generate *vehement discrimination* against PWID in community and health care settings; which in turn created *mistrust* in PWID against outsiders and social institutions. A couple of patients recounted incidents where they were falsely accused and beaten by groups in retaliation for assumed crimes. As one patient recounts, "They accused me of stealing when I did not. They beat me up, but they discovered the real thieves later, but they had already humiliated me." Providers and patients characterize discrimination as worse for women who use drugs as compared to men who use drugs, as many WWID engage in sex work. WWID are seen as crossing strict norms around appropriate expressions of sexuality and sexual behavior for women in Swahili culture. Several women patients described being "chased from their homes," "locked out," "cast out," "disowned," "deserted" or "beaten" when family learned of their drug use and involvement in sex work. Others talk about community "gossip" and "name calling", hurtful enough that one woman noted it made "even my oldest son cry." The quote below summarized this key concept that came up throughout interviews with patients:

"In Dar, a woman who does drugs is more vehemently discriminated against than a man who does drugs, because she is a woman. A man who does drugs is more tolerated. So a woman is discriminated against. There is a difference. A woman cannot get any support. She will not receive any support. So she is shut out."

– Woman in MAT Program, 38 years old

Being "shut out" for WWID included the *dago* and *vijiwe*, the public spaces where men would use drugs in relative freedom from harassment. While these spaces provided refuge for men, WWID

described the *vijiwe* as dangerous spaces, characterized by assault and robbery. PWID assumed women engaged in sex work and thus might have cash. In addition to robbery, women attested to the threat of sexual violence in the *vijiwe* and *dago*. Rather than risk assault in the male hang outs, WWID would share small apartments. During outreach field visits, we would sometimes glimpse these shared spaces, although entrance was more guarded and access limited as compared to the *dago* and *vijiwe*, given heightened *mistrust* of outsiders as potential perpetrators. The quote below exemplifies the violence a few women patients described that can take place at the *vijiwe* or *dago*.

"There is cruelty. For example, you might be at the spot (*vijiwe*) getting high and a guy there also wants to get high, but doesn't have any money and he sees you and thinks you have money. He might use force on you and take your money or maybe another one might be attracted to you and not know how to talk to you so he takes you by force and does it to you right there"

– Woman in MAT Program, 33 years old

The rejection, ridicule and abuse that WWID received from their families, communities, and other drug users generated "skepticism" of almost anyone except women injectors. Negative experiences piled up to create *mistrust* of people who did not share an equal vulnerability. Rather than face society's cruelty and disdain, WWID "hid" themselves. In hiding, WWID minimized their chances of hurt, yet also withdrew from potential sources of support.

Vehement discrimination in the health care setting

Before coming to the MAT program, *vehement discrimination* characterized many PWID's experience in health care settings. PWID described seeking medical care only in the most extreme cases of assault or injecting related harm, such as infected abscesses. Women additionally talked about accessing health care for reproductive concerns related to giving birth or getting birth control. Accounts described rampant discrimination in medical settings: "the attitude is, 's/he is a junkie. Don't bother with him/her;" "we are stigmatized from registration to the consultation room, even doctors stigmatize us as patients;" "they probably won't assist you until everyone else is attended to." Felt stigma and discrimination lead to the anticipation of stigma, generating deep *mistrust* in PWID of medical institutions. Provider accounts confirm the discrimination directed at PWID in health care settings. One provider, with over a decade of experience as an advocate and service provider for WWID and sex workers, noted, "...even from those you see who are courageous, it is sometimes difficult for them to walk into a clinic. Some of the health care workers are not so friendly. They don't say, 'go away' but this girl will not come back." For WWID, reaching out for reproductive health care included tolerating treatment "without respect." Discrimination in medical settings- places of healing- fueled *mistrust* of people purporting to be care providers.

Effective strategies to develop 'Trust' through outreach

Provider and patient narratives identified several outreach strategies that they employ to overcome the *mistrust* PWID had for outsiders and health service institutions. Rather than expecting PWID to seek out services in the MAT clinic or CBOs, outreach teams visited the *dago* and *vijiwe*. During direct observation of outreach, we noted how supervisors negotiated entry into these spaces, talking first with the "leader" to get the ok for "discussions" around safer injecting, blood borne illnesses, and MAT. Before conducting outreach, supervisors needed to get the "leader" to announce, "this is a friend, you can come and discuss," one

provider summarized. Once inside the invisible boundaries of the *vijiwe*, as none were literally closed off spaces but rather open camps, peer Community Outreach Workers (COWs) played a key role in building *trust* in PWID. Many of the COWs were known to PWID in the *vijiwe* from before they enrolled in MAT. While the first cohort of COWs had recently finished outreach training at the time of data collection, preliminary feedback seemed promising in regards to the COW's enhanced ability to make connection with PWID. We observed the ease with which newly trained COWs could engage PWID in sensitive conversations about addiction and treatment. In a majority of observed cases, these "discussions" occurred man-to-man, in part because the majority of PWID at *vijiwe* were men and the majority of COWs were also men. COW narratives described their ability to overcome the "fear" and "suspicion" that PWID have against outsiders. The quote from a COW below exemplifies a common narrative thread:

"They are suspicious that other people who have never used drugs are looking down on them and that they don't understand anything that they go through. They listen to me easier because they know that I have used heroin and I know everything about it. They get some kind of motivation from that because they can see that methadone has helped me to change"

– Man in MAT Program, COW, 32 years old

While peer outreach at drug hang outs effectively enrolled men in MAT, providers and patients recognized that additional times, outreach locations and women peers were needed to have similar success recruiting women. WWID rarely frequent the *vijiwe*, rather they "hide themselves in houses", out of public view and comparatively protected for assault or robbery. Additionally, women kept different schedules than the men, due to engagement in sex work. All but one of the female patients interviewed described previously conducting sex work. They attested to picking up clients along the side of the road, "*tunaenda rodi*" (going to the road – a common euphemism for sex work) or in bars, mainly at night. WWID "work during the night and during the day they just sleep," patients and providers confirmed. A couple of providers suggested that nighttime outreach to women on the road might be a more effective way to connect with WWID: "we can get more women at night;" "we should do a nighttime outreach." Training women peer COWs who are former sex workers could increase the chances of accessing WWID and building *trust* to enroll them in treatment. WWID, more than their male counterparts were described by patients and providers as "afraid of disclosing their behavior," many are "ashamed" and "hidden." In narratives, informants suggested that women COWs might be better at bridging these barriers than the mainly male peer workforce currently employed at the CBOs. Below a provider delineates an argument a number of informants shared:

"Drug use amongst young girls is very hidden in this community, actually by culture and by the way they operate. But sex work is a bit more obvious, but also a lot of silence around it. Meeting with the girls is a bit difficult. In the afternoons, they need rest. In the evenings, they go out. So the best person to work with the girls is somebody from the same group who can be with the girls when the time is appropriate for the girls"

– Program Coordinator, Referral CBO

For women who had enrolled in MAT, more so than men, developing *trust* in the service provider proved a necessary first step to connect them to services. At first encounter, women patients recounted that they perceived outreach workers as "trying to use us" or "do something shady." To overcome initial doubts, providers either developed *trust* over the course of

multiple outreach conversations or via connection from someone close to the woman. A number of patient and provider accounts attested to the persistence and time investment required in order to build sufficient *trust* in WWID to make their first visit to one of the referral CBOs. A provider described that, "the outreach workers first build friendships with them . . . that motivates them to reach our offices." One patient described her enrollment story, which fit a common narrative, where she first "ignored" the outreach workers, even "cursed" them. However by the "fourth visit", she went with them to enroll in MAT. In contrast, male patients expressed a readiness and willingness to try out MAT and avail themselves of supportive services without the same degree of relationship building, "I heard about MAT from the COWS, I was ready when they passed me in the street;" "One COW came to me, I don't remember his name . . . we went to the CBO and I was brought here;" "The first person who told me about this was another injector . . . I went to get some more information . . . then after that to Muhimbili to get treatment."

In other cases, outreach workers leveraged existing trusted relationships to recruit WWID into treatment. About a third of the female patients interviewed initiated treatment after their male partners had enrolled in MAT. In these cases, the boyfriends encouraged the WWID to join the methadone program, assuring the women that treatment works. "My boyfriend persuaded me to join the program," noted one woman, expressing a common thread across a couple of women's enrollment stories. Since methadone is new to the country, some PWID initially distrusted or doubted the effectiveness of the medication. From interviews with patients and their providers, men seemed more likely than women to take the initial risk and try the medication. Male patient narratives described proactively following up about treatment once they learned about it from outreach workers or other PWID. Once the early adopters enjoyed the benefits of treatment, gaining weight and looking healthier than when they were injecting heroin, some reached out to friends or girlfriends to join them in MAT. Patients recalled noticing something "different" or "changed" about the newly enrolled MAT clients. The quote below is drawn from one women's account of how she began treatment after her partner had already started medication. His experience helped her to overcome doubts about methadone.

He [my boyfriend at the time] told me, 'Let's go to the methadone clinic so that you can get help.' I told him there is no medication. And he told me, 'Don't you see that I am using it?' And I told him ok, we will go. But I thought he was joking . . . We went on like that for a while and finally he brought me here and I was accepted at Mama M's place. I came and started using the doses.

– Woman in MAT Program, 25 years old

Some outreach workers recruited women into the program via establishing an initial connection with their family. Dense neighborhoods, where people know one another and each other's family stories, facilitated this type of personal outreach from community organizations. In these cases, conversations around harm reduction and treatment availability occurred first with a WWID's mother or other close family member, overcoming family "disbelief" in MAT as a first step. The family member, once in support of treatment entry, could help facilitate this: "[the provider] told my mother to take me to the organization." Female patients described the emotional weight these conversations held for them, noting that it was moving to hear a family member ask for them to get treatment. Given the familial rejection and *mistrust* that many female patients recounted experiencing, outreach through a loved one conveyed a powerful message of hope.

Regaining trust from family: A motivation for treatment

Rebuilding relationships and regaining *trust* from family proved a central *motivation* to enter treatment for patients interviewed. Most patients described reaching a point where family *loss* and *social isolation* led them to change and enter treatment: “[my family] stopped caring for me. I was the last person that mattered . . . I got tired of such a lifestyle;” “My father could not even look at me. And I wanted to be human again, that’s why I joined;” “I felt lonely because I was using drugs alone.” Providers described waiting for PWID to get to the point where they asked for help before beginning the enrollment process. Given the scarcity of methadone in Tanzania, the MAT program reserved spaces for PWID who demonstrated serious commitment to ending heroin use. The enrollment process thus included an orientation session, two health education sessions, and a requirement for a sponsor that pledged to support the patient while in treatment. PWID needed strong *motivation* to go through those initial screening visits. One provider noted he waited for PWID to get “fed up with drugs. So they are serious when it comes to treatment.” He gauges their commitment with their “words” when, “They say, ‘my family doesn’t want me, they don’t share any family matter with me and I want to go back to my family, please help me.’”

For women, rebuilding their relationships with their children proved a major *motivation* for enrollment. Unlike in many countries in Europe and North America, in Tanzania the family rather than the state intervenes to take children into a safer environment when parents are using drugs. Of the 13 parents in MAT who were interviewed, all recounted that their children lived with other relatives when they were using heroin. Women patients in particular noted that a desire to be able to care for their children was their motivation for beginning treatment. One patient described her daughter “crying” and “begging” her to stop using drugs. Others described wanting to be able to “provide for” their children and “take good care” of their families. Summarizing a common narrative, one woman disclosed, “When I saw that I am suffering and my children are suffering while I still have eyes to watch them and hands for serving them, I decided to enter the program (woman in MAT program, 28 years old).”

Supportive services for patients in MAT focused on helping them to reunite with their family. Patients work the 12 steps at CBOs and learned to address the hurt they caused their family and express their own desires for re-building relationships. Narratives highlighted regaining trust with family as a marker of success in the MAT program. Providers noted that most of the patients in MAT were newly “trusted by their families,” that they “count it as a success” when patients “re-join” with their families, often by moving back into the family home. Patient narratives resounded with satisfaction when recounting how their “relationships are closer now, because before I wasn’t trusted and now they trust me;” “[my family] are hopeful . . . they trust me more, the trust is renewed to a certain degree;” “we are happier than before cause she no longer doubts me as now I am a father who is trustworthy.”

Adapting enrollment criteria to include Women who Smoke Heroin

Currently the MAT program is limited to people who are long-term heroin injectors, as the risk of HIV transmission is highest among this group. A number of service providers and patients interviewed advocated for allowing women who smoke heroin to also be eligible for treatment. Providers noted, “The program should be extended to cover drugs users who smoke too. They are out there crying for help;” “Most of the women are smoking and this program deals with injecting drug users . . . I think we should also help the women who smoke.” Although smoking heroin in hand rolled cigarettes mixed with cannabis, commonly referred to

as *cocktails*, carries no risk of HIV transmission; the accompanying drug dependence can increase the chances of sex work without condoms. Several women in the MAT program recounted that when they were “sick,” “didn’t have any money,” and were “in desperate need for a fix,” getting paid took precedence over reducing the risk of disease transmission through condom use, particularly since some customers will pay more for sex without a condom. “I didn’t care that I will be infected, I was just thinking about money for drugs,” recounted one woman.

Enrolling smokers in treatment might have the additional benefit of stemming progression to injecting drugs. MAT patients identified smoking as a precursor to injecting in their drug use careers: “I started out smoking *cocktails* and then I graduated to needles;” “I was smoking for about six months . . . then I found out that the syringe is better;” “. . . I started injecting after seeing that it was feeling so nice compared to the *cocktails*.” Enrolling women smokers in MAT could prevent them from accelerating drug use. Given the high prevalence of HIV among women who use drugs, reducing barriers to connect them to drug treatment and HIV care takes on added importance.

Discussion

This study reported findings from ethnographic research and 25 in-depth interviews with service providers and patients in the first publically funded MAT program on mainland sub-Saharan Africa, in Dar es Salaam, Tanzania. Our formative research adds to the conceptual and implementation science literature around MAT service delivery in limited resource settings (Chawarski, Zhou, & Schottenfeld, 2011; Gu et al., 2013; Rhodes et al., 2015; Tran et al., 2015), delineating the key role that trust/mistrust plays in the treatment enrollment process and how this differs by gender. Literature from other contexts has explored how felt and anticipated stigma shaped mistrust of medical interventions in PWID (Harris, Rhodes, & Martin, 2013; Treloar, Rance, Yates, & Mao, 2015). Our findings identified similar mechanisms underlying weak care engagement in WWID, due to particularly strong social and cultural stigma that generated *mistrust of PWID* by families and communities and *mistrust in PWID* of medical settings and outsiders. Combined mistrust and discrimination created social isolation, with WWID dwelling in hidden shared apartments. As a result, providers faced additional hurdles locating and engaging WWID in outreach. The process of building trust and leveraging motivation for treatment in WWID required additional strategies and time investment from providers. Programmatic adaptations such as adding outreach times and locations, recruiting more women COWs, and reducing enrollment requirements for women, could help increase their participation in available treatment services.

Our research highlighted the effectiveness of street-based outreach to link PWID to MAT, while demonstrating that additional outreach strategies are needed to increase women’s service utilization. The heightened risk of assault and robbery for women as compared to men who inject drugs drove them into more hidden spaces. Outreach at *dago* and *vijiwe* thus missed WWID with harm reduction education, the first step to enrollment in MAT services. Reduced outreach to women contributed to their low participation in treatment services, both in absolute numbers and proportional to their representation in the general population of PWID (Lambdin et al., 2013). At the time of data collection, the MAT program had just begun to train and deploy peer COWs to assist in daytime outreach. Interview narratives and observation of outreach activities demonstrated the potential of the COW strategy and in line with literature from other developing country contexts that peer outreach helps to connect hidden populations with HIV prevention services (Campbell & Mzaidume, 2001; Medley,

Kennedy, O'Reilly, & Sweat, 2009). Engaging more women peers, who are also former sex workers and imbedded in these hidden social networks could help identify and connect WWID with services. Previous research from the US provides evidence that nighttime outreach can successfully link women, many of whom are street-based sex workers, with MAT programs. Working with a similar population of WWID in New York City, Nuttbrock, Rosenblum, Magura, Vilano, & Wallace (2004) reported that 40% of female sex workers contacted through street-based, nighttime outreach entered methadone treatment following referrals.

Yet outreach is not the only potential role for a peer workforce. Treloar and Ableson explored the potential for peers to share safer injecting information with each other, documenting that often information on injecting is passed on from more experienced users to new initiates (Treloar, Rance, & Backmund, 2013). COWs could educate WWID to provide health information to each other, non-contingent on treatment entry or stopping heroin. Given the intimate and secluded social networks described in interviews, this type of in-group peer education could prove an effective route for promoting harm reduction. For women in treatment, increasing women-only peer interventions such as support groups could provide a venue to discuss histories of abuse and share stories of healing. Hearing other women in a similar situation share their adversities and treatment milestones could provide community and companionship alternative to family, while women work to regain trust and rebuild intimacy with loved ones.

Findings demonstrated that leveraging familial relationships could help build trust in medical services and provide motivation for women to enter treatment. In Swahili culture, the family unit is paramount. Strong social norms govern hierarchies of respect and responsibilities between parents and children, and among siblings, based on birth order and sex (Creighton and Omar, 1995). MAT patients lamented the ways they had hurt their family when they were heroin dependent. At the same time, they shared heartbreaking accounts of familial rejection. Women in particular were ostracized due to perceived transgression of acceptable expression of sexuality, in addition to drug use. Reuniting with their family and rebuilding relationships with loved ones motivated the women patients who participated in our study to enter care. Similar to findings from other contexts, the prospect of being a better mother to their children was a key factor in this process (Eiroa-Orosa et al., 2010). Conducting outreach to WWID by first engaging their families to support enrollment proved successful for a few of the women we interviewed. This family-centered approach could be scaled up through increased direct outreach to families with WWID. It is important to note that our interview participants were more likely to be married and parents than the general MAT population. The role of family in the decision-making process to enter treatment might thus be exaggerated in the sub-set of patients who participated in interviews, as compared to the general patient population.

Recruiting women who smoke heroin, in addition to women who inject heroin, into MAT could increase women's utilization of harm reduction services and reduce HIV transmission risk. A majority of patients interviewed first smoked heroin before beginning to inject it, similar to a progressive drug use trajectory that has been documented previously with a similar study population (McCurdy et al., 2005, 2006; Ross et al., 2008). Treating women who smoke could prevent progression to injecting drugs, a much more risky behavior. Recruiting women who smoke heroin into MAT could lower their risk of HIV transmission via sex work, while reducing morbidity and mortality associated with heroin use. In a review of methadone as an HIV prevention intervention, Sullivan et al. (2005) found that both injecting and non-injecting people with heroin dependence reduced sexual risk behavior and experienced improved health after entering methadone treatment. Additional research suggests that concurrent methadone

treatment and HIV treatment optimizes health outcomes for people living with HIV (Roux et al., 2009). Given the high HIV prevalence among women who use heroin in Dar es Salaam, MAT integrated with HIV treatment could reduce the risk of onward transmission to the general population (Bruce, 2010). In the context of declining prevalence among the general population, policies to minimize the potential of women who use drugs to act as a bridge population is key to maintaining gains in the struggle to reduce HIV burden of disease (Needle et al., 2012). Further, reducing structural barriers to program entrance could help bring more women into care (Blankenship, Reinhard, Sherman, & El-Bassel, 2015).

How might CBOs reduce the pervasive stigma and discrimination directed at PWID and women who inject drugs in particular? Increasing education and outreach in community settings could help reduce the high levels of mistrust and prejudice against PWID. CBO's could consider presentations at church events to reach a general audience and educate around addiction and harm reduction resources available. Telling stories of resiliency from COWs could foster hope in the capacity for change in PWID and normalize chemical dependence as a health concern. Church presentations could help families and neighbors understand what goes on when loved ones are chemically dependent, perhaps fostering support groups for families affected by addiction. Access to information could help dispel stigma against PWID and educate their families that there is treatment to help. Current printed social marketing campaigns that CBO's distribute are geared towards an audience of PWID. Adapting messages for a non-drug using audience and placing materials on buses or neighborhoods signposts could increase referrals. A community-level HIV stigma reduction "hub" in South Africa employed similar strategies with success. Reducing underlying stigma against PWID has the potential to reduce their mistrust of care providers and medical settings, potentially increasing the proportion that reach out for care, while improving the day-to-day realities of those who continue to inject.

Conclusion

This study contributes to a growing body of literature on methadone as an HIV prevention and treatment intervention in limited resource settings. Our formative research identifies outreach strategies to address gender inequities in access to drug treatment, exploring trust and mistrust as key factors in the enrollment process for women. Based on our findings, we delineated strategies to adapt outreach and enrollment policies to increase women's participation in MAT, without requiring much additional investment. This research reflects service delivery in a densely populated urban setting in the largest city in Tanzania. Future research evaluating the implementation and effectiveness of services tailored to WWID in a rural or lower density peri-urban setting in Tanzania, could build on these findings. Given the high HIV prevalence in WWID in Dar es Salaam, increasing their access to available care is urgently needed to protect their health and reduce onward transmission. Findings hold implications for the development of MAT programs in other parts of Tanzania and in other coastal East African countries, where an increase in PWID has emerged as a critical component to HIV epidemics.

Conflict of interest

The authors declare that they have no conflict of interests.

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