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Reducing health disparities: key factors for successful implementation of social network testing with HIV self-tests among men who have sex with men with a non-western migration background in the Netherlands

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ABSTRACT

Improving testing uptake among men who have sex with men with a non-western migration background (MSM-NW) is a public health priority, as people who are unaware of their HIV infection are at higher risk of transmitting HIV and are unable to benefit from HIV treatment. Formative semi-structured interviews with 13 MSM-NW assessed key factors for the successful implementation of social network testing with HIV self-tests (SNT-HIVST). Interviews were thematically analysed. Participants mentioned that SNT-HIVST might overcome barriers to regular HIV testing including; being seen while testing, disclosure of sexual identity, and stigma related to HIV and sexual practices. Trust between the HIVST distributor and receiver was important. Finally, SNT-HIVST requires tailored peer support to address practical, informational, and emotional needs. MSM-NW distributing HIVST can have an important role in reducing health disparities in testing uptake among MSM-NW. Provided sufficient trust among MSM-NW; key factors found for successful implementation were education through an e-tool, and establishing quality support by a peer-coordinator for unanticipated questions. In conclusion, HIVST distribution has the potential to reduce health disparities in testing uptake, in particular, if adjusted to MSM-NWs individual preferences and the needs and preferences of the person they are inviting to test.

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HIV; social network testing; HIV self-test; migration background; health inequity

Introduction

In the Netherlands, as in many Western countries, health inequities exist between populations in HIV prevalence, timing of HIV diagnosis, and awareness of HIV status (Van Sighem et al., 2016; Visser et al., 2018). Reducing the number of people unaware of the HIV diagnosis is a public health priority, as people who are unaware of their HIV infection are at higher risk of transmitting HIV to others and are unable to benefit from HIV treatment (Bezemer et al., 2008; Marks, Crepaz, & Janssen, 2006).

Men who have sex with men with a non-western migration background (MSM-NW) have higher levels of HIV infection compared to western and ethnic Dutch MSM (Visser et al., 2018). MSM-NW are also likely to enter care late or with AIDS-related symptoms (Op de Coul et al., 2016). These authors found that late diagnosis could be addressed by strategies encouraging testing.

In 2012, 31% of all MSM were estimated to be unaware of their infection, with large differences between

subgroups; among people with a non-western migration background, an estimated 40% were unaware of their HIV infection (Op de Coul et al., 2015). In 2017, the percentage of MSM unaware of their infection was already much lower (9% of all MSM) (Van Sighem & Op de Coul, 2018). However, differences between subgroups still exist and the proportion of MSM-NW unaware of their status is likely to be above the 9% for MSM in general.

Heckathorn (1997) found that intra-ethnic connections are more common than inter-ethnic connections. Therefore, it is likely that MSM-NW cluster together in social networks including people who not only share key demographic characteristics, but also behavioural characteristics, and cultural norms that influence HIV risk (Amirkhanian, 2014; Drumright & Frost, 2010). Differences in social or sexual networks can place certain groups at greater risk of HIV (Berry, Raymond, & McFarland, 2007). Indeed previous research has shown among black MSM in the United States, higher HIV

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prevalence despite lower risk behaviour (Berry et al., 2007; Harawa et al., 2004). Risk clustering can be utilized to reduce health disparities, for instance employing social networks to increase testing uptake among MSM-NW, so-called social network testing (SNT). In SNT, people at high risk for HIV or people living with HIV are enlisted to encourage people in their social network to be HIV tested.

Currently, the main HIV testing approaches in the Netherlands include going to the general practitioner, Public Health Service (PHS), or testing online (Van der Helm, Zuure, Fennema, Davidovich, & Prins, 2012). At PHS, MSM can access free HIV testing. HIV testing at the general practitioner may incur costs, if people's compulsory financial contribution to annual health care costs has not yet been exceeded. However, some people might not seek care in healthcare settings. MSM-NW might also not be reached by general awareness campaigns or other initiatives to increase testing uptake (den Daas et al., 2018).

SNT has the possibility to overcome several barriers at individual, social, and structural levels associated with impeded uptake of testing in other settings. An important barrier is that hard-to-reach populations are characterized by strong privacy and confidentiality concerns, due to stigma related to HIV or sexual practices (Blondell, Kitter, Griffin, & Durham, 2015; Heckathorn, 1997). The adverse personal and social consequences of testing for HIV can be substantial, due to fear of disclosure of sexual preference or behaviour (by being seen while testing) or fear of the test result. This can cause reluctance to test (De Wit & Adam, 2008; Deblonde et al., 2010), especially in groups in which stigma related to HIV and sexual practices, notably sex between men, is high (Herek, 2007; Meiberg, Bos, Onya, & Schaalma, 2008; Smit et al., 2012; Stutterheim et al., 2012). With SNT, people do not have to disclose their sexual behaviour to anyone, which might reduce their reluctance to test.

Another limitation of traditional testing approaches might be that people are more comfortable with and open to their peers than to health care workers (Veronese et al., 2018). Furthermore, client-initiated testing opportunities might be especially limited in reaching people who do not perceive their behaviour to be high risk (Blondell et al., 2015; De Wit & Adam, 2008; Deblonde et al., 2010), whereas in SNT people in the social network determine possible risk. SNT may prove a viable alternative to improve HIV testing among MSM-NW targeting these barriers and reasons that might impede testing specifically.

Previous studies from the United States used SNT successfully and have found positivity rates as high as 6% (CDC, 2005; Fuqua et al., 2012; Golden et al., 2006;

Gwadz et al., 2017; Halkitis et al., 2011; Kimbrough et al., 2009; Lightfoot et al., 2018; McCree et al., 2013; Vargo, Agronick, O'Donnell, & Stueve, 2004). A Belgian study showed that HIV-testing uptake among people who migrated from sub-Saharan Africa was facilitated when someone else (i.e., providers aided by community leaders) initiated HIV testing (Manirankunda, Loos, Alou, Colebunders, & Nostlinger, 2009).

To overcome even more barriers, SNT can be combined with HIV self-testing (HIVST), which has previously successfully been done in an American (Lightfoot et al., 2018) and South-African setting (Lippman et al., 2018). It is well established that HIVST is ethical, effective, and highly acceptable among MSM populations in various contexts, and does not seem to lead to any unintended harm (Figueroa, Johnson, Verster, & Baggaley, 2015; Jakobsen et al., 2018; Krause, Subklew-Sehume, Kenyon, & Colebunders, 2013; Witzel, Rodger, Burns, Rhodes, & Weatherburn, 2016). Therefore, we anticipate that SNT HIVST among MSM-NW will reduce barriers and encourage MSM-NW to test.

In the present study, formative interviews assessed key factors for successful implementation of SNT HIVST among MSM-NW in the Netherlands. Topics discussed include network characteristics (i.e., who could benefit from SNT HIVST, anticipated approaches and responses, and possible facilitators and barriers) and practical requirements for implementation. The findings of the current study will be used to inform the development of a pilot of SNT HIVST (Op de Coul, et al., *Manuscript under revision*) implementing SNT for HIV among MSM-NW. Briefly, in PREVENT people handing out the HIVST in their network (peers) will follow an online training. After finishing the e-tool, peers will initially receive five HIVST to distribute in their social network. Peers will be able to contact a peer-coordinator for additional HIVST, questions, and any support. Interviewees fit the peer profile, i.e., being MSM-NW, willing to participate in a SNT HIVST study.

Methods

Participants and recruitment

MSM-NW (e.g., Eastern Europe, Central Europe, Asia excluding Japan and Indonesia, Middle-East, Africa, Turkey, Latin America, Caribbean(CBS, 2000)), above 17 years, having MSM-NW in their social network, and ability to communicate in Dutch or English, were eligible for inclusion.

We used purposive sampling, aiming for heterogeneity in migration background. Professionals of PHS Rotterdam-Rijnmond and Amsterdam, STI Aids

Netherlands, and P&G292 (sex-worker organization) recruited participants. In addition, we asked respondents could approach other MSM-NW within their social network (snowball technique). All participants were interviewed between May and July 2017 and compensated with a 20-Euro gift card.

Data collection

A semi-structured interview guide was constructed using expert opinion, peer-reviewed literature, and (international HIV-testing guidelines (Van Bergen et al., 2013; World Health Organization, 2015). The interview guide was pre-tested with colleagues and revised afterwards. After inquiring about familiarity with PREVENT, the interview guide focussed on the characteristics MSM-NW in participants' social network, i.e., who in participants' network could profit from an SNT HIVST intervention, anticipated approaches and responses. If certain topics did not come up in the interview naturally, participants were asked about them, for instance: Why this person/these persons, why could SNT work? To assess impeding factors in SNT HIVST participants were also asked about MSM-NW in their network who might suitable, but whom they would not approach.

Subsequently, interviews focussed on ideas participants had on key factors for successful implementation of SNT HIVST, how participants would go about handing out HIVST. For instance, How/where/when would they approach this person, do participants have any concerns? The final part of the interview assessed what information the e-learning tool should contain and whether the e-tool and peer-coordinator suffice, what kind of information would they need, and should peers meet in person as well?

The face-to-face, semi-structured interviews were conducted by an interviewer (MG), who received training in qualitative interviewing methods. Interviews were conducted in a private setting at the PHS of the participant's choice. Interviews were audio-recorded and transcribed verbatim.

Data analysis

Thematic analysis method (Braun & Clarke, 2006) was performed to explore factors that influence the implementation of SNT HIVST with an inductive process to derive themes. Analyses were done by two investigators (MG and CDD), initial coding was compared, and discussed among the coders and project group; the code scheme was refined until consensus was achieved. Initial codes were generated and combined into overarching themes (CDD).

Data were analysed using NVivo (QSR International). The quotes of the Dutch interviews used in this study were translated into English for reporting purposes; analysis was done in the original language. Grammatical errors in the quotes reflect what was said in the interviews, passages in brackets [] were added by the researchers.

Ethical considerations

The Ethics Committee of the Faculty of Social and Behavioural Sciences of Utrecht University approved the study protocol (FETC17-45). Participants signed informed consent. They were informed that participation was anonymous and voluntary, and that they could always withdraw from participation without explanation or consequences.

Results

Participants

Thirteen interviews lasted an average of 80 min (range 33–95 min). Countries of origin of the participants were Aruba, Brazil, Curacao, India, Iran, Iraq, Jordan, Romania, Surinam, Turkey, and former Yugoslavia. Eleven participants had a first-generation migration background, and two a second-generation migration background. The average age of the participants was 29 years (range 20–37 years). We found several factors that were important for successful implementation of SNT HIVST among MSM-NW, described and illustrated by quotes below.

Need for trust in social networks

The quality of the relationship between men was a key factor for successful implementation of SNT. Openness in communication was often mentioned, as without openness initiating a conversation about testing is difficult (for quotes see Table 1, quote 1). All men indicated that they would consider offering SNT HIVST to friends they considered close or close enough, usually men that came around their house or with whom they had conversations about topics that could be transitioned into HIV testing, such as sexual behaviours from the past weekend. Although some men indicated they might not actually need a bridging topic to initiate a conversation about HIV testing (quote 2). Furthermore, trust that the people distributing the HIVST are doing this for the best interest of their network associates was crucial, as was trust they will not share the possible results (quote 3).

Table 1. Quotes associated with the five themes identified in the interviews with 13 MSM-NW in the Netherlands.*Need for trust in social networks*

- 1 But if it's just ordinary friends with whom you do not talk about it [HIV testing], I do not think you will easily start about it.
- 2 Well, actually yes. You can just talk about it and offer it [a HIVST].
- 3 I think it has to do with trust between the person who wants to get tested using that kit and the person who hands out the kits. Yes, they have to be good friends, or know each other well. However, people who know each other loosely, that's not an option.

Tailoring, peer influence and support in SNT

- 4 I am a dominant type. They [network associates] know this. That uhm ... that is how I do things, character, but also culture. Thus, I say they have to do something and they do it, hahah, yes. ... Uhm, but then that also lowers the barrier!
- 5 Calmly tackle it, first explore, not too quick. See if that person would be interested at all, because if that is not the case, you have to try to adjust your approach.
- 6 Yes, imagine it is positive! The trouble I took to visit him, bring it [HIVST]. You do not want to do that home alone. So, you make an appointment and then he comes to me or I come to him. Imagine you are positive ... You have to stay there, and then you grab that person's hand. No, not just handing it out and finished.
- 7 It is a one-way street, not a two-way street. A peer only has to hand it [HIVST] over and possibly provide some information, preventive, emotional to a certain extend else give a referral.

Overcoming fear of being seen, considerations on sexual identity and concerns about stigma

- 8 Yes they have double stigma anyhow. Thus maybe being gay and maybe being HIV positive, they are linked. If you are gay, maybe you have an HIV infection. And if you have an HIV infection, you might be gay.
- 9 But it often happens that these men [with Islamic background] are not "out of the closet". I know many of them have a wife, and at the same time, they sleep with men. They do not acknowledge this. Do not do anything with testing.
- 10 You can just do it [testing] together right away. Telling that whole story is not necessary, no appointment. You remove all those barriers.
- 11 And then also being recognized by someone. That really is a risk ... in that case such a package could come in handy.
- 12 Yes, for me it has all become much easier, my family lives 100 km further away. The odds that something goes their way are minimal. [...] However, one thing then to test, it is important for everybody that this happens anonymously.
- 13 ... when I met him, we wanted to test etcetera, ... , but he couldn't via his general practitioner, because that was his uncle or aunt.
- 14 Tolerance means that they cannot be ok with it, but just dealing with the situation and keeping boundaries. Keep some fences, make some kind of regulations. Acceptance is more like; you can be part of it. There is more tolerance, but no acceptance.

Addressing fear and denial through SNT HIVST

- 15 ... they are still afraid from this disease, they don't have the knowledge about the disease. The know it will lead them to AIDS and they do not know we are done with AIDS now. ... Promotions, brochures is needed! Keep it simple, keep it readable. If you write a lot, it is too much.
 - 16 It is a kind of secrecy culture, I don't know how to say this. So, I think that if you keep that in the back of your mind, you might be less inclined to take a test. Because they are afraid to find out something, something they should keep a secret.
 - 17 but I think it is less [the fear], it removes the fear. Because you then know immediately, within 20 minutes. It is really different from having a test as usual.
 - 18 Say that someone for even for one or two seconds thinks, hmm, maybe I should do a test, and you persevere a few seconds, you can test immediately.
- Requirements to testing via SNT HIVST: provider capacity to offer support*
- 19 It would be nice if I had more information or training, that I know how to support him. But also before someone does such a test, that I can also provide advice. However, also emotional support is an important component. So, a [peer]-coordinator can help you if it gets worse.
 - 20 I think this training and being coordinator and these things is good, it is already good once more, it is very comprehensive I think.

Tailoring, peer influence and support in SNT

Tailoring means peers can choose how to broach SNT HIVST, how to start a conversation on HIV testing or sexual risk, and even amend their strategy for each approached person or to their own personality. Indeed participants indicated they would use vastly different strategies; One man would strongly encourage his network associates, whereas another participant would take the opposite approach (quotes 4 and 5). Similarly, participants had different strategies in supporting their network associates. One participant strongly felt that you should do the test together, read the results together, while another participant would not want to be there (quotes 6 and 7). These differences illustrate the benefit of being able to tailor the SNT HIVST approach.

Overcoming fear of being seen, considerations on sexual identity and concerns about stigma

Three factors were closely interconnected, and mentioned together by participants. First, the stigma around both HIV and sexual practices was a barrier for

traditional HIV testing among MSM-NW (quote 8). Concerns regarding stigma related to sexual practices were reflected in the importance of being discrete about sexual identity. Most participants thought of network associates who were not openly gay, might identify as heterosexual, or were married with children. These network associates were perceived as at risk for an HIV infection, but not testing (quote 9).

Although SNT HIVST does not affect stigma related to HIV and sexual behaviour, testing within one's social network can lower these barriers, because there is no need to disclose behaviour or talk about sexual identity (quote 10). Another strong barrier for testing was the possibility of being seen at a testing facility (quote 11). Notably, these concerns seemed stronger for men who had a smaller physical but also social distance to their family or a closer-knit community (quotes 12 and 13). Although all participants mentioned stigma related to HIV and sexual practices, some men (especially those living in the Netherlands longer) could be less affected by it and noticed that there still is much to do to eliminate stigmas (quote 14).

Addressing fear and denial through SNT HIVST

Participants still noticed misconceptions and strong fears regarding HIV. One participant called for more information suited for MSM-NW (quote 15). Fears were linked to denial; participants indicated that their network associates just do not want to know their HIV status. Participants linked this to cultural considerations of secrecy (quote 16). Although SNT HIVST does not directly address these barriers, indirectly SNT HIVST could overcome them (quotes 17 and 18).

Requirements to testing via SNT HIVST: provider capacity to offer support

In response to questions on requirements for the e-tool and other support, participants indicated that peers would need practical (i.e., how to perform the test), informational (i.e., window period, about HIV), and emotional support (i.e., how to react when someone receives a positive diagnosis; quote 19). Multiple narratives drew attention to the need for support, and the wide array of supportive needs. The online training and the peer-coordinator, whose role is to communicate with the peers, answer questions and offer support was deemed sufficient (quote 20).

Discussion

Effective approaches to reduce health disparities in testing uptake are needed to detect undiagnosed HIV among MSM-NW. SNT HIVST could be an option. All interviewed MSM-NW could think of someone they would approach. If the important condition of trust was met, SNT HIVST could overcome some of the barriers to traditional HIV testing directly or indirectly. In line with barriers identified in previous research, MSM-NW indicated that stigmas on HIV and sexual practices are a big concern when testing for HIV (Blondell et al., 2015; Heckathorn, 1997). Network associates have privacy concerns, including not wanting to disclose their sexual identity to health care workers, and not wanting to be seen at regular test facilities. SNT HIVST seems to be able to circumvent stigma regarding HIV and sexual practices, by eliminating privacy concerns, as only the peer would be involved. Finally, MSM-NW did indicate that they might require training and support in the case of possible emotional reactions or positive diagnosis; but they indicated SNT was possible and needed.

A limitation of our study is that our convenience sample of MSM-NW included individuals who were not necessarily hard-to-reach. Our participants might be skewed towards those who already favour SNT

HIVST, however, since recruitment of peers would be implemented in a similar way, this is likely a good representation of the peers willing to participate in SNT HIVST.

A strength of our study is that we succeeded in recruiting MSM-NW with vastly heterogeneous migration backgrounds, years living in the Netherlands, and religious background, and therefore differ in cultural background, and norms. Presumably, these all affect the types of people in their social network (Amirkhanian, 2014; Drumright & Frost, 2010) and their openness to HIV (testing). Another strength is that we were able to detect themes valid for all participating MSM. Nevertheless, we were not able to include MSM-NW from Africa or South-East Asia during the planned recruitment time. Therefore, SNT HIVST could be combined with other approaches that might work better for other groups of MSM-NW, such as the HIV testing week (den Daas et al., 2018) or respondent-driven sampling techniques.

Participating MSM-NW were not actually expected to participate in SNT HIVST and offer HIVST to their friends. Therefore, indicating you would definitely approach a person, and just ask whether he is interested in a HIVST, might be optimistic and more difficult in real life. However, we believe that participants were aware of the difficulty of asking someone to test for HIV, as indirectly reflected in all mentions of necessity of having a strong relationship with the network associate.

The next step is to translate the need for support in the e-tool into text or videos, and start the recruitment of peers for PREVENT, which will evaluate the acceptability and feasibility of SNT HIVST among MSM-NW. One of the implications of our findings is that although men should receive information and training, peers should not be required to use a one-size fits all approach. An advantage of SNT HIVST is that peers can appraise network associate's needs, and how, when, and where to approach them. This comes naturally; almost all men had an idea of how they would approach certain people. SNT HIVST can fit various needs as assessed by people who probably know best how to tailor their approach to suit their network associates.

Conclusions

Addressing HIV testing uptake among hard-to-reach MSM-NW is challenging. This study showed that SNT HIVST could potentially contribute to reaching these people and reducing health disparities in awareness of HIV infection. Also, as people distributing the HIVST can adjust their approach to their individual preferences and the needs of preferences of the person they are

inviting to test. SNT HIVST is not a one-size-fits all approach, which could address all types of reasons for not testing for HIV that the main testing approach are unable to address at this moment.

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Disclosure statement

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