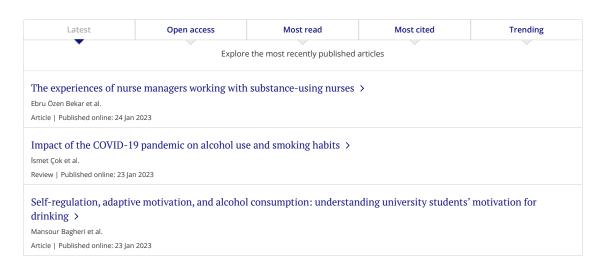


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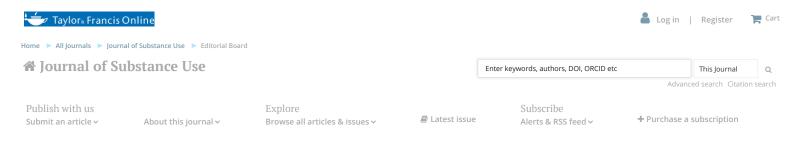
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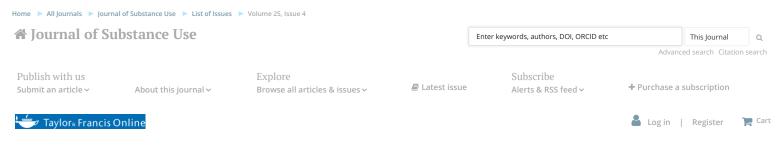






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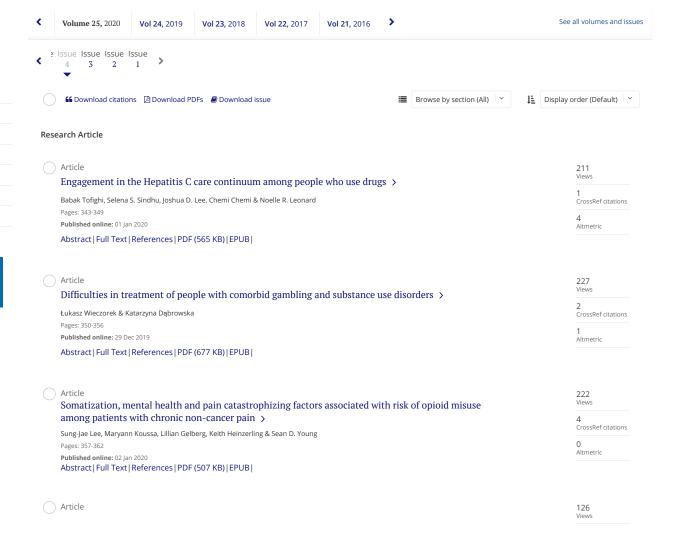
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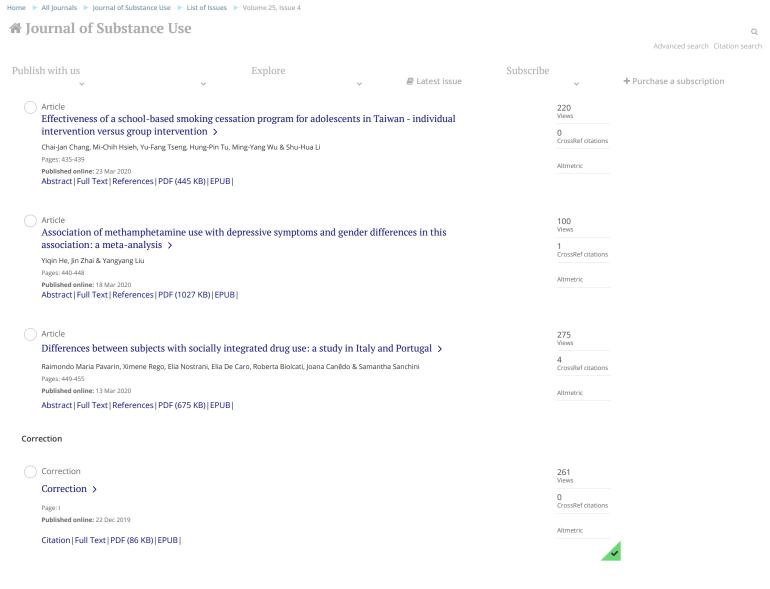
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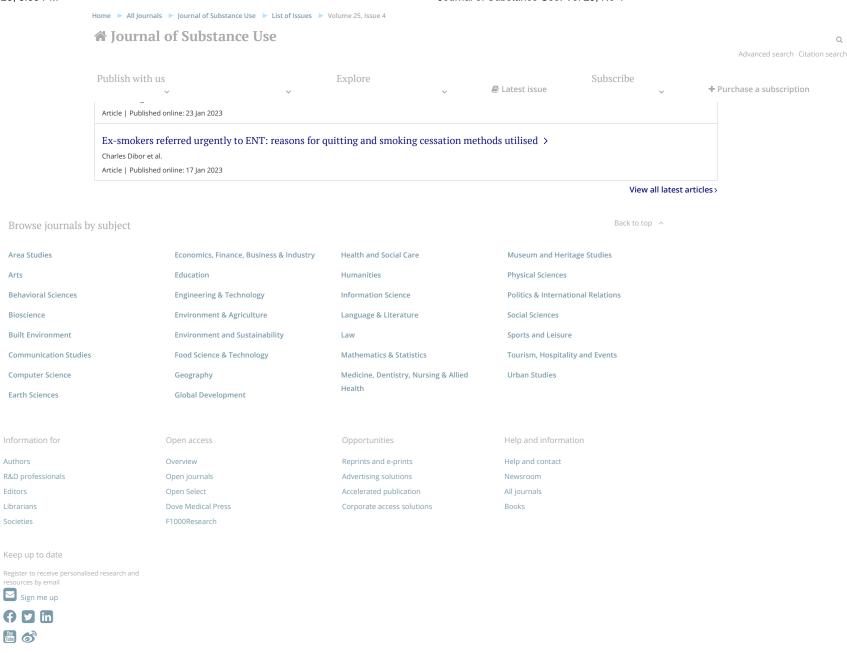
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Luh Putu Lila Wulandari, I Made Adimantara, Ni Made Sri Nopiyani & Ni Wayan Septarini

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Understanding why people who inject drugs in Indonesia are disengaged from HIV testing and treatment: gaps in the HIV treatment cascade

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ABSTRACT

Background: Being ranked second among countries with the highest estimated number of people living with HIV in South East Asia, 28.8% of PWIDs in the country are HIV-infected. Despite the UNAIDS 90-90-90 target, gaps exist across the HIV treatment cascade, including testing of those likely to be HIV positive, linking those tested HIV positive to care, and sustaining the antiretroviral (ARV) drugs uptake. Objective: This study aims to evaluate why such gaps exist, by exploring the barriers and challenges present at each stage of the cascade.

Methods: A qualitative study was conducted in Bali, in 2016. Interviews were performed among PWIDs who experienced challenges at any stage of the cascade. The interview covered various questions including on HIV, HIV testing, and treatment adherence. Data was analyzed thematically.

Results: Participants said they sought testing only when they were concerned about their health; were afraid of testing positive to HIV due to the stigma around HIV; and that starting ARV treatment early was not necessary because they still felt healthy. Participants also expressed the need for support from health providers, peers, and family to stay on ARV, particularly in the face of treatment fatigue; and issues around the quality of care to maintain retention.

Conclusions: Challenges hamper each stage of the HIV treatment cascade. Implications and recommendations are discussed.

ARTICLE HISTORY

Received 15 July 2019 Revised 2 November 2019 Accepted 27 January 2020

KEYWORDS

People who inject drugs; HIV testing; ARV treatment; HIV treatment cascade; challenges; Indonesia

Background

Globally, people who inject drugs (PWIDs) accounted for 12% of new HIV infections among people aged 15–49 years in 2018 (UNAIDS, 2019). In Indonesia, being ranked second of the five countries with the highest burden of the estimated number of people living with HIV (PLWH) in the South East Asia region (World Health Organization Regional Office for South-East Asia, 2016), 52% of the HIV cases reported to the Indonesian Ministry of Health from January to March 2019 alone were among PWIDs (Indonesian Ministry of Health, 2019a). A national population survey in the country in 2015 reported a similarly concerning picture, noting an HIV prevalence at 28.8 percent among this group (Indonesian Ministry of Health, 2016).

UNAIDS set a target of 90-90-90 by 2020, under which 90 percent of people who are HIV positive are diagnosed, 90 per cent of those diagnosed receive ARV, and 90 per cent of those who take HIV treatment achieve virus suppression (UNAIDS, 2014). Various programs have been established, particularly for PWIDs in Indonesia, which support this goal. These include a collaboration between civil societies and health services aiming to expand access to HIV prevention, testing and antiretroviral (ARV) treatment under the name Layanan Komprehensif Berkesinambungan (LKB) (Indonesian Ministry of Health, 2012; The Indonesian National AIDS Commission, 2015). This is referred to as

a continuum of comprehensive prevention and care service. The approach was strengthened by the introduction of a Strategic Use of ARV (SUFA) approach intended to accelerate the reach of these strategies to affected populations so as to increase ARV treatment at the time of diagnosis and maintain treatment and care (The Indonesian National AIDS Commission, 2015).

The HIV treatment cascade is used to monitor and evaluate these programs. It assesses progress toward the UNAIDS 90-90-90 goal by identifying the number of individuals who are engaged at each stage of the HIV treatment cascade, from those who are tested, to those who learn of their HIV status, to their linkage to care, the initiation of ARV, and their retention in care until they reach viral load suppression. Stakeholders use the cascade to monitor their success in reaching people at each stage of this continuum of care. The number of people engaged at each stage of the cascade gives workers the data they need to identify which parts of the cascade need greater attention; stakeholders can identify missed opportunities in the continuum of care and so be better placed to achieve the target of suppressing viral load in the target population.

Recent reports show huge gaps across the cascade in Indonesia. These include challenges for testing those who are likely to be HIV positive, linking people who test positive to care and treatment services, and sustaining ART for viral

load suppression (Akolo, 2018; Januraga et al., 2018), and there were great variations in care across provinces (Indonesian Ministry of Health, 2014).

Studies in Indonesia and other countries in Asia have noted factors that might hinder or facilitate HIV testing, ARV treatment initiation, or adherence to treatment among PWIDs. The barriers include not knowing where to go for a test (Sagung Sawitri, Sumantera, Wirawan, Ford, & Lehman, 2006), difficulties in accessing the clinic due to distance and inconvenience opening hours (Go et al., 2019), financial obstacles (Go et al., 2019; Sagung Sawitri et al., 2006), the cost of ARV treatment (Sharma et al., 2007), clients' monthly income (Sharma et al., 2007), insufficient information with regards to HIV testing and or ARV treatment (Go et al., 2019; Lancaster et al., 2019), insufficient counseling (Sharma et al., 2007), stigma (Go et al., 2019), fear of positive results (Sagung Sawitri et al., 2006), fear or experience of the side effect of ARV treatment (Go et al., 2019; Sharma et al., 2007), and the perception of feeling healthy (Go et al., 2019). On the other hand, the facilitators include the presence of social support (Go et al., 2019; Lancaster et al., 2019), the availability of more accessible services (Go et al., 2019), and integration with other services such as methadone maintenance therapy (Tran et al., 2016).

While each of the above previous studies has looked at the barriers and facilitators of HIV testing, or treatment initiation, or adherence to treatment, limited attention has been put toward looking comprehensively at all components of the HIV treatment cascade in their studies in one population of interest. Using the HIV treatment cascade as a framework, this study begins to fill this gap to explore the challenges and issues that PWIDs in this setting face at each of its steps of the HIV treatment cascade.

Materials and methods

A qualitative study was conducted among six PWIDs in Bali from early to mid-2016. A phenomenological approach was used to explore participant 's real experiences on how they make sense of the HIV testing, HIV treatment initiation, and ARV treatment adherence (Pistrang & Barker, 2012). Semistructured interviews were conducted with PWIDs who had encountered challenges at different stages of the cascade. Participants were recruited using a purposive sampling method to ensure they had experiences relevant to the study questions (Devers & Frankel, 2000). Those recruited had encountered delays in diagnosis and treatment, interruptions or the cessation of ARV treatment, and their viral load had not been suppressed as a result of treatment.

Outreach workers from the Yayasan Kesehatan Bali (Yakeba) approached potential participants by phone and told them of the study. The outreach workers would explain the study to the participants and described the voluntary nature of participation. If the participants agreed to participate, they were introduced to the researcher (NWS), who conducted the interviews. The outreach workers then arranged a meeting for the participants to meet with the researcher at a time and place convenient for the participants. Most of the interviews took place at public spaces

with an area where the interview could take place in private. Incentives were given in exchange for the time they gave to be interviewed.

Each interview took 45-60 minutes on average. An interview guide, containing questions about HIV, HIV testing, treatment and adherence, HIV services in general, and the challenges that interviewees encountered in following up the treatment cascade, was used.

Interviews were recorded and transcribed. Thematic analysis was undertaken to analyze the data (Braun & Clarke, 2012). To improve the validity of the qualitative data, the researcher checked to ensure that what the participants had said was understood (Mays & Pope, 1995, 2000). Peer debriefing among researchers was also conducted (Mays & Pope, 1995, 2000). Reflexivity was valorized throughout the study process (Mays & Pope, 1995, 2000). LPLW, NMSN, and NWS who were involved in the data analysis, are medical doctors and are trained in qualitative research. IMA is an activist who has been involved in supporting PWIDs in Bali. The researchers were aware that the experiences and backgrounds of the researchers would influence how the data was collected and analyzed, but the strategies mentioned above were conducted to improve the data quality.

Translation of the whole interview transcripts was not conducted as all of the researchers are Indonesian native speakers. The translation was conducted only for particular sections of the transcripts which were selected to represent particular themes. The three of the research team members then read the translation made individually, and the discrepancy was solved by discussion. To limit any potential ethical issues, a pseudonym was applied in the transcription, analysis, and writing up of the manuscript.

The development of this report was guided by the COREQ qualitative reporting guidelines (Tong, Sainsbury, & Craig, 2007). Ethics approval was gained from Udayana University/Sanglah General Hospital Ethics Committee on December 28, 2015.

Results

The participants' ages ranged from 26 to 43 years, and their education levels covered the range from elementary to senior high school. The lengths of their engagement in drug use were from seven to 22 years. Themes emerged around each step of the HIV treatment cascade, as described below.

Themes around accessing VCT services and being tested for HIV

What if it turns out to be positive?

Stigma around HIV affected people's decisions not to be tested, since they feared the social ramifications of a positive result, and becomes one of the barriers to HIV test. Participants of this study mentioned about their feelings of ashamed and fear if they tested positive.

"It is between the feeling of ashamed and fear. Fear if the test result turned out to be positive." - Ona, 36 years old.



"I was afraid. I felt that I was not ready [to take an HIV test]. What if it was positive? But I had to take the test. I was so confused" - Lema, 43 years old

"I hope I will go for a test soon. .ehmm but I am afraid to see the results though ... " - Lev, 26 years old

Health issues prompt HIV testing

On the other hand, the participant in the current study said that a critical health condition led him to accept the offer of and facilitate HIV testing. They were not aware of their HIV status until they became very sick.

"I kept getting diarrhea. It only stopped for one to two days, but then it happened again. I lost weight and I was getting thinner day by day. My friend told me to have HIV testing. I finally got tested and the result was positive." - Naa, 43 years old

"Everything dropped. Everything seemed so severe. Got very skinny. I thought I already died ... [that is when I got tested]." - Lema, 43 years old

A need for services within their reach

Participant mentioned that sometimes an HIV test had to be sought from distant facilities. One of the participants expressed that Voluntary Counseling and Testing (VCT), that is more proximate and more convenient to access, needs to be developed to facilitate testing.

"So that friends who live far can reach the service ... I live in Yang Batu area and I think I better go to that community health centre, which is closer." - Ona, 36 years old

Themes around starting ARV and treatment retention

Some barriers that emerged in relation to starting and retention to ARV treatment included the feeling healthy or strong, treatment fatigue, intention to have a child, lack of monitoring from health service providers, and family members' lack of knowledge on ARV treatment.

I feel I am still strong enough

Some participants perceived themselves as not needing treatment due to the absence of symptoms or signs. One participant said they did not need ARV because they still felt healthy:

"I feel I am still strong enough now. Once I am not strong anymore ... Well I do not want to think about it right now ... I just wanna think what is important today. What happens tomorrow, let's just think about it tomorrow." - Ynn, 41 years old

Treatment fatique

The boredom expression with regards to taking ARV was expressed, particularly due to it being a lifelong requirement. Participants mentioned that they had several friends who ceased treatment because they were tired of taking medicine.

"Just tired ... they said they just tired." - Naa, 43 years old

"They said that they were tired of taking the tablets (ARVs). They complained about not feeling any changes. They were just tired and bored." - Ynn, 41 years old

Intention to have a child

Intention to have a child is also one factor identified as a reason to stop ARV.

"I decided to stop the medicine [efavirenz] because I want to have a child. I discussed it with the doctor and she told me and my wife to get checked. There was no problem with my wife but my sperm was of poor quality. At that time, the doctor said that the medicine [efavirenz] affected the sperm. And to improve the sperm quality, the medicine should be stopped or substituted. Since the doctor did not provide me with any clear decision, I, by myself, decided to stop the medicine. My wife got pregnant after three months of me stopping efavirenz." - Ona, 36 years old

With insufficient information and supports from the healthcare providers regarding the intention to have children, this led to participant's decision to stop ARV. This situation was then exacerbated by the provider's lack of monitoring mechanism of loss to follow up.

Lack of a monitoring mechanism to prevent loss to follow-up

The participant expressed that there had been insufficient monitoring by the health service to prevent their loss to follow-up:

"I dropped for efavirenz for three months. After my wife was pregnant, I should have continued the medicine. But I didn't do it. I just stopped for more than a year. What I wonder was why the health service didn't follow me up? Could it be because they weren't aware that my treatment was interrupted or what, or they just ignored it." - Ona, 36 years old

Family member's lack of knowledge on ARV treatment

One participant said that family members often have insufficient knowledge about HIV and ARV treatment; and limited information was provided to them by the health staff.

"My wife was only being told to remind me to take the tablets. That was it. Not being explained about the medicine, the side effects, no explanation at all [to my wife]." - Ona, 36 years old

Despite this situation, participants expressed the need of supports from family members and peers for starting and continuing on treatment.

Supports from peers and family members

A participant expressed the presence of support from peers to encourage them to start and stay on treatment.

"Because of the supports I got from my friends ... My friend E referred me here (to CST service). I felt like the tablets (taking ARV) were too much for me, but he told me not to give up." - Kej, 39 years old

Participants also expressed a need for support from their family members in order to improve adherence to lifelong ARV and avoid treatment fatigue.

"My friends helped me. Back then I didn't have my motorbike, so they took me everywhere I need to go ... went for a test ... got to the centre to get the medicine. My mother also supported me; she reminded me to take the tablets." - Naa, 43 years old

"It's basically the support from family [that they need]. At least there is someone who cares about them when they have to take the medicine." - Ona, 36 years old



"I have told my wife about it [HIV status]. My wife always reminds me to take care of myself, to take the tablets [ARVs], and told me not to be too tired" - Kej, 39 years old

Discussion

Despite the UNAIDS 90-90-90 goal, recent reports reveal poor HIV testing rates and adherence to HIV care among PWIDs in Indonesia (Akolo, 2018; Januraga et al., 2018). Understanding why HIV-infected PWIDs are disengaged from HIV testing and treatment is important in order to patch the leaks in the HIV treatment cascade. This is among the first qualitative study undertaken in Indonesia to explore the gaps in each step of the HIV treatment cascade from the point of view of the target PWIDs population. Using a qualitative method, the barriers and challenges present at each stage of the cascade - from seeking a test, to starting ARV, and staying on treatment – have been explored. Several themes emerged from each stage of the cascade.

Participants said they had accepted an offer of HIV testing only because of a critical health condition. A similar finding was yielded in a study in China, reporting a link between perceived health issues and HIV testing (Dai et al., 2015). This dynamic has also been explained by a theory of Health Belief Model that suggests a threat to health and the perceived benefits of healthcare contribute to a person's decision to seek HIV (Damgaard, 1995). This circumstance may impede efforts to increase HIV testing among those who are at risk of HIV transmission but have not yet developed any symptoms and feel healthy, and so thwart the targeted achievement of testing 90 percent of those who are infected. It is therefore vital to disseminate knowledge about HIV infection and the importance of early treatment among this PWIDs group, which was particularly found to be more likely to be late presenters into HIV care compared with other key groups (Jeong et al., 2015). Community education services that spread knowledge and awareness, particularly among those at risk or more likely to be HIV positive, are therefore paramount to patch the leak in the HIV treatment cascade.

The development of care services that are convenient in terms of cost, time, and location is worth considering if we are to encourage people to be tested and maintain treatment (Indravudh et al., 2017; Liu et al., 2016). It is interesting to note that the Indonesian government has made a huge commitment to increase the rate of HIV testing facilities. There are at least 6924 VCT facilities and 1063 ARV treatment and care facilities across Indonesia as of June 2019 (Indonesian Ministry of Health, 2019b), yet testing rates among this group are still low. Participants in this study expressed concerns about the social impact of an HIV diagnosis, which may be partly due to stigma related to HIV. The impact of stigma and HIV interventions in this setting has long been acknowledged (Sagung Sawitri et al., 2006; Wulandari, Lubis, Rowe, & Wirawan, 2011). Other studies confirm this finding, suggesting the potent influence of stigma on HIV testing (Smolak & El-Bassel, 2013; Wulandari, Ruddick, Guy, & Kaldor, 2019).

Given the effect of this stigma, it is important to recognize convenience and privacy as critical aspects of HIV testing (Indravudh et al., 2017; Wolff et al., 2005), and that these should be kept in mind when choosing test modalities so as to improve testing rates. Studies in the current setting have shown the potential of HIV self-testing to address the low testing rates among men who purchase sex (Wulandari, Kaldor, & Guy, 2018). HIV self-testing procedure benefits users in that they can access testing onsite in a place, often in a private setting, and at a time convenient to them (Krause, Subklew-Sehume, Kenyon, & Colebunders, 2013; Stevens, Vrana, Dlin, & Korte, 2017). Its potential use and acceptability should therefore be trialed among PWIDs in this setting.

The above themes, which acknowledge the challenges PWIDs face at the testing stage, were compounded by challenges they encountered at the next stage of the cascade: linkage to care. While WHO guidelines recommend an accelerated ARV initiation following diagnosis (World Health Organisation, 2016), this study found that challenges exist, particularly among those who felt that they still feel healthy. This finding is similar to that from previous studies in Indonesia and Vietnam (Go et al., 2019), and Ethiopia (Assefa, Van Damme, Mariam, & Kloos, 2010) which identified feeling healthy as a reason for poor linkage to care. Unless people prioritize seeking care, it might not be likely that people will attend the necessary treatment (Iwuji & Newell, 2017). This theme demonstrates the importance of providing comprehensive information about ARV treatment to those who have not developed any symptoms and feel healthy, and the effectiveness of early treatment in preventing disease progression and transmission, so that people will make it a priority.

Improved access to and effectiveness of ARV treatment over the last few years have reduced the number of vertical HIV transmission from infected mothers to their children (UNAIDS, 2016); and have improved the survival of PLWH (The Insight Start Study Group, 2015). Due to an increased chance of long and healthy life among PLWH on treatment, many of them wish to have children. In order to respect and support the fulfillment of PLWH's reproductive rights, providers should be able to provide fertility planning services which address PLWH's needs. Moreover, close monitoring and supports should also be provided to PLWH who are trying to conceive to ensure their adherence to ARV.

Participants expressed encountering issues with the health services' attempts to monitor clients' retention in care. This issue might arise from the fact that health services deal with many competing priorities and have limited resources to deal with them. Challenges exist within the SUFA program in this local setting, for example, in terms of the quantity and quality of human resources, particularly in Bali (Nopiyani, Wulandari, & Utomo, 2015). Human resources adequate to ensure people stay with their treatment is therefore needed (Nachega et al., 2014), as is a mechanism to follow up those who stop ARV treatment. If we are to improve the cascade of treatment, it is paramount that we strengthen human resources to provide services at each stage of the cascade.

Treatment fatigue is common among those who have been on ARV (Claborn, Meier, Miller, & Leffingwell, 2015), and it has been acknowledged among PWIDs in this setting (Mcnally, Mantara, Wulandari, & Lubis, 2013). The expression of this matter links suitably with the previous subtheme,



reinforcing the need for sufficient human resources to offer support during treatment. To overcome barriers of starting ARV and treatment fatigue, participants expressed the value of peer and family support. This is particularly noteworthy in light of a study made in this and other settings that also revealed the importance of peer support in accepting therapy. This theme is also in line with a study conducted in Uganda that also pointed to the significance of family supports during the treatment (Lubogo, Ddamulira, Tweheyo, & Wamani, 2015).

There is value in health providers offering ARV information not only to their clients but also to their clients' family members or important others. Better knowledge of HIV treatment among immediate family members can form the basis of support for the family member being treated. Immediate family members would then be better placed to support treatment and the retention of care.

The results of this study have several implications. First, strategies are needed to encourage more people to undergo HIV testing, particularly those without symptoms. Community education is important to ensure that those at risk realize the need to know their status, even if they do not develop symptoms. Second, due to the stigma surrounding HIV in this setting, PWIDs need testing strategies that offer more confidentiality and privacy and therefore allay their fears of social consequences. HIV self-testing has been formally recommended by the WHO as a means of testing more people in the community, particularly targeting those who are reluctant to seek an HIV test at the clinic (World Health Organisation, 2015). Studies around the world have noted the high acceptability of this testing strategy among PWIDs (Green, 2016; Witzel et al., 2018), including men who purchase sex in this setting (Wulandari et al., 2018). Future studies should therefore identify the applicability and acceptability of this strategy among PWIDs in this context. Third, due to the influence of HIV related stigma on a client's decision to be tested and seek care, strategies are needed in this setting that mitigate stigma. Fourth, peers and partners can play an important role in providing support for the commencement of therapy, retention in care, and mitigating treatment fatigue. Families should be informed about the disease and the need to collaborate with health workers to maintain treatment. Studies have noted that the involvement of family and peers in HIV treatment yields positive benefits to treatment adherence (Joanna, Ethel, Tsitsi, Hilda, & Ferrand, 2014; Roura et al., 2009). Future studies should look at how best to educate and involve family members and peers in encouraging clients to seek testing and stay on treatment in this setting. Last but not least, a strong health system and sufficient resources are among the essential ingredients for the success of universal testing and treatment (Iwuji & Newell, 2017). Therefore, efforts to strengthen both should be an integral part of strategies to reach the UNAIDS 90-90-90 goal.

As with other qualitative studies, the generalizability of findings from the current study is limited. Several efforts were, however, made to improve the quality of the data, including the purposeful selection of participants who have experience relevant to the aim of the study, and efforts to improve the validity of the data (member checking, peer debriefing, and reflexivity). The small number of participants

involved in this study is also a concern. Despite the length of the data collection period, only six men agreed to be interviewed. While no new information was obtained from the last participant, indicating that further collection of data are unnecessary (Saunders et al., 2018), pragmatic consideration was taken to not continuing data collection process due to time constraints and difficulties in accessing the population (Vasileiou, Barnett, Thorpe, & Young, 2018). PWIDs in Indonesia are the subject of stigma, and this stigma is exacerbated when the person becomes infected with HIV, presenting a challenge to this study's recruitment process. However, the findings found in the current study are consistent with those in the previous studies in Indonesia and other countries, suggesting that the results of the current study have provided valuable additional evidence to support the evidence on gaps in the HIV treatment cascade among PWIDs. The strength of this qualitative study is that this study aimed to provide a current picture of the experiences of individuals targeted for HIV treatment cascade calculation. Their views will shed light on how gaps in the HIV treatment cascade could be addressed.

Conclusions and recommendations

It is evident that enormous challenges hamper each stage of the HIV treatment cascade. Continuous and stronger collaboration among all stakeholders – individuals, peers, family members, community-based organizations (CBOs) and government institutions – to support and improve the program is needed to address these challenges. Implications for costs and resource allocation to address the challenges are worth considering in future studies.

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