A Persistent Epidemic of Exclusion

July 21 is #ZeroHIVStigmaDay. A collective of international agencies created the day to commemorate Prudence Mabele (1971-2017). She was the first South African woman to advocate by speaking out about her HIV-AIDS diagnosis. HIV-AIDS is stigmatized and people who are coping with the disease are marginalized. In addition to the stigma, many are also coping with co-morbidities and unstable daily living circumstances. People who perceive a high level of stigma are 2.4 times more likely to delay care until they are very ill. With developments in modern antiretroviral therapy (ART), if those who are HIV positive take medication, as prescribed, and viral loads are undetectable for six months or more, they will not transmit the disease to their partners. (<https://www.iapac.org/2022/07/21/zerohivstigmaday/>) However, efforts to end the epidemic have not succeeded in reaching targeted goals.

Worldwide 37.9 million people are living with HIV. There has been a significant decrease in mortality and a small decrease in incidence due to scale up of HIV treatments. In the U.S., HIV impacts men having sex with men and Black /African American communities disproportionately. At a higher rate than the general population, persons living with HIV (PLWH) experience mood disorders, anxiety, drug use, unhealthy alcohol use, and poorer quality of life. It is estimated that 63% of PLWH have a co-occurring mental health condition, compared to 31% of those without HIV. These conditions lead to lower engagement in HIV care and treatment, poorer health outcomes, including low viral load suppression and mortality (O’Grady et al., p 202). Based on a 2024 systematic review, there is an association between social determinants of health and depression in PLWH. Those with lower income levels, transactional sex, housing instability, long-term survivor status, low social support, poor educational attainment and food insecurity also had comorbidities of substance use, violence and other traumatic experiences. Substance use co-occurs with mental illness, which contributes to decreased viral suppression, increased hospitalization, and decreased quality of life. Trauma informed interventions were shown to be effective in improving ART adherence and health outcomes for adverse childhood experiences. (O’Grady et. al, p. 222)

Zimbabwean occupational therapists performed a scoping review of how occupational justice and social inclusion were related to the highly stigmatized chronic conditions of HIV and mental illness. Studies had only been conducted in high-income countries focused on mental illness. Using a social justice framework, treating people with HIV and those with mental illness in a more respectful and equitable manner needs emphasis. They contend that research and practice be directed towards “a moral imperative of addressing exclusions and injustices experienced by people living with HIV, those with mental illness and other stigmatized groups” (Nhunzvi et al, p.150). To promote equitable access for marginalized groups to opportunities for community participation with fairness, interventions will include a continuum of care and health and well being beyond viral suppression in HIV.

Kielhofner et al. conducted a study in Chicago in 2008 at four PLWH supportive living facilities. Supportive housing addresses the needs of PLWH, who are more likely to have comorbid mental illness, substance abuse problems, and are socioeconomically disadvantaged. Researchers used the Enabling Self Determination (ESD) model program to enable the participants to achieve productive participation, which included working, attending school or training programs, or volunteering. During 8 week group sessions, participants examined their own volition, lifestyle and skills, reflected on occupational narratives they were living or wished to achieve, and began to identify personal goals to enhance productivity. The process also used peer mentors who had successfully made the transition to employment or living on their own. The control groups received standard care of educational groups, referrals to community resources and received written materials. The effectiveness of the intervention was demonstrated using data collected at 3, 6 and 9 months. More than 72% of the clients who participated in the ESD program had productive outcomes.

To address the racial disparities in HIV care outcomes, researchers at Vanderbilt partnered with Street Works in Nashville on a community project to enlist Black barbers from central Tennessee. Tennessee has the lowest linkage to HIV care rates in the country, with only 64% of newly infected patients establishing care. This is below the national targets for viral suppression. Young black men comprise the majority of new HIV infections in Tennessee, but remain hidden from care. Because black barbers and barbershops are regarded as confidants in trusted environments, they have been successfully used to disseminate health education and treatment interventions for a variety of chronic health conditions. The recruited barbers attended a half-day, live, virtual workshop about basic HIV education, an assessment of HIV related knowledge and stigma among barbers, with a facilitated discussion about the potential roles of barbers and barbershops to improve the HIV outcomes for Black men. The focus groups identified cost and concern about poor treatment and /or negative interactions experienced within the health care system as an obstacle to access. They identified deeply rooted HIV stigma,. entrenched beliefs, concern about ability to cope with unwanted illness, and depression as obstacles to seeking care. Ways to address stigma and barriers were training barbers, providing conversation-promoting HIV related materials, and helping people to navigate key steps to establish care. The barbers suggested a need to positively reframe the HIV care message.

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