

# Editorial:

## Working with HIV today

In 2020, approximately 37.7 million people were living with HIV, 1.5 million of which were new infections, 680,000 died of HIV-related illnesses and 28.2 million were accessing anti-retroviral therapy in 2021 (UNAIDS). The largest number of people living with HIV are hosted in sub-Saharan Africa.

Significantly, between 1997 and 2005 there was a major decline in HIV global infection rates due to the introduction of highly active anti-retroviral therapies (HAART), generic and affordable drugs for developing countries, and effective and simpler HIV drugs. While there have been reductions in global infections, and a decline in HIV/AIDS-related deaths since the mid-2000s, new infections continue to emerge.

Highly effective anti-retroviral treatments have contributed to a significant shift in the discourse around HIV and how it was previously considered a 'death sentence'. HIV is now a long-term treatable and manageable illness. We continue to see improvements in the health of people living with HIV, and prevention of disease progression. Those with good adherence and disease management can effectively achieve undetectable viral loads and achievements in the elimination of horizontal and vertical transmission (Cohen et al., 2011).

Studies have also proven that treatment as prevention (TAP), and pre-exposure prophylaxis (PrEP) effectively result in prevention in transmission. Hence, the messaging around HIV currently focuses on the slogan "undetectable equals untransmittable" or "U=U" (Eisinger, Dieffenbach, Fauci, 2019).

With the outstanding progress around treatment and prevention, the Joint United Nations Programme on HIV/AIDS (UNAIDS) set an ambitious global target to end the HIV pandemic by 2030 through the 90-90-90 initiative calling for a global commitment to ensure 90% of people living with HIV are diagnosed, 90% of those are on antiretroviral treatment and 90% of those are demonstrating treatment successes

by achieving undetectable viral loads. They proposed several ways to achieve these targets through initiatives such as expansion of HIV treatment and prevention programmes, uninterrupted access to lifelong treatment, promotion of human rights, ensuring flexible health and community systems and self-replenishing financing mechanisms that can effectively support treatment programmes across the lifespan and more international funding for low-medium income countries.

Due to country-to-country economic challenges, lack of access to medication, resources, health infrastructures, social and legal impediments, social and sexual determinants of infection, inequity in access to effective prevention, treatment and support programmes, and the impact of coronavirus, not all countries have reached their initial 2020 targets (De Lay et al., 2021). Lack of political commitment, insufficient investment in prevention programmes, structural barriers and a failure to scale up evidence-based programmes in certain countries are additional barriers to ending the pandemic (Assefa and Gilqks 2020).

Concerns also remain that HIV-related stigma and discrimination persist not just in communities but also health and social care services, consequently affecting access to treatment, care and adherence. Moreover, lack of up-to-date professional knowledge about HIV and how it is acquired also contribute to systemic stigma and discrimination (Cane, 2017/18; Hedge et al., 2021). According to De Lay et al. (2021), the challenges around managing HIV today underscore the extent of work that still needs to be done not just to eradicate HIV, but to improve access to treatment and other services. They emphasise the need for social and societal enabler programmes, strengthening health systems, normalising integrated health and social care systems, and promoting behaviour and lifestyle changes as well as provision of non-judgmental and non-discriminatory services.

Social work can contribute meaningfully to the lives of people living with HIV through involvement in HIV prevention, treatment, care and support programmes, using a range of individual, family, group, community and systemic interventions and service delivery through biopsychosocial and holistic approaches, psychosocial education, as well as influencing policy and research. This special issue sought to understand how social work education and practice contribute to HIV prevention, care, intervention and service provision. The title 'HIV today' was envisioned to acknowledge the progress made around prevention,

treatment and care and to emphasise how conversations around HIV are very different today than before. Articles and arguments presented in this issue indeed also highlight progress in relation to social work with people living with HIV today. Ongoing challenges around stigma and discrimination from a global perspective are highlighted, and recommendations around prevention and support strategies are made from particular contextual standpoints. A key message is that there is an important and ongoing role for social work and social work education, and a need to draw on a range of theoretical perspectives and approaches to ensure good and critical social work practice globally.

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It has been a pleasure editing this special issue, presenting a collection of articles that cover a range of perspectives on HIV from the Global South.

The papers presented will cover a wide terrain, touching on different issues affecting people living with HIV in a range of social contexts, the role of social work and social work education.

We want to celebrate the diversity in culture and language used by researchers when they put together their research and articles. Some primary studies were conducted using native/local languages and translated to English. In terms of differences in culture and language, terminology may differ depending on each country's context.

Although this issue was a global call, there have been no contributions providing insight from social work in Western countries. This does not mean no work is happening around HIV in those countries; indeed, the editor of this issue is involved in HIV research within the UK. At the time of writing, she was involved in a project focusing on the impact of COVID on people living with HIV and post-traumatic growth. Her work identified social and psychological needs linked to loneliness and social isolation, and how these were exacerbated by the pandemic. She established that the shift from face-to-face support to remote and virtual interventions led to some people living with HIV withdrawing from services, struggling to seek support from family or friends, maintaining secrecy around disclosure (unsure whether to disclose or not), and having difficulties navigating the stigma around HIV at a time when family support is much needed, thereby feeling internally isolated around family who are unaware of their HIV status. Elsewhere in the West, we know work is being done around HIV-related reproductive health, parenting, child adoption as well as ageing with HIV. These

are all issues that call for social work education, social care and work interventions in both children's and gerontological social work practice.

Drawing from a South African perspective, the first paper presented in this issue is a study by Mange, Henderson and Lukelo, exploring experiences of older black gay men accessing hospital-based HIV treatment, utilising support systems including family and community support. The authors bring our attention to the level of double stigma and discrimination linked to an HIV-positive serostatus and sexual orientation (gay men). Participants endured prejudice and derogatory comments from frontline healthcare professionals who denied them equal treatment, access to services or respect. Lack of adequate support from family and community contributed to increased vulnerability to social isolation, fear of accessing services, and depression. The authors identify cultural expectations around child bearing and lineage in the IsiXhosa culture. Complicating the experiences of older gay men in rural Cape Metropole, Western Cape, South Africa, are societal expectations for them to have children. This consequently exacerbates the level of stigma and discrimination experienced by HIV-positive gay men compared to those in urban areas. The authors suggest that lack of education and awareness in rural areas contribute to HIV and homosexuality which are inadequately understood in rural communities. The authors indicated that, notwithstanding Simon Nkoli, an activist and HIV+ gay man considered a hero of gay liberation in South Africa, negative social attitudes around HIV-positive homosexuals persist along with disregard for human rights. The authors identified a lack of adequate training around gender and sexuality and up-to-date knowledge around HIV among healthcare professionals as a risk to ongoing discrimination against older gay men. The authors contend that social workers in South Africa should have an active role in educating communities, contributing to care planning, providing counselling support to people living with HIV, ensuring deeper engagement with Ubuntu community projects intended to promote human rights, and addressing marginalisation intersected between HIV, gender, sexuality, class and location.

The second paper considers the needs of HIV-positive teenage mothers also within a South-African socio-cultural context. Slabbert, Cornelissen-Nordien and Singwayo start by presenting the prevalence of HIV teenage pregnancies in South Africa. They argue that there has been a substantial increase in HIV-positive teenage mothers in South Africa whose needs are not always met by social care services. Their qualitative

research focused on understanding the unmet needs of unmarried teenage mothers receiving social work support from social service providers in rural Polokwane, Limpopo, South Africa. Authors identified poverty and lack of resources, information and education around HIV, contraception and reproductive health as factors contributing to this population becoming vulnerable to sexual exploitation. Teenage pregnancy leads to school exclusion and, consequently, lack of education, unemployment, and a continued cycle of risky sexual behaviours, seeking blesser-blessee transactional sexual relationships with older men, social immobility, living in unsafe communities, having further pregnancies and lone parenting. The findings in this paper suggest that teenage mothers in these circumstances present with unmet psychological needs, insecurity, lack of stability, feeling unsafe, and low esteem. The authors contend that child support grants intended to support teenage mothers are inadequate. They argue that the absence of sufficient social security and financial support leaves teenage mothers susceptible to unmet welfare needs, gender-based violence and neglect. They subsequently lack a sense of belonging, feel unloved and are prone to post-natal depression. To better address unmet needs presented by teenage mothers, the authors recommend provision of psycho-education, social support, coordinating services between community provision, social welfare and social security, strategies to reintegration/re-engage teenage mothers into education, career choices and employability guidance. They propose provision of direct work focused on equipping teenage mothers with life skills, safer sexual practices, better decision-making around family planning and better collaborative work with the police and community leaders to improve the safety of vulnerable teenage mothers, and their children.

On the subject of depression and wellbeing, our third paper, presented by Kalomo, Jun and Lee, explores the relationship between loneliness, depression and life satisfaction among older caregivers of children living with HIV in Northern Omusati, Namibia. The authors report that the high prevalence of HIV among people of reproductive age in this region contributes to over 200,000 children under 18 being orphaned by HIV/AIDS and/or living with HIV. They argue that the lack of comprehensive support for people living with HIV or provision of adequate home-based support for carers of children orphaned by HIV contributes to poverty, and financial instability among older carers of children orphaned by HIV. They emphasise that although the government provides subsidised

healthcare facilities, these are often inaccessible, resulting in an overburden on caring duties, and stress. Lack of adequate resources for this population, and the children they care for, as well as HIV-related stigma have reportedly led to poor mental health among adult caregivers. This paper utilises the ecological framework and the life satisfaction scale to help understand how complex systems interplay with loneliness, and depression. Their findings suggest that 50.5% of adult caregivers are slightly or extremely dissatisfied with their lives, 47% experience depression ranging from between mild to moderate to severe, and most are moderately lonely. Arguing that higher levels of loneliness lead to lower life satisfaction, the authors call for social care and health providers to pay more attention to the needs of caregivers and the negative impact of loneliness on their psychological wellbeing. While authors cautioned against their sample size and geographical limitations, they provide a useful reminder about the Namibian cultural context around the role of family members taking over caring roles, and how HIV-related stigma plays a significant part in caregivers' lives and their mental wellbeing, whether or not they have taken over a new caring responsibility or grown older while caring for a child orphaned or living with HIV, and the burden of maintaining secrecy during the course of their guardianship. The authors alert social workers to the accumulated stress for caregivers already burdened by their own health problems and how this leads to loneliness and other mental health conditions. They recommend improved provision for community social support systems aimed at addressing isolation and mental wellbeing for adult caregivers; better resourcing for mental health services, gerontological social work, education around mental health and care giving, accessible and affordable health services in rural areas, and improved mental health intervention strategies including bereavement and counselling support.

The fourth paper by Chereni, Nyathi and Mbizo draws our attention to male partner involvement in health interventions practices in Sub-Saharan Africa. They argue that the absence of male partner involvement i.e. support, participation, engagement with services offered to women results in low utilisation of maternal health, childbirth and post-natal services. The authors draw our attention to cultural factors in the Sub-Saharan region that deter men from supporting women. They suggest that pregnancy and childbirth are culturally preserved for women resulting in the maintenance gender roles that separate from the processes of supporting women during pregnancy, preparing for childbirth, active

involvement in women's maternal health, and inability to adequately prepare for complications that are linked to mother-to-child-transmission. Yet, culturally, male dominance and patriarchy in this region allows men to take key decisions around women's sexual reproductive health choices perpetuating men's powerful and dominant positions over women and in some instances leaving women vulnerable to HIV. The authors suggest flipping dominant cultural perspectives in a positive way by actively enhancing male engagement in maternal health and childcare. Their view is that this approach does not only improve knowledge around reproductive health, but utilisation of sexual health services, to ensure gender transformation that contributes to positive uptake of healthcare, improved quality of life for women, men's skilled attendance at childbirth and preparedness where there are pregnancy complications, better postnatal service utilisation, gender equality, and empowerment for women and girls. They argue that this shift will provide couples with positive lived experiences, psychologically, physically and emotionally. The authors highlight the need to address resistance in shifting gender norms, and complacency in male dominance over women's reproductive health choices and lack of adequate support offered by male partners. To promote partner involvement, the authors recommend strategies that incorporate community mobilisation while focusing on accessing hard-to-reach men, and standardising the involvement of men in clinic-based health interventions including antenatal care, antenatal HIV testing, treatment and counselling, and prevention of mother-to-child transmission initiatives as well as comprehensive education. The authors consider social work intervention crucial during HIV disclosure, in HIV prevention and treatment programmes, including collaborative working with community leaders and on community programmes aimed at protecting women's rights, their safety, social persuasion, and delivering culturally sensitive strategies that transform gender norms that detract from active male partner involvement in a range of maternal health and childbearing interventions.

The fifth paper presented by Dhaor starts by reporting 54,000 new HIV infections in India in the year 2020. The author argued that factors such as migration, sexual orientation, commercial sex, and lack of awareness are among the factors increasing HIV transmission in India. Dhaor also highlights a disparity between those tested, including partner testing, and those accepting anti-retroviral treatments. There is poor follow-up due to people living with HIV losing or withdrawing

contact from HIV services, and experiencing HIV-related stigma. Dhaor designed a practice framework for social workers drawing on professional experience working in non-governmental organisations with people living with HIV and findings from a primary study. The author's mixed-method study evaluated people living with HIV, their understanding of HIV transmission and their experiences of living with HIV, including diagnosis, access to treatment services, stigma, and protective and risky sexual behaviours. Findings reported included fear of testing and disclosure, risky sexual behaviours, internalised stigma and poor adherence. From this, Dhaor presents a practice framework that helps practitioners look at factors that affect people living with HIV at five layers of interventions, including inter-personal, intra-personal, institutional, community, environmental and policy levels. Alongside these levels of intervention, Dhaor's framework suggests that social workers can effectively support people living with HIV in six stages that explore pre-infection vulnerabilities, identification and understanding of key populations affected by HIV, taking HIV tests and managing a positive diagnosis, accessing anti-retroviral therapy, disclosure and living with HIV. While this framework is a helpful tool for social workers, Dhaor asserts that social workers need to be knowledgeable about HIV, culturally sensitive and able to consider individuals uniquely in light of their presented circumstances and experiences.

The sixth paper by Molefi, Gutura and Blokland argues that simultaneous polyamorous relationships involving more than two people have the potential to reduce the risk of HIV transmission. Their grounding argument is that sexual relationships are socially constructed and shaped by culture, social and religious norms. They also posit that individuals' cognitive processes, their personal beliefs, self-efficacy and goal expectations influence the type of relationships they wish to form and how they are managed. Drawing on a small sample of seven participants with varying sexual orientations, the authors conducted qualitative interviews using interpretative analysis to understand how people in polyamorous relationships create meaning in their relationships and how they cope with those partnerships. Findings suggest that those involved in polyamorous relationships were well educated about safe sex practices. Agreements between parties were deemed useful in demonstrating a commitment and responsibility towards each other and preventing HIV transmission. These relationships were not considered careless, but intentional open relationships underpinned by ethical

responsibilities, transparency and trust. It was interesting to note narratives of infidelity and sexually transmitted disease and openness around this in polyamorous partnerships, which critics hesitant to disrupt monogamy could associate these narratives as titillating infidelity and unacceptable, also suggesting that polyamorous relationships are not entirely risk-free. However, the authors established that due to norms around monogamy in South Africa, polyamorous relationships that defy traditional family arrangements, or monolithic lifestyles, are stigmatised. In addition, they experience rejection and discrimination similar to other sexual minority groups. Consequently, those in these relationships require psychosocial support focusing on the range of challenges emerging from mainstream cultural norms, lack of acceptance, and other matters that affect their partnerships. The authors suggest there is a role for social work in addressing stigma, discrimination, social isolation and potential impact on mental health. The authors contend that the negotiated safety approach to safer sex can play a part in starting wider conversations about alternative sexualities such as polyamorous relationships, as negotiated safety does not necessarily increase incidence of HIV where there are consistent partners and long-term maintenance of safe sexual practices – where, on the contrary, HIV risk is increased with unnegotiated safety including numerous casual partners without mutually agreed conditions.

Our final paper focuses on the impact of COVID-19 lockdowns among HIV-positive women in Chennai, India. Using case study examples from participants, Sahayam and Rathnasabapathy demonstrated that women living with HIV have been forced to self-isolate, or quarantine, otherwise lost their jobs and income resulting in financial crisis, emotional and psychological distress. Sahayam and Rathnasabapathy delivered crisis intervention to empower their participants to address the challenges experienced. Using a pre- and post-evaluation method with the depression and anxiety stress scale to understand the impact of their intervention, authors report they were able to assist women to develop adaptive coping skills, and manage social and psychological wellbeing. Authors argued that social work has an important part to play in times of uncertainty caused by pandemics, including addressing financial crisis and educating women about income-generating programmes, empowering women to become entrepreneurs, become financially independent, helping them develop the strength they need to cope emotionally and mentally, and navigating HIV-related stigma and

discrimination.

Our book review is based on Treisman Therapeutic Treasures Collection, Ollie the Octopus-Loss and Grief Activity Book. This review allows us to turn our attention to children and young people and prompts us to remember the needs of children affected by HIV and experiencing loss and grief. It complements the works of Kalomo, June and Lee, who explored the importance of caregivers and carers looking after children orphaned by HIV/AIDS. In addition, this book offers child-friendly direct work activities to help children with their emotions and feelings. Finally, it provides social workers with practical tools that can potentially be adapted to different cultural contexts.

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This special issue has brought together several valuable papers on the role of social work and social work education in addressing some of the social problems associated with HIV. The countries covered in this issue are at different levels in their journey to combatting HIV. These papers collectively highlight the vital role of social work in HIV prevention, testing, treatment, care and support. The authors present insights into the different initiatives, interventions, theoretical debates, and practice frameworks to guide social workers in their work with people living with HIV from pre-diagnosis onwards, their partners, families and carers. In addition, the authors have reflected on the continuation of HIV-related stigma and discrimination in different cultural contexts and the importance of disrupting attitudes, practices and norms that perpetuate stigma, discrimination and oppression towards vulnerable people living and those affected by HIV. There is more work to be done globally with social work continuing to support HIV services, systems, and pathways of care and address barriers to care and support for people living with and those affected by HIV.

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Tam Cane  
Lecturer in Social Work  
School of Education and Social Work  
University of Sussex  
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