An IAS 2023 satellite: Person-centred approaches to address the health needs of people living with HIV and co-infections and co-morbidities

Satellite session summary

Despite advances made by health systems to improve the care of people living with HIV, more people living with HIV report a higher burden of multimorbidity and poorer health-related quality of life than people without HIV. Ensuring the best possible quality of life for those living with and affected by HIV by reducing HIV acquisitions and related morbidity and mortality will only be possible through an integrated response to clients' health needs and preferences. Getting care right for people living with and affected by HIV requires a flexible healthcare system that allows people to decide on their degree of self-management.

This satellite session at IAS 2023, the 12th IAS Conference on HIV Science, highlighted the latest evidence, promising practices and reflections on the operationalization of person-centred care principles for HIV. A recording of the satellite session is now freely available to the public. Organized by IAS – the International AIDS Society – it featured every publication from the *Journal of the International AIDS Society* (JIAS) supplement on this topic, which was launched at IAS 2023. The supplement was guest edited by Georgina Caswell (Global Network of People Living with HIV, South Africa), Rena Janamnuaysook (Institute of HIV Research and Innovation, Thailand) and Jeffrey V. Lazarus (Barcelona Institute for Global Health, Spain).

The satellite session provided a platform for an in-depth exchange on the findings presented in the JIAS supplement between the supplement authors and IAS 2023 delegates. Although there were other sessions at IAS 2023 discussing person-centred care approaches, this satellite contributed a valuable summary of new evidence on person-centred care approaches in the HIV response. It was noted, however, that most research and analysis that was presented focused on person-centred care for people living with HIV and that additional effort is warranted to explore and create evidence on person-centred care for people who are affected by HIV and may benefit from access to HIV prevention services.

Satellite session highlights

Introduction

Marlène Bras (IAS, Switzerland) acknowledged the contributions of the Guest Editors of the supplement and thanked the sponsors for their financial support.

A people-centred health system must be the foundation for person-centred care in the HIV response - Editorial

Rena Janamnuaysook (Institute of HIV Research and Innovation, Thailand) provided context on the background and objectives of the supplement: to spotlight the latest evidence, best practices and community perspectives from around the world related to person-centred care approaches; and to enable research groups to share developments around implementing the components of person-centred care in their unique settings. In the supplement editorial, the Guest Editors reiterated: "PCHS [people-centred health systems] are programmes of care that provide individuals, families and communities with humanistic, holistic and trusted healthcare that must be acceptable and responsive to the needs, rights and preferences of people living with HIV and key populations."

They further commented: "Though it is recognized that each country is unique, and has distinct contexts and health systems in place, it is undisputed that PCHS is the foundation to addressing the challenges that exist in our current era of HIV care and management."[1] As outlined in the editorial, four key themes emerge from this supplement, which add understanding and capacity to future design and implementation of person-centred care (PCC) for people living with and affected by HIV:

(1) Person-centred care requires meaningful and sustained engagement between stakeholders, co-designed approaches and feedback mechanisms.
(2) Person-centred care results in higher retention in care and better HIV outcomes for clients.
(3) Healthcare providers encounter barriers to implementing person-centred care.
(4) Person-centred care must go beyond focusing on acuity and instead champion wellbeing.

"It is time for the HIV field to, once again, raise its banners as a champion towards equity in healthcare and strive for the accelerated and universal shift towards person-centred health systems globally." – JIAS-PCC supplement editorial

A person-centred approach to enhance the long-term health and wellbeing of people living with HIV in Europe – Viewpoint

Jeffrey V. Lazarus (Barcelona Institute for Global Health, Spain) noted that the World Health Organization publication, *Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030*, includes key outcomes beyond the treatment cascade relating to rapid treatment initiation, engagement in differentiated and

[1] Lazarus JV, Janamnuaysook R, Caswell G. A people-centred health system must be the foundation for person-centred care in the HIV response. J Int AIDS Soc. 2023 Jul;26 (Suppl 1):e26125. doi: 10.1002/jia2.26125. PMID: 37408462; PMCID: PMC10323313.

chronic care and achieving good health-related quality of life. This has come about after a sustained advocacy campaign over many years and is welcomed. However, he noted that the strategy falls short of committing to monitoring global progress toward improving health-related quality of life outcomes in people living with HIV and assessing impact and service coverage.

Uptake of a patient-centred dynamic choice model for HIV prevention in rural Kenya and Uganda: SEARCH SAPPHIRE study – Research article

Jane Kabami (Infectious Diseases Research Collaboration, Uganda) presented the interim analysis of the SEARCH SAPPHIRE study demonstrating that a person-centred care model incorporating structured choice in biomedical prevention and care delivery options in diverse settings was responsive to varying personal preferences over time in HIV prevention programmes. This analysis showed that the intervention was successfully delivered in settings that are entry points for HIV prevention and can be adapted as new prevention options, such as long-acting cabotegravir (CAB-LA), become available.

Provider perspectives on patient-centredness: participatory formative research and rapid analysis methods to inform the design and implementation of a facility-based HIV care improvement intervention in Zambia – Research article

Njekwa Mukamba (Centre for Infectious Disease Research, CIDRZ, Zambia) noted that healthcare workers largely endorsed the concepts of person-centred care but felt challenged in the practice of person-centredness by workflows and limited resources. This frustrated healthcare workers and resulted in some defensiveness in discussions around person-centred care. This led to a need for interventions to embrace mentorship that recognized the healthcare workers themselves and built on the existing person-centred care successes that were present in each facility, despite the challenges. Njekwa also noted that interventions should target organizational and structural barriers that inhibit person-centred care practices, including policies and facility dynamics and culture, and that improved person-centred care must include both clients and providers.

Patterns of person-centred communications in public HIV clinics: a latent class analysis using the Roter interaction analysis system – Research article

Njekwa also shared the results of a study that examined communication behaviours during routine HIV monitoring visits in Zambia. The study team observed that the majority of client-provider communication focused only on medical aspects of clients living with HIV with limited focus on psychosocial aspects or use of shared decision making but concluded that person-centred care communication was still possible within the public health HIV setting, as evidenced particularly by nurse-led interactions. However, improvements in client-provider communications are needed as "poor client-provider communication is a critical barrier to long-term retention in care among people living with HIV". To achieve this, the researchers called for systems of positive reinforcement of non-medical communication, training and mentorship of healthcare workers in good communication skills, and additional research to understand changes in client-provider communications over time. To this end, the CIDRZ team has applied human-centred design principles to develop a sustainable person-centred care activity package.

Facilitating person-centred care: integrating an electronic client feedback tool into continuous quality improvement processes to deliver client-responsive HIV services in the Democratic Republic of Congo – Short report

Davina Canagasabey (PATH, United States) showed that the use of an electronic client service quality feedback tool as part of a client-driven service quality monitoring system proved to be feasible and effective at rapidly identifying and deploying solutions leading to improved client perception of service quality. Long wait time, reported stigma, perceived confidentiality and viral load services were highlighted as key service quality issues. This client feedback collection tool and larger service quality monitoring system are promising mechanisms for advancing client responsiveness, and national scale up of the tool is proposed.

Clients in Uganda accessing preferred differentiated antiretroviral therapy models achieve higher viral suppression and are less likely to miss appointments: a cross-sectional analysis – Research article

Esther Nkolo (USAID, Uganda) shared data that illustrated that participants who were accessing their preferred differentiated service delivery (DSD) model had fewer missed appointments, more recent viral load results and had higher rates of suppressed viral loads than participants who were not in their preferred DSD model. She presented an audit tool that is used for micro planning at a facility level: multidisciplinary teams respond to differentiated risk at individual level; assess service gaps at all levels down to individual level; guide on how to optimize resources at clinic level; and once consolidated at the district level, can be used to identify and rapidly respond to service gaps, addressing structural barriers that may be outside the manageable capacity of a health facility. The information is consolidated to programme level to inform national responses and for partner management.

Person-centred, integrated non-communicable disease and HIV decentralized drug distribution in Eswatini and South Africa: outcomes and challenges – Commentary

Maggie Munsamy (National Department of Health, South Africa) shared the results of the Eswatini- and South Africa-based programmes for HIV and non-communicable disease (NCD) integration through decentralized drug distribution for chronic care. This approach adapts medication delivery to serve individual needs while decongesting health facilities, efficiently delivering NCD care, reducing healthcare costs borne by clients with multiple co-morbidities, and decreasing HIV-related stigma. Factors influencing its success included strong leadership from relevant government departments, a broad coalition of support from funders and stakeholders, and the absence of out-of-pocket costs to clients. To bolster programme uptake, additional reporting of integrated decentralized drug distribution models should include client health outcomes and mortality trends related to HIV and NCDs.

Lessons learned from community engagement regarding phylodynamic research with molecular HIV surveillance data in the United States – Research article

Brian Minalga (Fred Hutch, United States) shared the experience of the determined community-led activism that highlighted the ethical concerns related to HIV phylodynamic research and its potential to perpetuate HIV stigma. Researchers funded by the National Institutes of Health, who were on the cusp of publishing their investigation of HIV transmission based on stored HIV genetic sequences, became aware of the concerns and proposed engaging in a series of community consultations. These consultations enabled the researchers to understand the depth of concern related to lack of informed consent and the interlocking aspects of oppression underlying patterns of HIV transmission. Ultimately, the decision was taken not to publish the results of the phylodynamic research.

Instead, a paper outlining the consultation process and considerations for HIV researchers to consider when designing and conducting studies, not limited to phylodynamic modelling, was published. The new paper describes opportunities for researchers to promote autonomy, transparency and partnerships between communities of people living with HIV, public health agencies and research institutions. Brian strongly reiterated that HIV research must never serve to exploit human suffering or disease for academic profit or intrigue.

Person-centred care: shifting the power dynamic in the delivery of adolescent and youth-friendly health services – Viewpoint

Tung Doan (Lighthouse and Y+ Global, Vietnam) shared lessons learnt from the collaboration between the Global Network of Young People Living with HIV (Y+ Global) and Paediatric-Adolescent Treatment Africa (PATA) to investigate person-centred care in the context of health services geared towards adolescents and young people and provide practical recommendations related to staffing, service delivery standards and direct client support services.

The collaborators define person-centred care as "an approach in healthcare that shifts the power dynamic from the healthcare provider to the [client] by engaging [them] in decision making, promoting effective communication, offering multiple choices and fostering [client] empowerment, autonomy, and trust in their healthcare journey". Tools that prove to be successful in equipping healthcare providers to deliver adolescent-friendly person-centred care include: (1) training supporting health providers to reflect upon and re-define their own values; (2) relationship-building practice sessions for health providers on how to engage more meaningfully; and (3) the identification of person-centred care champions who lead the process of shifting power and changing entrenched mindsets. The crucial roles of peer support and community-led monitoring are also highlighted.

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