Living the Continuum: Creating an innovative, engaging and accessible learning resource to highlight the lived experience of HIV care

Authors:

Hollingdrake O¹, Howard C², Mutch A³, Dean J³, Lui C-W³, Fitzgerald L³

¹ School of Nursing, Queensland University of Technology, Brisbane

² Queensland Positive People, Brisbane

³ School of Public Health, University of Queensland, Brisbane

Background:

The HIV Care Continuum represents a linear clinical pathway incorporating HIV testing, diagnosis, care linkage, treatment initiation and viral suppression. Imagined from a provider's perspective, rather than from the perspective of people living with HIV (PLHIV), the continuum fails to capture the lived experience of care for recently diagnosed PLHIV. To promote understanding of barriers and facilitators impacting engagement across the continuum, we developed an innovative and engaging illustrated learning resource for health professionals, peer workers, students, carers and PLHIV.

Methods:

Developed through a collaborative and iterative drafting process involving representatives from Queensland Positive People and a professional illustrator, the graphic-based resource presents findings from the Testing to Treatment Trajectory in Queensland longitudinal study. Two in-depth interviews conducted annually with 42 recently diagnosed (<5 years) PLHIV captured experiences of HIV testing, diagnosis, linkage to care, treatment initiation and beyond. The graphic represents key themes, including barriers and facilitators to HIV care.

Results:

Using imagery of a road, with hazards and short cuts, the continuum is presented as a 'convoluted journey', featuring complexities impacting the diagnosis experience and efforts to engage in care according to participants. Challenges highlighted include poor health literacy, health service access, disclosure, and stigma. The work of positioning HIV within the individuals' social life and identity is captured. The importance of emotional and peer support for recently diagnosed PLHIV is emphasised. Beyond viral suppression, PLHIV move forward with resourcefulness and strength.

Conclusion:

As a 'conversation starter' this innovative and engaging learning resource encourages discussions about social factors relevant to both PLHIV and care providers. It is accessible to diverse audiences, including those who may not access reports or journal articles. Incorporating the resource into health curricula and peer support programs will encourage more open dialogue about the social and emotional intricacies of a seemingly simple clinical pathway.

Disclosure of Interest Statement:

This research received funding from the HIV Foundation Queensland. The presenting author was the recipient of an APA Scholarship. Joint funding from The

University of Queensland and Queensland Positive People was used to develop the resource. No pharmaceutical grants were received in the development of this study.