LIVING THE CONTINUUM: Creating an innovative, engaging and accessible learning resource to highlight the lived experience of HIV care

The HIV Care Continuum (Figure 1) is a linear clinical pathway that incorporates HIV testing, diagnosis, care, treatment initiation and viral suppression (5).

The Continuum does not represent the social and emotional complexities of HIV diagnosis and care (6). Learning about these complexities is key to support people living with HIV. PLHIV need to cope with the challenges of living with the disease. To promote understanding of barriers and facilitators impacting engagement across the HIV Care Continuum, we have developed an innovative educational tool for health professionals, peer workers, students, carers, and PLHIV.

The Journeys Through the HIV Care Continuum Map (Figure 2) was informed by findings of the Testing to Treatment Project in Queensland (7). A longitudinal study involving UQ School of Public Health and Queensland Positive People. Two in-depth interviews were conducted over 12 months with 62 PLHIV diagnosed 12 months or greater, to explore experiences of HIV testing, diagnosis, care, linkage, treatment initiation and viral suppression. The maps were developed in collaboration with a professional illustrator to present key study findings. Imagery of a road, signposted with key milestones, represents the HIV care continuum as a constructed journey. Complexes depicting the diagnostic experience are captured, including barriers and facilitators (genetic) to care. Speech bubbles represent participants’ statements to elaborate specific experiences or challenges.

Results

Complex social factors impacted early experiences of HIV and care engagement. Protective factors included supportive relationships, family, friends, and partners. HIV diagnosis was a life-changing moment. Poor health literacy was a barrier to care engagement. Professionals facilitated care engagement by delivering a calm and well-informed diagnosis, listening without judgment, and providing clear follow-up.

Antiretroviral treatment regimens were simple; however, participants reported with side effects, and long-term adherence. Exploring different treatment regimens was important, and medication adherence facilitated adherence.

Stigma featured through people’s journeys at many points, impacting mental health and quality of life and posing a risk for people to go off the road and disengage from care.

Results cont.

Undetectable viral load was the clinician goal and was visible to many. It was empowering for PLHIV to know that a sustained undetectable viral load (UUVL) they could not transmit the virus, but the journey did not stop here.

Beyond viral suppression, people worked to position HIV as a part of social and medical life. Social and emotional support were integral to engagement across the continuum, including peer access to support. With ongoing support, PLHIV move forward with resourcefulness and strength.

Conclusion

This resource can be used to start a conversation about social factors relevant to PLHIV and care providers. It is designed to be used by a diverse audience, including those not accessing reports or journal articles. Incorporating the resource into health curricula, HIV pathways of care, and peer support programs will encourage open dialogue about the social and emotional intricacies of a seemingly simple clinical pathway.

Limitations

Information used to develop this resource was provided by T20Q study participants. We acknowledge the map may not represent the full spectrum of experiences of living with HIV. Including the unique experiences of gender and culturally diverse people and First Nations people. The study team seeks to highlight those experiences in future work.

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References