

# HIV care: learning from the past, and the right to health

Ian Hodgson

Independent Consultant, HIV Education and Research

Welcome to the 2018 spring issue of *HIV Nursing*, in its exciting new format! Since the last edition of *HIV Nursing* we've seen World AIDS Day come and go. It's surprising to think that 2017 was the 29th World AIDS Day, and reminds us that the HIV sector has a strong and rich legacy; there is still much to learn, but it's important not to forget the past. One example of how this can be prevented is the 2017 film *AIDS: Doctors and Nurses tell their Stories* [1], which includes interviews and insights from those involved in supporting people affected by HIV, and those affected, in its first decades. This was a difficult time, when effective treatment was not available and AIDS seemed on the ascendant. A second example is the EUROPACH project [2], launched in 2016 and led from Berlin's Humboldt University. This research study aims to track the historic development of HIV policy in four European countries since the 1980s to map the dynamics of activism and the HIV response that eventually led to significant policy change. We can always learn from history, and the legacy of that time must not be forgotten.

The global topic for 2017, promoted by UNAIDS, was 'right to health'. This was not just about access to health systems, but nutrition, gender equality, health education, and a safe and clean environment; all areas in which people living with HIV (PLWH) are potentially adversely affected [3]. For the UK, the Terence Higgins Trust highlighted stigma [4] that remains a significant barrier to health even 40 years since HIV first appeared. Many writers, including this one, regularly write about the context and manifestation of HIV stigma, especially within health care. Sadly, this prevails. For example, a paper published in 2017 provides details of stigmatising attitudes towards PLWH in Lao [5], Southeast Asia. Though the study is limited by being questionnaire-based, results suggest the need for tailored interventions to address possible causes of stigma in Lao, including formal education on HIV, and a deeper understanding of stigma and its prevalence in the caring professions. In this study, as with others, negative attitudes are associated with lower HIV-knowledge levels.

The year 2017 also saw examples of access to HIV services, case testing and treatment having a significant impact. One London clinic, 56 Dean Street, reported a decrease of 80% in HIV diagnoses since 2015 [6]. Associated with access to pre-exposure prophylaxis (PrEP), this remarkable improvement provides further evidence of PrEP's benefits. The debate around PrEP continues, particularly around points of access and funding and broader concerns from a small number of advocates that PrEP can over medicalise HIV prevention

and requires effective adherence. But the benefits can't be denied, and the eventual rollout of PrEP – as of now it remains accessible in many countries only through research or pilot projects, or direct purchase – will inevitably result in further reduction of HIV transmission. For London, 2017 brought another achievement when it joined other cities, including Amsterdam and Copenhagen, in attaining UNAIDS's 90-90-90 target (90% of people with HIV diagnosed, 90% on treatment, and 90% virally suppressed) [7]. A second treatment-related topic gaining purchase in 2017, and now part of a large campaign, is U=U (Undetectable=Untransmissible). Since the early 2000s, evidence has been accumulating that PLWH who are virally suppressed cannot transmit HIV: 'U=U is a simple but hugely important campaign based on a solid foundation of scientific evidence' [8]. With U=U, the lives of PLWH can be greatly improved, with a reduction in stigma and moving one step closer to ending the epidemic.

Treatment advances are important, but effective care delivery, with nurses at the forefront, remains paramount for PLWH and their retention in care, especially around building strong relationships between patients and supportive care delivery. This helps establish problem-solving skills, an understanding of HIV, and addressing any changes in behaviour that may be beneficial. The nature of this relationship does influence patients' quality of life and treatment effectiveness. For example, the importance of keeping PLWH on treatment was highlighted in a recent report from Zambia, where PLWH mortality rates of those receiving treatment are 10-fold higher than patients in Europe, which the study attributes to PLWH being late, or lost to treatment [9]. The World Health Organisation (WHO) in 2017 released further data highlighting the benefits of nurse-led services, especially in resource-deprived areas [10]. Here, data show patients at facilities offering nurse-led ART services are 'more likely to be retained in effective HIV care and treatment at 12 months after adjusting for facility- and patient-level characteristics'.

An interesting study from Japan, published in 2017, explored the experience of newly diagnosed PLWH interacting with the health system and the role of nurses working closely with patients immediately following diagnosis [11]. The study highlights that the quality of this interaction has a significant effect on acceptance of the diagnosis, with a lack of HIV knowledge in healthcare workers having a direct impact on retention in services. Healthcare workers in low HIV prevalence countries such as Japan [12] may benefit from interacting with other, more experienced nurses

internationally to ensure their care reflects best practice. Initiatives such as the NHIVNA Nursing Academy programme [13], and other community-focused packages such as that offered by the European AIDS Treatment Group (EATG) [14] should be promoted as widely as possible. Nurses will always play a central role in progressing towards the 90-90-90 goals, and a pooling of knowledge ensures best practice.

Finally, the self-care approach that the UK's NHS is promoting widely also has significant relevance to HIV. According to the Terence Higgins Trust, self-care is defined as 'the strategies utilised by individual patients to manage health or to prevent or detect illness. Self-care is especially important for those living with chronic illness such as HIV, both to manage symptoms and also to improve quality of life' [15]. Self-care is not a new phenomenon within health (in the UK, at least since 2005), though to be effective a number of components need to be in place [16], including: problem solving; decision-making; resource utilisation; the formation of a patient-provider partnership; action planning and behaviour change; and patients tailoring management. Finding out about the best approaches to maximise self-care in HIV was a topic examined by a 2017 US study [17], where an anonymous online survey conducted with PLWH asked respondents to share self-care strategies used to manage 28 commonly experienced symptoms. Respondents' sources of information varied, with results suggesting that some groups, such patients without a college education, men who have sex with men, and women, are more likely to use the internet for their information. Importantly, healthcare professionals were more likely to be rated 'helpful' by patients as sources of useful information, above relying on 'common-sense'.

In the context of HIV, self-care can include a number of components such as meditation, complementary and alternative medicine – used in conjunction with HIV treatment – and stress management [18]. One key component of self-care: agency and decision-making in care and treatment planning, has been at the core of the HIV response for many years, but still requires the availability of accurate information, likely provided by a healthcare provider, and underpinned by an empowering two-way relationship. One example of an innovation to address this component is a Belgian programme for PLWH due to start in 2018. In this programme, in facilities offered by the University of Leuven, patients will have access to their records, including all laboratory reports, and be provided with information about what various test results may mean. They will have the space to review their records, measure their own blood pressure, weight, and BMI, and prepare an agenda for any planned interaction with a healthcare provider. Learning resources will be available, and a system in place so PLWH can request consultations directly with other services, such as with a dietician. The aim is to motivate patients to be fully involved in their care, process available information to apply to their own experience, and identify additional areas requiring further resources; this is 'co-creating

health'. Such a patient-centred approach, as part of broader programme of self-management, 'has particular value, in that it represents an amalgamation of the goals of the patient, family, community, and the clinician with everyone working in partnership to best manage the individual's illness while facilitating comprehensive care' [19].

The 'right to health' is therefore multifaceted and can be maximised through informed and knowledgeable community advocates and health professionals promoting best practice and learning from the past; and there is a legacy to learn from. This edition of HIV Nursing includes articles with an international focus, an exploration of diabetes, and a reflection on training for HIV nursing leadership.

The management of non-HIV diseases in PLWH is a constant feature of HIV care. For example, the number of PLWH affected by diabetes is escalating. In our CPD article in this edition of HIV Nursing, Juliet Bennett explores in some depth the nature of diabetes, focusing on the management of care for people living with diabetes and HIV. The article includes opportunities for reflect on learning.

In Europe, one of the largest regional patient-led PLWH advocacy organisations is the European AIDS Treatment Group (EATG), which has nearly 200 members and a strategic priority since 2013 has been to focus on women living with HIV. Globally, HIV disproportionately affects women, and there is evidence that women are far less represented in clinical trials and in general have a lower level of access to science. Christina Antionadi, focuses on the challenges facing women living with HIV, and concludes with a call for nurses to advocate actively for services that address particular issues facing women living with HIV.

Our research article is a report from Indonesia, written by Kumbayono Kumbayono and colleagues. A phenomenological approach is used to explore the lived experience of 27 PLWH, their distress following an HIV diagnosis, and their coping methods. The article recommends interventions to ensure that PLWH can maintain a healthy lifestyles and quality of life. Perhaps most importantly, it reminds us that nurses have a key role as counsellors and educators to assist PLWH adapting to an HIV diagnosis.

Preparing HIV nurses for management and leadership roles is a topic discussed by Kirstie Weeks, who reflects on attending sessions offered in 2016 by the NHIVNA Academy. Launched in 2016, the NHIVNA Academy aims to provide a place for HIV nurses to study new topics away from workplace stresses. For the author, modules provided during the programme gave opportunity for participatory learning alongside other HIV nurses, and the sharing of best practice.

We hope you enjoy this edition of HIV Nursing, and as always we invite feedback on these articles. If you would like to comment please send a message to: [hivnursing@mediscript.ltd.uk](mailto:hivnursing@mediscript.ltd.uk) and visit our website at [www.hivnursing.net](http://www.hivnursing.net) to view articles on line and see HIV Events and News.

## Acknowledgments

Many thanks to Rita Verstraeten, HIV Nurse Specialist, UZ Leuven, for details on the Belgian initiative.

## Conflicts of interest

The author declares no conflicts of interests regarding the funding and publication of this article.

## References

1. *AIDS: Doctors and nurses tell their stories*. Iridescent Films. Available at: [www.iridescentfilms.co.uk](http://www.iridescentfilms.co.uk) (accessed February 2018).
2. EUROPACH. *Disentangling European HIV/AIDS politics: activism, citizenship, and health*. Available at: [heranet.info/projects/hera-2016-uses-of-the-past/disentangling-european-hivaids-policies-activism-citizenship-and-health/](http://heranet.info/projects/hera-2016-uses-of-the-past/disentangling-european-hivaids-policies-activism-citizenship-and-health/) (accessed February 2018).
3. UNAIDS. *2017 World AIDS Day: right to health*. Available at: [www.unaids.org/en/resources/campaigns/right-to-health](http://www.unaids.org/en/resources/campaigns/right-to-health) (accessed January 2018).
4. Terence Higgins Trust. *Worlds AIDS Day 2017: See Red*. Available at: [www.tht.org.uk/our-charity/Media-centre/Blog/2017/September/See-Red-for-World-AIDS-Day-2017](http://www.tht.org.uk/our-charity/Media-centre/Blog/2017/September/See-Red-for-World-AIDS-Day-2017) (accessed January 2018).
5. Vorasane S, Jimba M, Kikuchi K *et al*. An investigation of stigmatizing attitudes towards people living with HIV/AIDS by doctors and nurses in Vientiane, Lao PDR. *BMC Health Serv Res* 2017; **17**: 125.
6. Nwokolo N, Hill A, McOwan *et al*. Rapidly declining HIV infection in MSM in central London. *Lancet* 2017; **4**: e482–e483.
7. Public Health England. *PHE publishes elimination of HIV and HIV testing reports 2017*. PHE, 2017. Available at: [www.gov.uk/government/news/phe-publishes-elimination-of-hiv-and-hiv-testing-reports-2017](http://www.gov.uk/government/news/phe-publishes-elimination-of-hiv-and-hiv-testing-reports-2017) (accessed February 2018).
8. Editorial. U=U taking off in 2017. *Lancet* 2017; **4**: e475.
9. Holmes CB, Sikazwe I, Sikombe K *et al*. Estimated mortality on HIV treatment among active patients and patients lost to follow-up in 4 provinces of Zambia: findings from a multistage sampling-based survey. *PLoS Med* 2018; **15**: e1002489.
10. Rabkin M, Lamb M, Osakwe ZT *et al*. Nurse-led HIV services and quality of care at health facilities in Kenya, 2014–2016. *Bull World Health Organ* 2017; **95**: 353–361.
11. Imazu Y, Matsuyama N, Takebayashi RN *et al*. Experiences of patients with HIV/AIDS receiving mid- and long-term care in Japan: a qualitative study. *IJNSS* 2017; **4**: 99–104.
12. UNAIDS. *Report to UNAIDS–HIV/AIDS trends in Japan: April 2016*. Available at: [www.unaids.org/sites/default/files/country/documents/JPN\\_narrative\\_report\\_2016.pdf](http://www.unaids.org/sites/default/files/country/documents/JPN_narrative_report_2016.pdf) (accessed January 2018).
13. National HIV Nurses Association. *NHIVNA Academy*. Available at: [www.nhivna.org/NHIVNA-Academy](http://www.nhivna.org/NHIVNA-Academy) (accessed February 2018).
14. European AIDS Treatment Group. *EATG Training Academy*. Available at: [www.eatgtrainingacademy.com](http://www.eatgtrainingacademy.com) (accessed February 2018).
15. Kukielka E. Sources of information for self-care among patients living with HIV. *MD News*, February 2018. Available at: [www.mdmag.com/medical-news/sources-of-information-for-selfcare-among-patients-living-with-hiv](http://www.mdmag.com/medical-news/sources-of-information-for-selfcare-among-patients-living-with-hiv) (accessed February 2018).
16. Pal K, Eastwood SV, Michie S *et al*. Computer-based diabetes self-management interventions for adults with type-2 Diabetes Mellitus. *Cochrane Database Syst Rev* 2013; **3**: CD008776.
17. Schnall R, Liu J, Iribarren S *et al*. Information sources of self-care strategies for persons living with HIV. *Int J Med Inform* 2018; **111**: 1–6.
18. Carter M. For people with HIV, self-care can change your health – and your life. *The Body Resource Centre: Living well with HIV* November 2016. Available at: [www.thebody.com/content/78748/for-people-with-hiv-self-care-can-change-your-heal.html](http://www.thebody.com/content/78748/for-people-with-hiv-self-care-can-change-your-heal.html) (accessed February 2018).
19. Grady P, Gough LL. Self-management: a comprehensive approach to management of chronic conditions. *Am J Public Health* 2014; **104**: e25–e31.

---

Correspondence: Ian Hodgson  
hodgsonian@gmail.com