



## COMMENTARY

### Considerations for select transitions of care for people with HIV: adolescent to adult, prison to society and the postpartum period

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#### Abstract

Proper transitions of care for people with HIV (PWH) are necessary to ensure continuity of care, medication adherence and maintenance of successful clinical outcomes. Three transitions of care may lead to suboptimal outcomes if PWH are not correctly engaged: adolescent to adult, prison to society and the postpartum period. The management of these care transitions is a vital part of engagement in treatment. Evidence highlighting the gaps in care transitions

provides a potential framework to optimize outcomes for PWH.

**Keywords:** adolescent, HIV, people with HIV, postpartum, prison, transitions of care.

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## Introduction

In 2019, there were approximately 1.2 million adults and adolescents in the United States living with HIV, representing a significant population requiring specialized care throughout their lifespan.<sup>1</sup> The HIV care continuum conceptualizes the steps necessary for people with HIV (PWH) to receive care and achieve treatment success: diagnosis, linkage to care, retention in care, antiretroviral therapy (ART) and viral suppression.<sup>1,2</sup> A person's adherence to care and medications as well as retention in care and treatment persistence have broadly been described as engagement in ART services and can be the most challenging aspects of the continuum for PWH.<sup>3-5</sup> Each is vitally important and has been linked to viral suppression.<sup>6-12</sup> Both barriers and enablers exist that can affect the various steps within the care continuum and have an impact on engagement. The ultimate goal of treatment is undetectable HIV RNA, which typically requires 95% adherence.<sup>2</sup>

Most PWH face a range of social issues such as stigmatization, depression and cultural beliefs. These issues can affect their quality of life not just from a physical health perspective but also their mental and social wellbeing.<sup>13</sup> A transition of care (TOC) occurs when a person moves between levels of acuity and/or to another location or team of providers due to a

change in health or social status.<sup>11,14,15</sup> Whilst some may be possible for all PWH, specific populations experience a TOC that is associated with particular barriers and enablers that have an impact on engagement. PWH are increasingly experiencing various TOCs as ART has allowed HIV to become a chronic condition; other comorbidities are increasingly the primary reasons for changes in health status and hospitalization.<sup>16-18</sup> Three TOCs may lead to suboptimal outcomes if PWH are not adequately engaged: adolescent to adult, prison to society and the postpartum period.

### Adolescent to adult

The CDC reports that 1 in 4 new HIV transmissions occur in young people aged 13-24 years.<sup>1</sup> The TOC from adolescence to adulthood is an active, planned progression from paediatric care to adult-centred care with special healthcare requirements. There are many challenges in this specific TOC, including mental health, medication adherence, identity (e.g. sexual, reproductive and gender), socioeconomic and health insurance status, stigma and disclosure, disrupted relationships with paediatric care providers, and communication.<sup>19</sup> In addition, neurocognitive impairment and mental health issues tend to be more prevalent in adolescents and young adults with HIV than in those without HIV.<sup>20</sup>

Paediatric HIV clinics tend to have a more interdisciplinary model of care with more readily available psychosocial services and case management than adult clinics.<sup>20</sup> Addressing psychosocial barriers in adolescents with HIV is especially important as depression and anxiety have been linked with worse HIV-related outcomes and non-adherence.<sup>20–22</sup> Children with HIV develop a sense of comfort with the family-centred, child-friendly primary care specialty services offered to them, which consist of paediatricians, paediatric nurse practitioners, social work case managers, child-life therapists, psychologists, nutritionists and dedicated caregivers.<sup>19</sup> Children with HIV are given extensive medical and emotional support that may be removed if not correctly transitioned into adult care.<sup>19</sup>

Adolescents with perinatal transmission generally have had longer clinical courses complicated by more extensive ART histories leading to drug resistance and complex regimens relative to those that acquire HIV later in childhood or adolescence.<sup>23,24</sup> It is therefore essential to develop an individualized TOC plan, which accounts for medical, psychosocial and financial aspects before the actual switch into adult care.

Adolescents with HIV may require different considerations when developing a TOC plan depending on how they acquired HIV, whether through vertical (perinatal) or horizontal transmission. For example, those that acquired HIV perinatally may require more focus on ART history and drug resistance.<sup>23,24</sup> Above all, adolescents with HIV require special attention to provide adaptability as they mature.<sup>25</sup> As a person's ability to keep medical appointments is considered an indicator of a successful TOC, this should be an essential point for consideration.<sup>26</sup> The person's sense of ownership of their medical care is another indicator that may affect medication adherence, awareness and understanding of the disease, scheduling appointments, and the ability to communicate symptoms and health concerns to providers. There is no 'right time' for the TOC to occur and it should be a flexible process. Overall, creating a model that encompasses person-specific needs and educates the patient and healthcare team is critical to optimizing the TOC process.<sup>27</sup>

## Prison to society

In the United States, it is estimated that about one in seven people diagnosed with HIV is imprisoned at least once in their lives.<sup>28</sup> Following their release into the community, those previously incarcerated face many barriers hindering their access to medical care. Cost and social stigma may lead to poor medication adherence or interruption of critical therapy.<sup>29</sup> A gap in services provided to justice-involved persons during the transition from release to the establishment of care in the community can result from prioritizing other necessities such as securing housing, employment and transportation.<sup>30</sup> TOC clinics aim to help these justice-involved persons gain access to appropriate medical care.<sup>31</sup> The delay in services and resulting consequences indicate the need for better TOC support and

education before justice-involved persons are released into the community. The 3-month period after release is critical, with a high risk of recidivism, substance use relapse and overdose.<sup>31</sup> It is necessary to integrate substance use treatment and preventive care to achieve optimal health outcomes.<sup>32</sup>

Transitional care coordination programmes have been recognized as vital in a health system to address gaps in TOCs leading to poor health outcomes amongst PWH.<sup>33</sup> Many outcomes are available for intervention by TOC clinics to assist justice-involved persons with re-integration into the community. These interventions include linkage to HIV care and social services, receipt of ART, decreased HIV risk behaviours, reduced substance use, retention in HIV care, HIV RNA suppression, use of the hospital/emergency department, stable housing, employment and recidivism.<sup>34</sup> Although HIV care post-incarceration accompanies many other challenges for those re-entering the community, successful clinical outcomes cannot be achieved until barriers are recognized and removed.

In order to address the financial barriers associated with transitioning back to the community, affordable medications or alternative, effective therapies can be recommended to persons with medication access needs.<sup>35</sup> If possible, applications for Medicaid or state-specific AIDS Drug Assistance programmes should be completed prior to release. Depending on resources, some institutions may provide a 30-day supply of ART upon release. Furthermore, it is vital to leverage patient assistance programmes, prescription discount cards, co-payment cards or patient assistance grants to ensure that PWH have consistent medication access and feasible long-term costs. Over-the-counter medication recommendations may also be appropriate in certain self-care situations.<sup>36</sup>

## The postpartum period

Overall, perinatal diagnoses of HIV in the USA declined by 54% between 2014 and 2018.<sup>1</sup> Despite engagement in care during pregnancy, PWH that recently gave birth face many challenges, including physiological changes, postpartum depression risk, increased child and family obligations, and infant HIV-related anxieties.<sup>37</sup> Parents often prioritize their children's needs above their wellbeing, leading to barriers in scheduling clinic visits or disruption in treatment routine.<sup>37</sup>

Age has been inconsistently linked with pregnancy status and engagement in ART services. Some studies have found that younger PWH were more likely to disengage from HIV care and be non-adherent to ART during pregnancy.<sup>38,39</sup> However, others have found that non-adherence can significantly increase with age, possibly due to the higher demands on older PWH with young children.<sup>40</sup> For example, one study observed that adherence to ART declines in the postpartum period, at 53% compared to 75.7% antepartum.<sup>41</sup>

Lack of engagement and specifically ART adherence postpartum may have an impact on viral control, with several

studies demonstrating that viral rebound occurs at significant rates in postpartum PWH.<sup>4,42</sup> One study found that a lack of postpartum HIV treatment relative to pregnancy was highly correlated with failure to return for a postpartum neonatal visit, with rates ranging from 64% attending an initial clinic visit to as low as 39% retained in care after 1 year of delivery.<sup>43</sup> A specific subset of pregnant PWH, namely those with perinatal transmission, face other unique barriers to engagement in care. These PWH may have had multiple treatment regimens due to lifelong HIV and potential childhood non-adherence with medications. Resistance may limit their treatment options during pregnancy. After delivery, they may have low retention in care and viral suppression.<sup>44</sup>

Involvement to promote adherence and care in treating PWH before, during and after pregnancy is essential.<sup>43</sup> One intervention is to identify and assist with treating the nausea induced by antiretrovirals or reducing pill burden as appropriate to assist with adherence. Interventions with

non-HIV medications, such as prenatal vitamins or anti-nausea medications, build a relationship that aids a more robust transition to the postpartum period. Efforts must also be made to engage people with perinatally acquired HIV during pregnancy to streamline care in the postpartum period.<sup>44</sup>

## Conclusion

All TOCs require clinical coordination and continuity of care as they are vulnerable to treatment-related problems spurred by a lack of communication with clinicians, follow-up and education, medication reconciliation and engagement in therapy management.<sup>35</sup> By ensuring proper support during TOC, PWH may be retained in care and treatment goals may be obtained. The management of these TOCs is a vital part of engagement in treatment. Evidence highlighting the gaps in care transitions provides a potential framework to optimize outcomes in PWH.

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