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Enroling and retaining human immunodeficiency virus (HIV) patients in their care: A metasynthesis of qualitative studies

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ABSTRACT

Objectives: To report the findings of a metasynthesis review of qualitative studies on patient and provider experiences and perspectives on linkage and retention in HIV care.
Design: The review is an extraction, aggregation, interpretation and synthesis of qualitative findings based on the Sandelowski and Barroso method.
Data sources: A search of the literature was conducted in the databases Cumulative Index to Nursing and Allied Health, PubMed and PsycInfo for articles published from 2008 to 2013. Inclusion criteria were qualitative research articles published in English from across the world and in peer-reviewed journals. Literature reviews, conference abstracts and grey literature were excluded from this metasynthesis.
Review methods: The review consisted of a) comprehensive search, b) study classification, c) abstraction of findings, d) synthesis. Of the 4640 citations screened, 69 articles were included for this metasynthesis.
Results: 69 unique articles from 44 countries were included. This metasynthesis takes into account the perspectives of at least 2263 HIV-positive participants (740 men, 1008 women, 78 transgender individuals and 437 unspecified sex) and 994 healthcare providers, family members and community members. The most salient barriers and facilitators to HIV linkage and retention in HIV care affirm ecological factors that are mostly beyond individual patients' control. Triadic streams of influence concurrently affect care engagement that include a person's psychological state upon diagnosis and their informational challenges (intrapersonal stream); one-on-one interactions with providers and their immediate community (social stream); and life demands, overall quality of care experiences and other structural barriers (cultural-attitudinal stream). Each stream's influence on HIV care engagement varies at any given point to reflect an individual's evolving and unique experiences with HIV infection throughout the illness trajectory.
Conclusion: There is sufficient evidence that detail how to best link and retain patients in HIV care. Themes identified indicate going beyond individual-level factors and towards shifting attention and resources to systems that patients navigate. Forceful structural-level actions are needed to correct these long-identified barriers and enhance care engagement facilitators.

What is already known about this topic?

- The inability of patients to be linked and retained in HIV care diminishes ART efficacy to prevent AIDS-related sequelae.
- Patients successfully engaged in HIV care reduce transmission of the virus.
- Linkage and retention to HIV care is affected by multiple individual-level factors that either serve as barriers or facilitators to care engagement.

What this paper adds

- This metasynthesis identified seven ecological factors across three streams of influence that affect linking and retaining patients with HIV in their care.

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- Healthcare providers' actions during the clinical interface have lasting repercussions in the engagement of patients to their HIV care.
- This study described the evolving nature of care engagement through the illness trajectory that explains how patients are linked and attempt to stay engaged with their medical care.
- Focus on individual-level factors without regard to long-identified structures beyond the control of patients will continue to hamper successful linkage and retention in care of people with HIV.

1. Introduction

The combined advancements in HIV testing technology plus mass screening campaigns have resulted in an increase of people diagnosed with HIV. Developments in treatment options in the last two decades have transformed a diagnosis of HIV infection into a manageable chronic condition. Timely engagement with HIV care has implications for long-lasting successful treatment and antiretroviral adherence for people who test positive for HIV. As seen from a seven-year treatment program in South Africa, linking newly diagnosed people to care is crucial because those retained in care have substantially lower HIV viral loads than those who are not (Stinson et al., 2014). Additionally, a multi-state, epidemiological project in the United States showed that virally-suppressed, HIV-infected adults were likely to engage in less risky sexual behavior than those who are not suppressed (Mattson et al., 2014). Further, findings from retrospective studies established that individuals engaged in care had better survival outcomes than those not as engaged with the healthcare system and that missed visits specifically within the first year of outpatient HIV treatment had deleterious effects on long-term mortality (Giordano et al., 2007; Mugavero et al., 2009). Finally, linkage and retention are also crucial in preventing transmission as viral suppression among people with HIV reduces transmission (Cohen et al., 2011; Yehia et al., 2014) and thus is a pillar of Treatment as Prevention.

A delay in enrolling patients in care and losing them to attrition undermines the benefits of HIV screening campaigns and virologic suppression from mass distribution of antiretrovirals (Gardner et al., 2011). Failure to engage and retain in care can lead to cessation of ARV medication adherence and reversal of the benefits of antiretrovirals (Bangsberg et al., 2007; Deeks et al., 2009). Globally, with only 65% of eligible patients in 2012 receiving antiretrovirals, UNAIDS established an ambitious goal ('90-90-90') that aims to increase to 90% the total number of people with HIV who are diagnosed, are receiving antiretrovirals and are virally suppressed by 2020 (UNAIDS), 2014. In the United States, the National HIV/AIDS Strategy has been updated to also increase from 65% to 90% the proportion of newly-diagnosed patients in clinical care three months after their diagnoses (ONAP, 2015). However, virologic suppression is premised largely on patients' sustained medical engagement. Given the variety of care services provided between high-resource and resource-challenged settings, there is currently no consensus definition on HIV linkage and retention to care (Okeke et al., 2014). For purposes of this review, linkage to HIV care is defined as an initial encounter with an HIV care provider within 90 days of diagnosis while retention comprises two or more kept visits at least 90 days apart in a 12-month period (United States Department of Health and Human Services, 2012).

This report is part of a larger metasynthesis study that examined factors affecting the HIV Treatment Cascade. Also known as the HIV/AIDS Care Continuum, the HIV Treatment Cascade is informed by population-level surveillance and clinical-record metrics (Gardner et al., 2011). However, lost in these statistics are the perspectives of those who delay, are partially retained or those who cycle in and out of medical care that may not be consistent with the standard continuum of care measures (Castel et al., 2015). Individual perspectives are needed because engagement and retention are the crux of HIV treatment and are the inextricable link between testing seropositive for HIV, linkage to care and effective reduction in viral load (Brennan et al., 2014). Qualitative studies from 2008 to 2013 that had data on linkage and retention factors were analyzed to capture recent findings from patients, providers and key stakeholders about factors that inhibit or facilitate quality of care engagement. Qualitative metasynthesis was selected because this form of inquiry offers an integrated strategy to describe and explain behavior rather than providing a mere summary view of unlinked features (Sandelowski and Barroso, 2007). To facilitate a better contextual understanding of perspectives on engagement and retention in care, this metasynthesis focuses on the literature about patients linking to and staying in care after a diagnosis of HIV infection, the two middle segments of the HIV Treatment Cascade. The first aim of this report was to determine factors that influence linkage and retention in care with which people diagnosed with HIV infection must contend. Also, because metasynthesis studies are an efficient way to condense literature for clinical practice, our second aim was to determine what healthcare providers can do to enhance linkage and retention in care for people with HIV infection.

2. Methods

2.1. Search strategy

This review follows key metasynthesis guidelines developed by Sandelowski and Barroso (2007) starting with a comprehensive automated searches of the literature found in three electronic databases (Cumulative Index to Nursing and Allied Health Literature [CINAHL], MEDLINE [PubMed] and PsycINFO). The following cross-referenced search terms (i.e., index terms, keywords, proximity terms) were used: 'Human Immunodeficiency Virus', 'Acquired Immune Deficiency Syndrome', 'qualitative', and 'themes'. The combination of Boolean terms (*and, or, not*) were also added. Table 1 is an example of the complete CINAHL search strategy protocol. The inclusion criteria for this review include: a) qualitative research studies or the qualitative findings from mixed methods studies, b) published in English and in peer-reviewed journals, and c) published from 2008 to 2013. Reports published prior to 2008 were excluded because we wanted to capture the most current experiences and insights of participants and to avoid the relevancy issues associated with dated findings (Barroso et al., 2006). Grey literature, reviews, and articles not written in English were also excluded. No geographic restrictions were used during the search because we wanted to reflect the global experiences and views of people with HIV across study settings and regardless of resource availability.

We sought the assistance of an information specialist from the Duke University Medical Library to assure search thoroughness. Additionally, principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) framework for data retrieval were adapted for this metasynthesis study (i.e., identification, screening, eligibility, and inclusion). Additionally, the 21-item Enhancing Transparency in Reporting The Synthesis of Qualitative Research [ENTREQ] statement (Tong et al., 2012) was also utilized to report the common stages we undertook in the synthesis of these qualitative health reports. Finally, to ensure that a thorough search with maximum specificity was conducted, the validated McMaster Qualitative Filter was used (Letts et al., 2007).