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Article begins on next page

Experiences of HIV infected adults and health care providers with health care delivery practices influencing engagement in primary health care settings: a qualitative systematic review

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Review question/objective

The objective of this qualitative systematic review is to examine the experience and impact of health care delivery on health care engagement for adults infected with human immunodeficiency virus receiving primary care. This review will identify and synthesize the best available evidence on health care structures, processes and practices that promote patient engagement in primary health care. The review question to be addressed is: “What are the experiences of people living with human immunodeficiency virus (PLWH) and their health care providers with health care delivery processes and practices that impact engagement in primary health care settings (clinics, physician offices, and other community-based health care settings)?” Specifically this project will compile the evidence:

- To illuminate health care system structures, provider practices, care delivery and programmatic processes that PLWH and their providers find to impact engagement in primary health care.

Background

HIV is a major public health problem that has claimed the lives of more than 34 million people world-wide.¹ Tragically, in 2014 alone, 1.2 million people died from HIV-related causes globally. At the end of 2014, 36.9 million people were reported to be living with HIV; and 2 million people were estimated to be newly infected each year. In mid-2015, it was estimated that only 54% of all PLWH knew that they were infected.¹ The United States Centers for Disease Control and Prevention (CDC) estimates that at the end of 2012, 1.2 million people in the U.S. aged 13 years and older were living with HIV, which includes 156,300 people who did not know that they were infected. In 2014, 44,073 new infections were estimated annually with the highest numbers of new infections occurring in people aged 25-29 years, Black/African American, through male to male sexual contact.²

The introduction of combination antiretroviral therapies (ART) available since the 1990s has dramatically decreased morbidity and mortality associated with HIV infection.³ With the availability of ART, HIV is now a treatable, yet a complex chronic illness. Access to care and ongoing engagement in care for antiretroviral (ARV) medication adherence and psychoeducational support are critical to achieving desired outcomes of reducing risk of further HIV transmission, morbidity and mortality, and managing other commonly co-occurring health, social and behavioral conditions thereby maximizing wellness. Gardener et al.⁴ reported that PLWH who had been tested, but not well-engaged in care accounted for a large proportion of patients with detectable HIV viral loads, and further identified that there were significant gaps in testing and engagement. Similarly, Stinson and colleagues⁵ examined HIV viral load for those remaining in care after testing and those lost to follow-up, and found significantly greater virologic suppression in those engaged in care compared to those lost to follow up. Mattson et al.⁶ and Skarbinski et al.⁷ found that individuals who knew their HIV diagnosis and were linked and engaged in care had less risky sexual behavior and a lower HIV transmission rate underscoring the point that effective treatment prevents further HIV transmissions. With ongoing linkage and engagement in care showing results of persistently lower HIV viral loads and lower transmission rates, it is imperative to better understand what keeps people engaged in care.

In 2013, the HIV Care Continuum Initiative directed U.S. federal departments to accelerate efforts to test and then engage PLWH into care.⁸ To this end, the Continuum developed a series of steps or stages of care that if followed are likely to lead to HIV viral load suppression. The first step is to be tested and diagnosed for HIV. The next step is to link all HIV-infected patients to a health care provider within one month of the initial diagnosis/positive test. The final stages

require ongoing engagement in order to control the infection and subsequent HIV viral load suppression through lifetime administration of ART.

Data compiled in the U.S. shows significant gaps along the HIV Care Continuum from testing to engagement and treatment. The 2014 CDC report, *HIV in the United States: The Stages of Care*⁹, pointed out several facts: approximately 14% of Americans with HIV in the US don't know that they are HIV-infected. Of those who do know their HIV diagnosis, 80% are initially linked to HIV care but only 40% are actually retained or engaged in HIV care, and only 30% reach the goal of HIV viral load suppression. In response to these poor outcomes the US National HIV/AIDS Strategy has set an ambitious goal that 85% of newly diagnosed patients must enter care within one month of their diagnosis.¹⁰ Globally, UNAIDS has set a goal that by the year 2020 90% of all PLWH will know their HIV status, 90% will be diagnosed and receive sustained antiretroviral therapy, and 90% of people receiving ART will have viral suppression.¹¹ To reach these goals and to control further transmissions by suppressing HIV viral load, engagement is a priority.

A systematic review conducted on the role of patient engagement as a risk factor for healthcare outcomes in chronic disease reinforces the notion that meeting outcome goals will require enhanced engagement. In this review Simmons et al.¹² (p.1-2) found that patient engagement helps individuals “self-manage chronic disease” and improve outcomes. The authors’ stress that patient engagement itself may be one of the most influential and “modifiable risk factors” for chronic disease outcomes. They recommend that patient engagement measures should be included as a component of ongoing health risk assessments, however do not address health systems, structures or practices that promote engagement.

Engagement is not simply retention in care, but is the ongoing process/connection/partnership between the patient and the health care system that influences involvement in self-care and retention. Engagement is influenced by a variety of factors that can be categorized as individual characteristics and resources (gender, age, resilience, mental health, coping mechanisms, financial means), health care system/practice characteristics and resources (wait times, privacy, coaching and coordination), and societal attitudes and resources (stigma, transportation, social services, health insurance). What is clear is that engagement is not simply a responsibility of the patient; rather efforts must be taken within and across each sphere for maximal patient engagement.

In the U.S., a renewed emphasis on improving primary care and outcomes associated with primary care have generated new health care delivery models, structures and processes aimed to promote patient-centeredness and patient engagement. These changes have targeted quality, safety, efficiency, communication, teaching, and coaching roles of providers, adapted structures to facilitate patient flow for ease of care access, and incorporated tools to support patient self-management. Similarly the international community through the leadership of the World Health Organization¹³ produced a report in 2000 that comprehensively outlines a strategy for improving health systems throughout the world and emphasizes that systemic improvements are needed to reach goals to promote, restore and maintain health. The concept of people-centered health care that focuses on responsiveness to patients and their families, improves access to services and designs systems that improve upon the organization and delivery of care are highlighted as essential to a well-functioning health system.

Several qualitative studies have captured engagement from the perspective of health care structures, processes and practices. Christopoulos et al.¹⁴ and Koester et al.¹⁵ found that empathy without judgment was key to engagement. Bakken et al.¹⁶ and Bofill et al.¹⁷ (p. 604) describe that having a connection with a health care provider that is “not paternalistic or directive” but collaborative where the provider helps the patient manage their HIV care, allows for involvement in care planning and accepts individual preferences as key to engagement. They found that patients who

had this kind of relationship with a health care provider reported better adherence to treatments and consistency in taking medications. Similarly, Greene and Yedidia¹⁸ found that for patients with complex chronic conditions, there was a perception of provider support that was predictive for participation in self-management, a key component of engagement. Bofill et al.¹⁷, Messer et al.¹⁹, and Reimen et al.²⁰ found that for PLWH in addition to empathy and collaboration, a critical component of this provider-patient relationship was maintaining confidentiality and discretion as patients were concerned with the stigma associated with the disease. Bogart et al.²¹ found that patients experienced considerable difficulties with scheduling appointments, inflexible clinic hours, long wait times, and disrespectful communication from the health care team as barriers to engagement.

A search of the Joanna Briggs Institute (JBI) Database of Systematic Reviews and Implementation Reports, Cochrane Library, MEDLINE and CINAHL found several reviews that examined the relationship between engagement and health outcomes^{12, 22-29}, self-management and outcomes, and specific intervention strategies to retention in care. In a quantitative review conducted by Rosen and Fox²² retention rates of HIV patients in sub-Saharan Africa were examined at different stages along the HIV care continuum and they found loss of patients at every stage. Two systematic reviews presented a narrative analysis of quantitative studies examining practices that promote linkage to care²³⁻²⁴. Govindasamy, Ford and Kranzer²⁴ focused on retention in care of patients during the period of receiving an HIV-positive diagnosis and taking ARV medications, and identified transportation costs, travel distance to the clinic, long waiting times, stigma, and fear of confidentiality as important factors in this initial period of health care. Higa, Crepez and Mullins²³ provided a narrative review of 10 quantitative studies of interventions supporting linkage to, and retention in care highlighting the importance of provider behaviors (rapport, coordination, teaching, coaching and counseling). Three systematic reviews examined the effectiveness of self-management programs or interventions. Although not directly addressing engagement, these studies are valuable as self-management is seen as an outcome of engagement.²⁵⁻²⁷ A quantitative systematic review examining the use of mHealth HIV self-management interventions led to the conclusion that mHealth may be a strategy in the self-care management toolbox.²⁵ A mixed methods systematic review on technology-based self-care methods and its impact on antiretroviral adherence supported the value of self-care technology approaches.²⁶ In this study 12 qualitative studies were included, however there is no report of the patient experience beyond identification of the strategies used. Millard, Elliott and Girdler²⁷ in a quantitative systematic review explored self-management educational interventions and found that these interventions led to short-term improvements in physical, psychosocial, health knowledge and behavioral outcomes. However, this review did not specifically address whether these interventions improved engagement in care. Liao et al.²⁸ report that their systematic review on interventions to promote linkage to and utilization of HIV medical care was a qualitative systematic review, however all of the studies were quantitative and a narrative review of the studies was presented. They identified the importance of coordinating care, using motivational counseling, accompanying patients to medical visits and indicated that almost all interventions focused on individual level factors. Flores, Leblanc, and Barroso²⁹ recently published a meta-synthesis of qualitative studies examining patient and provider experiences on linkage and retention in care of HIV-infected individuals. They examined an eight year period of literature retrieved from three major databases opting, however, not to use critical appraisal based on lack of universal agreement as to what constitutes good qualitative research. Findings identified significant barriers in three streams of influence: intrapersonal (psychological state and information challenges), societal (healthcare provider interactions, societal experience) and cultural-attitudinal (life demands, quality of care and structural barriers) which influenced entry and ongoing retention in care.

The majority of the systematic reviews have been quantitative using narrative review as the synthesis approach. Only one study truly examined the qualitative literature, but examined the broad influences on engagement at the intrapersonal, societal and cultural-attitudinal levels.²⁹ Although very valuable to understanding the concept of engagement, more clarity is needed on health care system structures, provider practices, care delivery and programmatic processes that PLWH and their providers find to be supportive of engagement. This proposed study will review qualitative studies examining the experience and impact of health care delivery on health care engagement for PLWH receiving primary care in the US. Health care engagement is defined as an ongoing process/connection/partnership between the patient and the health care system that influences involvement in self-care (self-management, adherence) and achieving the desired outcomes of the steps of the Care Continuum (from initial testing to initial linkage to care, ongoing lifetime engagement in care, and subsequent HIV viral load suppression). To truly change and transform our primary care system to be more responsive to the needs of PLWH, we must look at the system through the eyes of patients and their health care providers. Synthesizing this literature will inform efforts at restructuring and transforming the health care system.

Inclusion criteria

Types of participants

This review will consider studies that include adults, aged 18-65 years inclusive, infected with HIV who have received a clinical diagnosis of HIV and their health care providers (physicians, nurses and others providing care to these patients in the primary care health care setting).

Phenomena of interest

This review will consider studies that evaluate the experiences with health care structures/processes/practices that influence engagement in adults infected with HIV and their health care providers.

Context

This review will consider studies from a US perspective that examine the experiences with health care structures/processes/practices that influence engagement of PLWH and their health care providers in primary health care settings (clinics, physician offices, and other community-based health care settings).

Types of studies

This review will consider studies that provide qualitative data including but not limited to, designs such as phenomenology, ethnography, grounded theory, action research, and qualitative descriptive.

Exclusion criteria

Studies that address other components of engagement without addressing health care structures/processes/practices will be excluded. Studies which address an acute care hospitalization will also be excluded.

Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be used in this review. An initial limited search of MEDLINE, CINAHL and Web of Science will be undertaken followed by analysis of keywords contained in the title or abstract and index terms used to describe relevant articles. A second extensive search will be undertaken using all identified keywords and index terms. The third step will be a hand search of the reference lists, bibliographies of all relevant articles and all identified reports for additional studies and the table of contents of the following journals: *AIDS*, *PLOS One*, *AIDS Patient Care and STDs*, and the *Association of Nurses in AIDS Care*. Studies published from 1997 to the present will be considered for inclusion in the review. In 1997 highly active antiretroviral therapy (HAART) became the HIV standard of care.³⁰

The databases to be searched include:

- CINAHL
- MEDLINE -PubMed
- Scopus
- EBSCOhost-Academic Search Premier TRIP
- Web of Science
- EMBASE

The search for unpublished or grey literature will include:

- Dissertation Abstracts International
- MEDNAR/Google Scholar
- Virginia Henderson Nursing Library
- Robert Wood Johnson Foundation Research and Publications
- Health Resources and Services Administration Special Projects of National Significance

Initial keywords to be used will be:

- Qualitative Research
- Adult
- HIV/Human Immunodeficiency Virus
- AIDS/Acquired Immune Deficiency Syndrome
- Engagement in HIV care
- Retention in HIV care (HIV Retention)
- HIV care continuum
- Linkage to HIV care (HIV Linkage)

- Adherence with HIV care
- HIV self-management
- HIV primary care

Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion using the Joanna Briggs Institute's critical appraisal instrument for use in JBI Systematic Reviews (JBI SUMARI).³¹ A preliminary review of the literature identified a high volume of qualitative studies on this topic. All studies will be appraised using the full criteria, however, papers not meeting criteria 2, 3, 4 and 8 will be excluded without further review as they are considered lower quality studies. Any disagreement will be referenced and resolved by discussion or with consultation by a third reviewer.

Data collection

Data will be extracted from papers included in the review using the standardized JBI Data Extraction Tool for Qualitative Evidence.³² These data extracted will include specific details about the phenomena of interest, populations, study methods and experiences/perceptions of significance to the review question and specific objectives. Data will be extracted from studies by two reviewers independently using this data extraction function, a tool that logs study findings including textual data and study conclusions as reported by the author(s). The reviewers will then assign a level of validity or credibility such as unequivocal, credible or unsupported evidence to each finding. Primary authors will be contacted to clarify/gain additional information pertaining to the methodological appraisal stage and data collection.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI SUMARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation- through assembling the findings rated according to their quality and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

Conflicts of interest

None identified

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