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RESEARCH ARTICLE

Healthcare Empowerment and HIV Viral Control: Mediating Roles of Adherence and Retention in Care

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Introduction: This study assessed longitudinal relationships between patient healthcare empowerment, engagement in care, and viral control in the Women's Interagency HIV Study, a prospective cohort study of U.S. women living with HIV.

Methods: From April 2014 to March 2016, four consecutive 6-month visits were analyzed among 973 women to assess the impact of Time 1 healthcare empowerment variables (Tolerance for Uncertainty and the state of Informed Collaboration Committed Engagement) on Time 2 reports of ≥95% HIV medication adherence and not missing an HIV primary care appointment since last visit; and on HIV RNA viral control across Times 3 and 4, controlling for illicit drug use, heavy drinking, depression symptoms, age, and income. Data were analyzed in 2017.

Results: Adherence of ≥95% was reported by 83% of women, 90% reported not missing an appointment since the last study visit, and 80% were categorized as having viral control. Logistic regression analyses revealed a significant association between the Informed Collaboration Committed Engagement subscale and viral control, controlling for model covariates (AOR=1.08, p=0.04), but not for the Tolerance for Uncertainty subscale and viral control (AOR=0.99, p=0.68). In separate mediation analyses, the indirect effect of Informed Collaboration Committed Engagement on viral control through adherence (β=0.04, SE=0.02, 95% CI=0.02, 0.08), and the indirect effect of Informed Collaboration Committed Engagement on viral control through retention (β=0.01, SE=0.008, 95% CI=0.001, 0.030) were significant. Mediation analyses with Tolerance for Uncertainty as the predictor did not yield significant indirect effects.

Conclusions: The Informed Collaboration Committed Engagement healthcare empowerment component is a promising pathway through which to promote engagement in care among women living with HIV.

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INTRODUCTION

Empowerment involves the transfer of power and mastery from one entity to another on issues of concern to that entity.[1] Empowerment can occur at multiple levels, including psychological empowerment at the individual level, within specific subgroups (e.g., women and minority populations), and at the educational and policy levels.[2–6] This transfer has emerged as an important health determinant, guiding intervention approaches that seek to build empowerment as a goal in its own right, but also as a means to promote health and reduce health inequities.[6–9]

Empowerment has also been applied to chronic disease management. Patient empowerment typically focuses on cognitive dimensions that indicate the motivation and perceived ability of a patient to make decisions about his or her own health care and an increased sense of responsibility for health outcomes.[10–13] Although patient empowerment should lead to improved health behaviors, better health outcomes, and reduced healthcare costs,[10,14–18] the advancement of research and theory in this area has been limited by diverse conceptual definitions.[13,17,19–22] In an effort to synthesize this literature, Johnson[19] and others[23,24] have advanced a unified construct of healthcare empowerment. In this model, healthcare empowerment is defined as "the process and state of being (1) engaged, (2) informed, (3) collaborative, (4) committed to one's health care, and (5) tolerant or resilient to uncertainties in treatment outcomes," and is measured based on two factors; the first is Informed Collaboration Committed Engagement (ICCE).[19] In ICCE, being informed refers to the importance to a patient of having information about health and treatment options, collaboration refers to the patient's perceived ability to be involved in clinical decision making, being committed involves the motivation to maintain and improve one's own health, and engagement refers to patient preferences to stay active in health care.[23] The second component refers to Tolerance of Uncertainty (TU) and involves the capacity to manage expectations and the consequences of medical decisions with unknown outcomes.[23] In the context of HIV management, for instance, TU may help patients stay involved in care when clinically recommended self-care behaviors do not result in desired changes in health.

In the U.S., women are less likely than men to be virally suppressed, and it is estimated that only 44% of women with HIV have sustained viral suppression.[24] This difference is explained, in part, by differences in adherence and retention in care.[25,26] Given that lifelong HIV antiretroviral (ART) medication adherence and retention in HIV primary care are important predictors of viral control,[27–30] healthcare empowerment could serve as an important organizing construct for improving HIV outcomes. Initial studies on healthcare empowerment conducted primarily with adult men and transgender women revealed positive correlations with medication adherence; relationships with HIV viral suppression and CD4 cell count have been less conclusive.[23,31–33] Further work is required to gain clarity on these relationships in additional populations, including women.

The purpose of this analysis is to describe associations between women's healthcare empowerment and both HIV ART adherence and retention in HIV primary care. Relationships between healthcare empowerment and HIV viral suppression are described and assessed for mediating roles of adherence and retention. This analysis utilizes four waves of data collection, spanning 2 years, and controls for established predictors of care engagement, including substance use, heavy drinking, depression symptoms, age, and SES.[34–44]

METHODS

Study Sample

Data were drawn from the Women's Interagency HIV Study (WIHS).[45] Eligibility for HIV-seropositive women included a positive HIV antibody status confirmed by Western blot. WIHS sites are located in Brooklyn and Bronx, New York; Chicago, Illinois; Washington, District of Columbia; San Francisco, California; Chapel Hill, North Carolina; Atlanta, Georgia; Miami, Florida; Birmingham, Alabama; and Jackson, Mississippi.[45,46]

Study visits included standardized self-report interviews administered by centrally trained interviewers in English or Spanish, and a blood draw for assessment for HIV RNA viral load. Participants provided written informed consent, and study visits were spaced at 6-month intervals. Women were remunerated for time associated with study visits in the range of US$50–US$80, depending on study site activities conducted during that visit, and transportation costs were covered. All study activities were approved by the site's IRB, and data are protected by a federal Certificate of Confidentiality.

The healthcare empowerment model suggests that increases in empowerment should cause increases in self-care behaviors of adherence and retention in care, which in turn should lead to sustained control of HIV infection over time. A temporal order was therefore used for modeling the predictor variable (healthcare empowerment), proposed mediators (adherence and retention in care), and outcome (viral suppression), to reflect the hypothesized causal order of mediation. Healthcare empowerment subscales and all covariates were assessed at Time 1 (T1), completed between April and September 2014. Adherence and retention were assessed at the next study visit (T2) from October 2014 to March 2015. Viral control was assessed across the subsequent two study visits (T3/T4), first from April to September 2015 and again from October 2015 to March 2016. Data were analyzed in 2017.