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Health information exchange interventions can enhance quality and continuity of HIV care

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ABSTRACT

Purpose: The purpose of this article is to describe how comprehensive HIV care is delivered within Ryan White Program (RWP)-funded clinics and to characterize proposed health information exchange (HIE) interventions, which employ technology to exchange information among providers, designed to improve the quality and coordination of clinical and support services.

Methods: We use HIV patient care quality and coordination indicators from electronic data systems to describe care delivery in six RWP demonstration sites and describe HIE interventions designed to enhance that care.

Results: Among patients currently in care, 91% were retained in care in the previous six months (range across sites: 63–99%), 79% were appropriately prescribed antiretroviral therapy (54–91%) and 52% had achieved undetectable HIV viral load (16–85%). To facilitate coordination of care across clinical and support services, sites designed HIE interventions to access a variety of data systems (e.g. surveillance, electronic health records, laboratory and billing) and focused on improving linkage and retention, quality and efficiency of care and increased access to patient information.

Discussion: Care quality in RWP settings can be improved with HIE tools facilitating linkage, retention and coordination of care. When fully leveraged, HIE interventions have the potential to improve coordination of care and thereby enhance patient health outcomes.

1. Introduction

During the past 30 years, dramatic progress has been made in the reduction of morbidity and mortality associated with HIV [1]. However, considerable deficiencies remain in the public and private health systems that have been developed to identify HIV-infected individuals, engage and retain them in care and improve the quality and effectiveness of care and treatment. In the United States, it is estimated that only 19% of those with HIV are on effective treatment [2]. Due to the complex nature of the disease, effective HIV care is multi-disciplinary. Primary care for people with HIV includes not only treatment of an infectious disease (via prescription of antiretroviral therapy and treatment of opportunistic infections and malignancies), but also treatment of the long-term effects of immune activation and the side effects of antiretroviral therapy (heart disease, diabetes, and metabolic

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abnormalities). Additionally, this care must address the psychosocial factors which impact patients' ability to engage and remain in care [3].

Recently, policy makers, clinicians and researchers have emphasized the importance of expanding the continuum of care for people with HIV to include not only primary HIV care and support services, but also linkage, engagement and retention in HIV care [4,5]. Previous research has identified many barriers to optimal linkage, engagement and retention in care [6–13]. These include structural barriers (e.g., housing, location of clinic and competing subsistence needs such as housing, food and transportation) [14–16], financial barriers (e.g., cost of services, lack of insurance) [17,18], personal and cultural barriers (e.g., attitudes and beliefs, racism, language, sexism, and homophobia) [19,20], co-morbidities such as mental illness and substance abuse [21,22], stigma, fear of confidentiality violations [23,24] and healthcare provider attitudes [25].

The Ryan White Care Program (RWP) was developed to address these barriers and associated deficiencies in HIV-related healthcare through the funding of quality HIV care and treatment for those who cannot afford it, provision of support services (e.g. transportation and housing) for those who experience challenges and/or obstacles in entering and remaining in care, and coordination of care (e.g. medical case management) for those who have co-occurring conditions that impact the effectiveness of HIV care [26,27]. Previous research in RWP-funded health clinics suggests receipt of care and support services in RWP-funded health clinics are associated with better engagement in care, retention in care and patient health outcomes [28–32]. However, these same findings also indicate that the improved engagement, retention and health outcomes are not yet at levels that would be considered ideal [30]. For example, only 45% of patients in RWP-funded clients reported any primary HIV care visits in the past year [28]. Among those in care, 61–74% were on recommended antiretroviral therapy [33].

Recent literature, as well as the National HIV/AIDS Strategy, has suggested that both individual and system-level interventions have the potential to improve linkage and retention in care and the quality of HIV care and support services [3,5,34]. These include case management, patient navigators, integration of care and support services and use of electronic health information to facilitate and coordinate care and services. For example, Mugavero et al. demonstrated that receipt of case management prior to an initial visit with a provider can improve linkage to care for newly identified HIV-infected individuals [5]. Several demonstration projects, funded under an initiative from the US Health Resources and Services Administration's (HRSA) Special Projects of National Significance (SPNS) demonstrated that case management and patient navigators can improve engagement in care, retention in care, adherence to care and treatment for at-risk HIV-infected individuals [28,30]. Integration of HIV primary care, specialty care and support services, as occurs within the Veterans Administration and Kaiser Permanente, has been shown to improve the quality of care across the entire continuum of care for people with HIV [34–36].

To date, few studies have explored to what extent sharing patient information across geographically disparate HIV surveillance, primary care and support service organizations can enhance linkage to care, retention and adherence to care and treatment, the quality of core and support services, as well as health outcomes for people with HIV. Health information exchange (HIE) is the process of electronic multi-directional transfer of identifiable, patient-level information between different organizations. HIE has been previously implemented in the context of other diseases to link public health surveillance programs to primary care services; laboratory and pharmacies to primary care; and primary and specialty care [37–41].

HIE interventions have the potential to close many of the gaps that lead to sub-optimal care for people with HIV. For example, if we share information between surveillance systems and primary HIV care, we can identify individuals with delayed entry or incomplete engagement in care. If we share information between laboratory and primary care settings, we can improve receipt of appropriate laboratory testing and reduce redundant testing. If we share information between primary HIV care and support services, we can enhance coordination of care.

To test the potential of HIEs for supporting better coordinated care in RWP settings, HRSA initiated a SPNS initiative within which six demonstration projects were funded to initiate bi-directional HIE which would enhance linkage to care, quality of HIV care and support services and enhance access to information and coordination of comprehensive care for people with HIV. This paper presents baseline information on patient characteristics and the quality of comprehensive HIV care within the six demonstration sites in the initiative in order to understand the clinical environment in which HIEs can be deployed. We also describe the HIE interventions proposed by each site to address deficiencies in linkage and retention in care, quality of care and access to information to enhance coordination of care. The results of this paper will help define the range of settings and data systems within, which HIE interventions can be implemented to improve comprehensive HIV care for people with HIV.

2. Methods

2.1. *Description of the initiative*

In 2007, HRSA funded the Information Technology Networks of Care Initiative to assess whether the use of health information technology to enhance sharing of information across public health surveillance programs, primary care programs and support service providers could improve the linkage of HIV-infected individuals into HIV care, as well as the quality, coordination, and effectiveness of that care. The initiative provided support for four years to six organizations (hereafter referred to as "demonstration sites") to promote the implementation of HIE interventions for people living with HIV in underserved communities. These six demonstration sites were: Bronx-Lebanon Hospital Center in Bronx, NY; the City of Paterson (Department of Human Services), NJ; Duke University (Center for Health Policy) in Durham, NC; Louisiana State University Health Services Center in New Orleans, LA; New York-Presbyterian Hospital in New York, NY; and St. Mary Medical Center Foundation in Long Beach, CA. In addition, one Evaluation and Support Center (hereafter referred to as the