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Social workers play an important role in recognizing and addressing barriers to retention in HIV care. Although there is a large body of literature and research supporting interventions that promote medication adherence, there is limited intervention research that addresses retention in care, the precursor to adherence. Despite many advances in HIV treatment, many African Americans are not engaged in regular care. In a systematic review, the literature was critically appraised to examine intervention research designed to retain HIV-infected African Americans in treatment. Only peer-reviewed studies published from January 2002 through October 2012 were examined. The initial search generated a total of 798 studies. However, of these, only 13 met the inclusion criteria. Results highlight interventions that can be replicated by social workers—such as the use of ancillary support services, the use of adherence manuals, and theory-based interventions—to engage this population in care. Policy implications are also discussed.

KEY WORDS: African Americans; highly active antiretroviral therapy; HIV; medical self-care

The Centers for Disease Control and Prevention (CDC) (2011) reported that African Americans face the most severe burden of HIV infection of all racial and ethnic groups in the United States. Although they represented only 14 percent of the U.S. population in 2009, African Americans accounted for 44 percent of all new HIV infections that year (CDC, 2011). As a result of the effectiveness of current therapies, HIV has evolved from an acute and usually terminal illness to a chronic one that requires ongoing symptom management strategies to reduce anxiety, fatigue, depression, HIV-related symptoms, and adverse effects of medication (Wantland et al., 2008). However, African Americans are more likely to report poorer adherence, are less likely to receive life-prolonging antiretroviral (ARV) medication, and disproportionately experience higher rates of HIV-related morbidity and mortality than their white and Hispanic counterparts (Metha, Moore, & Graham, 1997; Tobias, Cunningham, Cunningham, & Pounds, 2007).

Engagement in medical care after diagnosis of HIV infection is essential to initiate lifesaving antiretroviral therapy (ART) and facilitate the delivery of important prevention messages for reducing HIV transmission (Mayer, 2011). Engagement refers to an overall holistic care of self to manage HIV disease, which includes access to, as well as active involvement and retention in, both health care and general subsistence care (George et al., 2009). However, approximately 50 percent of individuals who are aware of their HIV serostatus and who have been linked to care continue to be actively engaged in care; the other half are sporadically in care; some will come for a few visits and then are lost for long periods of time (Mugavero, Davila, Nevin, & Giordano, 2010). Pecoraro et al. (2013) found that patients dropped out of care because of multiple factors such as substance abuse, unstable housing, psychiatric disorders, incarceration, side effects from HIV medication, denial about diagnosis, relocation, stigma, forgetfulness, and problems with the patient’s medical home.

Access to HIV treatment is critical to improving health outcomes (Andersen et al., 2000; Palacio, Kahn, Richards, & Morin, 2002). When specifically examining ART access, Andersen et al. (2000) found, after conducting a national U.S. probability study among a sample of 2,776 diverse HIV-positive individuals, that the odds of African Americans receiving early ART were less than half that of white Americans. Retaining patients in HIV care may take a considerable investment of time and

innovation among health care providers. Sitapati et al. (2012) explored methods for reengaging 716 patients out of care. The project used multiple outreach methods such as brochures, staff education, flyers, and a secure phone message line to reengage these patients in care. They were able to locate 87 percent of disengaged patients using these methods. Christopoulos et al. (2013) found that barriers to care change over time. Among their sample, the fear of death was an initial barrier to care when newly diagnosed, but this barrier subsided with patient education. This finding suggests that retention in HIV care is an ongoing process that requires multiple approaches throughout the continuum of a patient’s care.

Given the multiple challenges to HIV treatment retention, it is important to examine the current state of interventions that address these barriers. This systematic review explores the latest intervention research designed to retain and engage African Americans in HIV care. We specifically focused on intervention studies that sought to retain and engage African Americans receiving ART, undergoing medical self-care symptom management, or both. We discuss practice and policy implications for social workers with the goal of encouraging leadership in the development of new and existing retention interventions.

METHOD

Search Strategy

For this review of the literature, we used a systematic review process. Studies included in the review were identified through the following databases: Social Work Abstracts, Medline, PsycINFO, Academic Search Complete, and PubMed. We cross-referenced the following terms: HIV, African American, black, medical self-care, HAART, ART, ARV medication, access, treatment, engagement, retention, health care provider, social worker, physician, nurses, intervention, and mistrust. We retained only those peer-reviewed studies published from January 1, 2002, through October 31, 2012, because literature about ART was not widely available until 1996 and behavioral research did not begin to be published until around 2000. This systematic review includes both quantitative and qualitative intervention studies.

Inclusion Criteria

Studies were included in this review if they met all four inclusion criteria: (1) were published in peer-reviewed journals between January 1, 2002, through October 31, 2012; (2) recruited HIV-positive African American adult men, women, or both; (3) African American participants constituted the majority of the sample. Majority was determined by the percentage of African Americans in the sample of each study compared with participants of other racial and ethnic groups; and (4) focused exclusively on the engagement and retention of patients in HIV-related medical self-care symptom management, ARV medication treatment, or both.

Classification of the Studies

The research team consisted of a faculty member, one doctoral student research assistant, and an MSW student. The team searched the literature using the specified key terms and met weekly to discuss articles identified for possible inclusion in the study. This process was continued until saturation was met. Due to the heterogeneity of studies found, we each extracted and compiled study characteristics in tables describing the sample size, data collection methods, study design inclusive of the intervention, and key findings. The research team then examined the tables and individually classified the interventions into categories. The three interventions found to retain African Americans in HIV treatment were (1) outreach and ancillary support services, (2) theory- and perspective-based interventions, and (3) the use of intervention manuals to manage HIV treatment.

RESULTS

The team examined a total of 798 studies. Of these, 13 intervention studies met the eligibility criteria for inclusion in the review. Summaries of the interventions were compiled according to those that engaged African Americans in HIV medical self-care symptom management (see Table 1) and those that engaged them in ARV medication adherence (see Table 2). Three intervention categories were found to engage African Americans in HIV treatment.

Outreach and Ancillary Support Services

Six studies used outreach and ancillary support services to engage African Americans in HIV treatment. In a multisite, national study of 773 participants, Cabral et al. (2007) found that appointment reminders and problem-solving ongoing issues with providers reduced gaps in care. The study sample
was diverse and included low-income African Americans across multiple sites on the East and West coasts and in the Midwest. Naar-King et al. (2007) examined a national study across four different sites and found that outreach initiatives that focused on improving appointment attendance improved patient linkage to financial resources and reduced substance abuse among a sample of 104 newly diagnosed individuals.

All study participants were adults, 75 percent of them were male, and the study setting was three clinics in the Midwest. They found that READY improved ART retention by 50 percent, with no differences reported on the basis of length of the intervention. However, results may not be generalizable due to the small sample size and focus in one city. Bogart et al. (2012) evaluated the Treatment Advocacy (TA) program, which used client-centered counseling, advocacy, and resource referrals to engage them in care. TA clients used more self-care and had fewer unmet social needs. Although the use of a control group of non–TA clients was a strength of the study, the lack of random assignment was a major limitation. Results may also be due to extraneous factors prior to the intervention, because participants were already clients of the program before the study.

Two studies used ancillary support services as interventions to improve retention in HIV treatment. Messeri, Abramson, Aidala, Lee, and Lee (2002) examined whether support services such as transportation, case management, mental health, substance abuse, and housing services improved retention. They recruited 577 adults from 43 agencies in New York City through random sampling. They found that, with the exception of transportation services, access to case management, substance abuse

<table>
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<td>Bogart et al. (2012)</td>
<td>Community-based participatory research</td>
<td>Diverse sample of 121 participants (40 percent African American, 34 percent white American, and 24 percent Latino American).</td>
<td>Treatment advocacy programs (TA) that aim to engage clients into care and support antiretroviral treatment</td>
<td>TA participants (versus non-TA participants) used more social services programs and had fewer unmet social services needs.</td>
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<td>Enriquez, Cheng, McKinsey, &amp; Stanford (2009)</td>
<td>Pre–post group design with no control group</td>
<td>The sample consisted of 28 participants (71 percent African American and 29 percent white American).</td>
<td>READY intervention using nurse clinicians met to discuss past experiences taking ART and prior obstacles, and create new strategies</td>
<td>Results indicated that 50 percent of participants became adherent to ART and 79 percent remained so after 12-month follow-up. Treatment length did not make a difference.</td>
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<td>Feaster et al. (2010)</td>
<td>Mixed-method study</td>
<td>The sample consisted of 136 low-income urban African American women.</td>
<td>Structural ecosystems therapy (SET)</td>
<td>SET was significantly more likely to move patients to high adherence levels (95 percent and above) when the community approach was used.</td>
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<td>Fournery &amp; Williams (2003)</td>
<td>Convenience sample</td>
<td>A sample of 48 HIV-positive African American women with low health literacy rates.</td>
<td>ART adherence and low-literacy populations intervention</td>
<td>Participants liked the format of the book and tapes. Contents and structure of the materials were believed to be realistic, readable, and culturally appropriate.</td>
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<td>Gardner et al. (2005)</td>
<td>Prospective study with randomization</td>
<td>Diverse sample (N = 271): 156 African American, 80 Hispanic American, 17 White, and 18 other.</td>
<td>Antiretroviral Treatment Access Study</td>
<td>Participants older than 40, Hispanics, those newly diagnosed and without a recent crack cocaine addiction were more likely to have two visits with a provider.</td>
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<td>Weaver et al. (2005)</td>
<td>Longitudinal randomized trial</td>
<td>Diverse sample of 322 participants (59 percent African American; 22 percent white, and 12 percent Hispanic).</td>
<td>Cognitive–behavioral stress management intervention on ART adherence, health, and psychosocial factors</td>
<td>Lower social support was associated with greater use of avoidance coping strategies, which was, in turn, related to poorer ART retention and high viral loads.</td>
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linkage, and mental health services increased treatment retention. Similarly, Sherer et al. (2002) analyzed retrospective clinical data of 2,647 patients in a public hospital in Chicago. They found that retention increased between 15 percent and 18 percent for patients who received case management, transportation, mental health, or substance abuse assistance services.

**Theory- and Perspective-based Interventions**

Three studies used theory- and perspective-based HIV treatment retention interventions. Structural ecosystems therapy (SET) was used to reduce isolation by engaging African Americans and their families in the HIV care process (Feaster et al., 2010; Mitani, Prado, Feaster, Robinson-Batista, & Szapocznik, 2003). After two sessions of SET, family relational factors were found to predict treatment engagement for 49 low-income, African American mothers (Mitani et al., 2003). It is a limitation of the study that family relational variables were measured solely through mothers' self-reports. Feaster et al. (2010) found that SET was significantly more likely to move low-income, urban, African American women to high adherence levels (95 percent and above) when the community approach was used. In both cases, self-report may enable participants to overestimate their adherence. There is a need to assess the effectiveness of SET for men. Alternatively, Gardner et al. (2005) found that strengths-based case management was more likely to retain newly diagnosed individuals, individuals over 40 years of age, Hispanics, and participants who were not recent crack users in at least two visits with an HIV provider.

**Intervention Manuals**

Four studies used manuals as interventions to engage African Americans in HIV care. Corless et al. (2012) examined the level of general self-efficacy among a diverse sample that used self-care symptom management strategies. African Americans in the high self-efficacy group used fewer self-care activities than white and Latino participants. Fourney and Williams (2003) used a combination of a cartoon book and cassette tapes to educate African Americans about HIV adherence. They found that participants with lower literacy liked both interventions and believed that the materials were understandable and culturally appropriate. In another study, nurses used modules during home visits and provided follow-up telephone calls to provide therapeutic and emotional support for African American mothers with HIV (Miles et al., 2003). Mothers using this intervention reported fewer feelings of stigma, higher physical functioning, and reduced depression than those who received usual care.

**DISCUSSION AND THE SOCIAL WORKERS’ ROLE**

Social workers play an important role in the development of secondary prevention interventions to engage individuals in an outpatient HIV treatment setting (Strug, Grube, & Beckerman, 2002). Social workers play a role not only in delivering interventions, but also in adapting existing interventions and developing new ones (Wheeler, 2007). However, although social workers have been at the forefront of HIV/AIDS services, they all too often work in secondary roles or, worse yet, do not reveal that they are social workers (Linsk, 2011).

Social workers act as the conduits and facilitators of communication between patients and health care providers. The social workers’ mediating role between patients and providers can help foster adherence to HIV medication and self-care regimens. Ribner and Knei-Paz (2002) used a narrative research approach to identify factors that contribute to successful engagement between clients and their social workers. Positive connections with social workers was defined as having an “anchoring experience” to a specific worker; collaborating with a social worker; flexibility in scheduling and a social worker’s willingness to make home visits; regular communication on the phone; and finally, the feeling that the social worker was a client advocate. It is imperative that social workers develop similar methods to capture the narratives of HIV-positive African American clients to widen the base of understanding of where social services provision has failed to meet the needs of this population (Vyavaharkar, Moneyham, & Corwin, 2008), as well as the factors that have contributed to positive and conducive relationships between African American service users and their social workers.

Outreach and ancillary services were found to be necessary to improving entry into and retention in HIV primary care for African Americans. This finding is supported by literature indicating that case management that focuses on ART retention and frequent telephone contacts by providers improves the health and increases survival rates of patients.
living with HIV (Cunningham, Wong, & Hays, 2008; Giordano et al., 2007). Interestingly, results from the review suggest that patients most at risk of disengagement from HIV care might benefit the most from these services. Similar studies found that a combination of outreach and ancillary services improved HIV treatment retention for hard-to-reach populations such as substance users (Altice et al., 2004). Social workers can also improve retention by conducting periodic client risk assessments to identify sources of instability, including homelessness, unemployment, substance abuse, and mental health needs among patients in HIV care (Mallinson, Rajabian, & Coleman, 2007).

Intervention manuals were used to engage African Americans in medical self-care and ART. An interesting finding was that interventions that improved self-efficacy reduced HIV self-care and medication practices among African Americans (Corless et al., 2012). This finding contradicts a study conducted by Simoni, Frick, and Huang (2006) who found that higher self-efficacy improved ART retention and adherence among African Americans and Puerto Ricans even after a three-month follow-up. In addition, Fourney and Williams (2003) focused on the improvement of self-efficacy and retention to ART treatment regimens by engaging participants in the development of culturally relevant and understandable learning tools. Findings suggest that programs should review their current HIV-related educational materials to ensure both the legibility and applicability of these sources of information to the lived experiences of African Americans.

Social workers can also tailor existing outreach and educational materials by using methods such as cognitive interviewing with small groups of African American clients to develop, pilot test, and test the relevancy and literacy of HIV treatment manuals. Raja, McKirnan, and Glick (2007) tailored a peer-based Treatment Advocacy Program (TAP-Sinai)—originally developed for gay and bisexual HIV-infected men—to the specific needs of poor, urban, HIV-positive African American patients. They used focus groups with African American community leaders, peer educators, and clinical staff to design a peer-led intervention program.

Scholars used SET and strengths-based case management to improve HIV treatment retention (Feaster et al., 2010; Gardner et al., 2005; Mitran et al., 2003; Gardner et al. (2005) found that strengths-based case management reduced gaps in care by improving appointment attendance. In addition, SET was used to reduce isolation by bridging patients, their families, and providers together as integral components of the HIV treatment team. In addition to SET, social workers may want to review alternative empirical research using theory- and perspective-based interventions to retain patients with various medical conditions in treatment.

Of concern is that no intervention studies addressed mistrust as a retention barrier. Many scholars believe that HIV treatment noncompliance among African Americans stems from their mistrust of the health care system brought on by exploitation of health promotion efforts of the U.S. government and by university research (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Social workers can play a critical role in addressing this significant gap in the literature. An essential element of addressing African American clients’ mistrust is grounded in social workers’ consistent and earnest efforts to respond to the damage caused by bias, prejudice, and stereotypes as well as HIV-related care discrimination (Hall, 2007; Kennedy, Mathis, & Woods, 2007; Smedley, Stith, & Nelson, 2002). Social workers can meet patients and intervene with health care professionals by participating in educational seminars and grand-round discussions about the impact of mistrust on retention in HIV care.

Recent national policy initiatives are demanding that health care professionals provide innovative care that is comprehensive, cost-effective, and prevents medical crises by using evidence-based strategies that retain patients in care. The Patient Protection and Affordable Care Act (ACA) is one of the most important pieces of legislation in the fight against HIV/AIDS (CDC, 2012). The ACA improves access to insurance for people living with HIV/AIDS because the act expands health insurance coverage, helps individuals retain the coverage they have, and lowers the income threshold that will enable some previously ineligible individuals to become eligible for Medicaid prior to AIDS diagnosis (CDC, 2012). This enables individuals to become engaged in HIV care earlier in the course of their disease. Beginning in January 2014, most individual and small group health plans will be required to provide “essential health benefits” (EHB), a package of health services defined broadly by the ACA but customized by each state (National Association of Social Workers [NASW], 2012). Social workers should be aware of the EHB development process in their states to
ensure that their state EHB plan addresses the needs of people with chronic diseases and that care access is maintained and strengthened (NASW, 2012).

The U.S. Department of Health and Human Services (HHS) Healthy People 2020 initiative is another example in which practice can have policy implications. Overarching goals of Healthy People 2020 are to help patients attain care, help patients live longer lives, achieve health equity, create social and physical environments that promote health, and promote quality of life and health behaviors across all life stages (HHS, 2013). The ACA and Healthy People 2020 have complementary goals to improve health outcomes, especially for patients previously disengaged from care. Social workers should not only familiarize themselves with national policy, but also become knowledgeable about local policy that affects this disenfranchised population.

REFERENCES


