Published in final edited form as:

Home Health Care Manag Pract. 2011 December ; 23(6): 421–427. doi:10.1177/1084822311405457.

Promoting Self-Care Management among Persons with Serious Mental Illness and HIV

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Abstract

People with a serious mental illness (SMI) along with HIV have complex health conditions. This population also has high rates of poverty, difficulty in sustaining regular housing, and limited supportive networks. Typically, the combination of psychotropic and HIV medication regimens is complicated, changes frequently, and requires coordination among multiple providers. Furthermore, fragmented and divided primary health care and mental health care systems present substantial barriers for these individuals and for the public health nurses who care for them. In this paper, we present “real world” case studies of individuals with SMI and HIV and the self-care management strategies used by nurses to address medication and treatment management, build interpersonal skills, and develop sustainable health networks. The case studies can be used for quality improvement discussions among practicing public health nurses and for instructing nursing students in a self-care management approach.

Keywords

Serious mental illness; HIV; adherence; advanced practice psychiatric nurse; self-care management

Individuals with serious mental illness (SMI) who are also HIV positive present substantial challenges for public health nurses. For these clients, impaired mood and cognition further complicate the organizational, planning, and decision-making skills needed to achieve positive outcomes. Psychotropic and HIV medication regimens change frequently, often have negative side effects, involve a large number of medications, and require coordination among multiple providers. In addition, individuals with SMI often have high rates of

poverty, difficulty in sustaining regular housing, and a limited supportive network. Furthermore, a fragmented health system that divides mental health care from general health care presents substantial barriers to these individuals and to the nurses who care for them. In this paper, we present three “real world” case studies to illustrate thorny areas commonly experienced by clients with co-occurring SMI and HIV and by their nurses. The problem areas are medication management, relationship skills, and sustainable health networks. The case studies can be used by nursing students when learning about self-care management approaches and by practicing nurses to improve the quality of care for this population.

The advanced practice psychiatric nurses and individuals in the case studies participated in a randomized controlled trial (RCT) that examined the effectiveness of an advanced practice registered nurse (APRN) intervention provided in the community for individuals with co-occurring SMI and HIV. Clients’ names and any possible identifying characteristics have been changed to protect the confidentiality of the clients. To provide sufficient background on the challenges that these clients face and that community-based nurses face in providing their care, we present the demographic, clinical, and social characteristics for the total subsample of 128 clients who received the nurse intervention during the RCT.

Background

SMI is defined as a mental, behavioral, or emotional disorder that results in functional impairment that substantially interferes with major life activities (U.S. Department of Health and Human Services, 1999). SMI diagnoses include schizophrenia, schizoaffective disorder, bipolar disorder, or major depression with psychosis. These illnesses are characterized by significant functional impairment resulting from mood, behavioral, or cognitive disability (Druss et al., 2009). Approximately 12-15 million U.S. adults aged 18 years and older have an SMI (Hudson, 2009). Nearly 60% of adults with an SMI report one or more chronic medical disorders, such as hypertension, arthritis, or diabetes mellitus (Druss et al., 2009). Severe impairment of social functioning roles is a significant barrier to treatment success for both psychiatric and medical illnesses.

People with SMI are at higher risk of contracting HIV than the general population. HIV prevalence in the general U.S. population is estimated to be approximately 0.37% (Centers for Disease Control and Prevention, 2008), whereas the prevalence of HIV among persons with SMI is 3%-7% (Blank, Mandell, Aiken, & Hadley, 2002). SMI clients are highly vulnerable to contracting HIV partly because of their disadvantaged social status and exposure to poverty, which places this population in contact with high-risk populations (Parry, Blank, & Pithey, 2007). Persons with an SMI have also been found to have higher rates of substance abuse, homelessness, homosexuality, and sex for sale, all of which are risk factors for infection with HIV/AIDS (Bogart et al., 2006).

Participants: Urban Residents with SMI and HIV

Individuals with SMI who had HIV were recruited from a large urban setting in the mid-Atlantic region of the United States. APRNs, with experience and a master’s degree in behavioral health, made weekly visits over 12 months with the 128 individuals in the study’s experimental subsample. The study began in 2004 and ended in 2008. The APRNs focused on developing the client’s self-care management skills, giving attention to medication and overall treatment adherence, interpersonal skills, and the building of sustainable networks in their community. The nurses interacted with clients in their homes, at treatment facilities, in the community, or in the office of various general medical and mental health providers.

Table I shows demographic features of the 128 clients who received the nurse intervention. The mean age of participants was 43.9 years. Slightly more than half were men (52.3%).

Most were Black (81.2%) and had less than a high school education (51.9%). Nearly two-thirds were never married (61.7%). Most were unemployed (89.1%), and few had competitive jobs (6.3%). Over one-third of study participants lived alone (35.2%), and less than one-quarter lived with spouses (10.2%) or children (8.6%). At baseline it had been 10 years on average since clients had tested positive for HIV.

Table II summarizes symptoms and risk behaviors of the 126 final study participants in the experimental group. Over half of the experimental group had psychotic symptoms (57.1%) and/or affective symptoms (84.7%), over half used substances (82.7%) and over one third had risky sex behaviors (40.8%). Most participants had a medication adherence problem (85.3%), which included logistical problems, such as the inability to obtain or pay for a prescription (45.7%), and medication side effects (71.1%). Nearly three-quarters had a general medical problem, such as pain (77.6%), that significantly inhibited their ability to function (72.4%). More than one-third (35.7%) were hospitalized during the study for a major medical problem, approximately one-quarter (24.5%) had a psychiatric hospitalization, and 13.3% was admitted for drug or alcohol rehabilitation. Almost all met the poverty level (94.9%), more than a third had been incarcerated in the past year (36.7%), and nearly one-third had a housing problem in the past year (32.7%).

To summarize, the participants in the RCT were extremely vulnerable and therefore were challenging clients. The nurses who delivered the intervention in the RCT used a self-care management approach.

Self-Care Management

Self-care management is an approach used by nurses to engage patients in the process of shared decision making about their health. The self-care management approach guides patients toward a sense of meaning and purpose even while living with the challenges of co-occurring SMI and HIV. Living with comorbid conditions, one of which is an SMI, and having impaired cognition, low health literacy, and difficulties in navigating the health care system all affect self-care management (Riegel et al., 2009). Nonetheless, self-care and self-management strategies are tailored to maximize the individual's capacity to care for him- or herself. Nurses coach patients to care for themselves and provide the bridge to recovery by assessing the strengths and weaknesses of their clients. They use the client's strengths to build internal resources for self-care management.

Nurses use educational materials to teach patients about their illness and recovery and to help them set and achieve realistic personal health goals. They help patients acquire the knowledge and skills to independently manage their illness (Whitley, Gingerich, Lutz, & Mueser, 2009). Using the self-care management approach, nurses employ individually tailored cognitive, behavioral, and motivational interventions. Working from the premise that everyone can achieve optimal health, the nurse focuses on stress vulnerability; social support; medication management; relapse prevention; coping skills to deal with stress, problems, and symptoms; strategies for getting needs met in the mental health and medical system; and drug and alcohol use (Hasson-Ohayon, Roe, & Kravetz, 2007).

The case studies reflect on the self-care and recovery of individuals with challenges in the areas of medication and health care management, interpersonal skills, and sustainable health networks.

Case Study 1: Medication and Treatment Management

Medication adherence is difficult for individuals with co-occurring SMI and HIV because of deficits in attention and concentration, working memory, cognitive flexibility, and motor

dexterity. The organization required to manage large numbers of medications prescribed for different times during the day is often a source of great distress for clients. Furthermore, medications are often prescribed by different providers and obtained from multiple pharmacies. Joanne's case, presented below, illustrates these issues.

Joanne is 47 years old and lives alone. She takes 18 different medications (3 for HIV, 3 for mental health problems; 3 to prevent opportunistic infections; 2 for hypertension, 1 for allergies, 2 for vitamin replacement, 2 for gastroesophageal reflux disease, and 2 to prepare for upcoming sex change surgery). Her medications were prescribed by three providers and filled at two pharmacies. In addition, the medications were refilled at various times of the month. Joanne admitted she was confused by her medication regimen and was often not adherent.

Joanne has a diagnosis of schizophrenia. Schizophrenia affects the frontal region of the brain and is associated with impaired executive function, which manifests as problems with organization, decision making, planning, and judgment. The APRN assessed that Joanne's problems with executive functioning were severe. At the initial visit, the nurse found Joanne's medication bottles scattered all over her apartment. Joanne did not know what medication she was taking, and she did not comprehend the directions. She reported that her pills had been stolen on several occasions. Her apartment was located in a high-crime district. Bottles of pills were found throughout the apartment with old, soiled, or missing labels. Sometimes pills were never found or were unidentifiable because they were outside of the pill bottles.

The APRN's first step in Joanne's case was to establish a valid list of medications. Joanne and the nurse gathered and recorded all the medications in her house. Each medication was associated with a prescriber and a pharmacy. The nurse called each provider's office to validate the list and doses of each prescribed medication. Once a valid list was established, the nurse examined the list for inconsistencies, medication duplication, and incompatibilities. The nurse considered the frequency, dose, and special considerations for ingesting or storing the medications within the context of Joanne's usual patterns of waking, sleeping, and eating. Any logistical problems, such as obtaining refills, as well as side effects and nonadherence were documented by the nurse. Joanne and the nurse discussed alternatives and ways to improve adherence. They made a list of alternative plans for managing medications, which the nurse later discussed with the prescribers and the pharmacists. Once a validated medication list was constructed, Joanne and the nurse made copies for Joanne to carry in her purse—one for each prescriber and one for the pharmacy. Updates to the medication list could be handled by the pharmacist.

The next step was for Joanne to select one pharmacy for obtaining medication and for consistent support with medications. Selecting the pharmacy was the client's choice because she had an opinion about where she had experienced the most respectful service. It is not uncommon that people with SMI are treated poorly by retailers selling goods. For this reason, clients are often savvy about where to get the best services. The role of the nurse is not to recommend a particular pharmacy but rather to guide the client to the pharmacy of his or her choice. Once Joanne selected the pharmacy she preferred to do business with, the nurse helped her establish a relationship with one particular pharmacist. Consistent provider relationships work best with individuals who have impaired executive functioning. The nurse and Joanne worked with the pharmacist to develop an automatic medication refill schedule. Joanne was given the pharmacist's phone number to call with medication problems. By making the pharmacist central to medication management issues, the client could get comfortable asking one person questions about side effects and information related to the medication. It also ensured that the client was able to obtain timely refills and

minimize gaps in the supply. Weekly visits by the nurse to work with the client reinforced patterns and routines.

Assessment of cognitive strengths is essential to the development of a self-care approach, particularly the extent to which the client is able to organize, make decisions, and remember instructions about medications and refills. Therefore, the nurse administers the Mini-Mental Status Exam (MMSE), which provides information about short- and long-term memory, the ability to organize and follow directions, insight, and judgment. With the results of the assessment, the nurse can formulate strategies that are tailored to the client's needs. For example, the nurse worked with Joanne by using organizational and reminder strategies. A place in Joanne's home was identified to keep all pills. The nurse set up a seven-day pill box organizer and taught Joanne a double-check method for filling the compartments. A system builds confidence about self-managing medication. Many return visits by the nurse were needed to reinforce this system, but over time it became routine. Joanne was encouraged to teach her case manager how she organized her medication. The nurse taught Joanne's case managers, pharmacists, and physician providers about the medication systems and encouraged them to reinforce these self-care management practices with Joanne. After 12 months, Joanne consistently used a pill box organizer, was 95% adherent to her medication regimens, and was contacting the designated pharmacists to resolve logistical and side-effect problems with her medication. Recovery from symptom exacerbations was promoted by building a manageable system for consistency of treatment.

Case Study 2: Relationship and Social Skill Building

People with an SMI have difficulties forming and sustaining relationships. Few are married, and rates of separation or divorce are high. Individuals with co-occurring SMI and HIV may be seen as or perceive themselves to be social outcasts and are often shunned by family and others who disapprove of their lifestyles or sexual preferences. The following case study shows how social isolation affects both medication adherence and social functioning.

Tyrone is a depressed 50-year-old African American who has a bipolar illness and HIV. Previously married with children, he left his family for a to be with another man. Tyrone's volatile temper and threatening behavior kept him isolated. He was often in abusive and sometimes unsafe relationships and situations. He had been arrested for assault on several occasions. Because of his frequent anger, people tended to keep him at a distance. He felt he had little control over his life or his current circumstances. At the time of first contact with the nurse, Tyrone used crack cocaine, particularly when depressed and feeling unhappy. When using illicit drugs, Tyrone stopped taking all medications, avoided care givers, and neglected his personal care.

Forming a therapeutic alliance with Tyrone was initially difficult. He had little trust of others, especially providers. Initially, he resisted working with the nurse. When he was using crack cocaine, the nurse would either avoid contact with him or join with the case manager to make home visits. Otherwise, the nurse continued to establish contact and treated Tyrone with respect and dignity. Over time, he began to talk with the nurse about his depression and the difficulties he faced with his former wife and family. As a result of this initial and consistent therapeutic relationship, Tyrone began opening up to other relationships. He realized that his abuse of substances gave him less control and placed himself and others in jeopardy. He became increasingly receptive to education about interpersonal skills and barriers caused by stigma and depression.

In Tyrone's case, cognitive-behavioral therapy (CBT) helped to build interpersonal skills and capacity for meaningful relationships. CBT promotes a collaborative and mutual relationship, reinforcing the notion that self-care and management are client responsibilities. The nurse worked with the client to identify distorted or dysfunctional thinking patterns that influence mood and behavior. The client learned to identify, evaluate, and modify thoughts in order to produce symptom relief and more functional interactions with himself and others. As life situations would arise, the nurse would focus on the specific context to examine thoughts and beliefs. CBT has a myriad of helpful tools and techniques to teach the value of personal boundaries, identify negative automatic thinking patterns, and build interpersonal skills. Some tools used by the nurse included written or experiential homework and feedback sessions to encourage mutual participation for the nurse and client. Timing, regular contact, visual cues, and simple instructions facilitate CBT for individuals with impaired cognition.

The use of CBT techniques had positive outcomes for Tyrone. He began a 12-step program that he had previously resisted. He made regular and appropriate contact with mental health providers where he previously was avoidant, which enabled improved self-care and control of his own health. He also slowly began to reconnect with family members, which greatly improved his mood. In addition, he decreased risky sexual behaviors and improved adherence to his medication regimens. The nurse modeled a positive relationship, and the client found that his relationships with others were more satisfying. Relationships are the basis of healing and recovery. Consistency in relationships over long periods of time helps to reinforce the social skills needed to form and sustain additional positive relationships.

Case Study 3: Sustainable Health Networks

Building supportive networks for individuals with an SMI is central to recovery and self-care. The nurse must be knowledgeable about system-level problems and client-level problems, because they are intricately related. The mental health, substance abuse treatment, and general health care systems often operate independently and do not communicate with one another efficiently. This leads to different financing arrangements and policies (Institute of Medicine, 2006). These systems are virtual silos of care and often a nightmare for consumers to negotiate. For individuals with an SMI, negotiating this fragmented health care system is not only burdensome but can be perilous and exacerbate symptoms (Hudson, 2009).

Compared with the general population, people with an SMI have less access to general health care and receive poorer-quality care when accessed (McIntyre, 2009; Rothbard, Miller, Lee, & Blank, 2009). Consumers are frequently concerned, often legitimately, that their general health care needs may be dismissed as symptoms of their mental illness (McIntyre, 2009). Research has documented that the general medical complaints of persons with an SMI are often ignored, and thus major health problems go undetected and untreated (McIntyre, 2009). Other studies describe long wait times, unsupportive staff, disrespectful communication, and even ridicule (Hahn, Speliotis, & Bachman, 2008). Therefore, consumers with an SMI sometimes do not seek help from primary care providers to avoid encounters in which they are likely to feel misunderstood and dismissed. Recent evidence of the outcomes associated with poor physical health and SMI is stark. Persons with an SMI die 25 years earlier than those in the general population (Colton & Manderscheid, 2006). One study showed the average age of death to be 51 compared with 76 for Americans overall (McIntyre, 2009).

Jerome, a 47-year-old single African American, lives alone in a one-bedroom apartment in an apartment complex known for high rates of crime and violence. He received a diagnosis of schizophrenia at age 19 and acquired HIV through sex with

a female at age 41. His case is complicated by hypertension, obesity, asthma, sleep apnea, and non-insulin-dependent (Type II) diabetes. He takes 13 medications (2 for hypertension, 4 for HIV, 2 for diabetes, 2 for mental health, 1 for cholesterol, and 2 inhalers for asthma). Jerome also has anxiety and stops taking his medications when his symptoms become overwhelming. During the study, he was hospitalized twice for medical problems.

Jerome required physical and mental health care management throughout the study. He had a primary care provider, a psychiatrist, and an infectious disease doctor, but he was confused about whom to call when. Jerome often called the wrong provider and was told to call another provider. Jerome self-managed his health care needs by going to the emergency department (ED), which he found convenient, easier to access, and less confusing given that he could access all of his needs in one place rather than from many. However, Jerome also experienced long wait times in the ED and felt stigmatized. He expressed feeling ridiculed and ignored by staff. When he would describe his physical symptoms, staff attributed the symptoms to his mental illness.

Jerome dreaded going to the ED. For this reason, Jerome's health care needs often went unmanaged; consequently, he required frequent hospitalizations. During both of his inpatient stays, his antiretroviral and psychotropic medications were not administered because the providers lacked access to reliable information about Jerome's treatment regimen.

The APRN began by bridging the various systems of care and providers. This took multiple calls to regular providers, home visits, and visits with Jerome while he was hospitalized or in the ED to coordinate with emergent and acute care providers. With the goal of maintaining consistent and regular contact for primary health care, the nurse helped Jerome establish positive working relationships with the primary care provider, infectious disease provider, and a psychiatrist. The nurse attended case conferences and accompanied Jerome to provider visits. These interventions helped Jerome and his providers understand his questions and interpret instructions. The nurse ensured that all providers had the same information about Jerome's medication regimen. Equally important, the nurse helped Jerome communicate his questions, symptoms, and concerns with each of his providers, building his confidence in such necessary interactions and furthering self-care potential. The organization of medications and treatment regimens began to make better sense to Jerome. With the nurse's help, Jerome learned to identify health problems and communicate with and use his health network appropriately.

Conclusion

Meeting the complex health care needs of individuals who have co-occurring SMI and HIV is a major challenge for home health nurses. This client population is extremely vulnerable to poor-quality care because of their cognitive impairment and underdeveloped interpersonal skills, societal stigma associated with mental illness and HIV, and a fragmented health care system that is difficult to negotiate. Despite the difficult circumstances these individuals face, their nurses help them recognize behavioral choices they are making, respond to barriers when they occur, and model and teach them how to take action that promotes health and encourages self-care. By developing meaning and purpose, the client grows to appreciate his or her successes, gaining a sense of self and place in society that is beyond the adverse effects of mental illness. The cases illustrated in this paper do not exaggerate the challenges faced by these individuals or the profound sense of joy they and their nurses experienced over small and large accomplishments.

The case studies presented here reflect meaningful results when self-care and recovery become the framework for nursing care within the health network. Consistent, collaborative relationships based on mutual trust, respect, and reciprocity are essential for developing a multifaceted healing system for recovery in these complex contexts. Endurance of healthy relationships promotes health and recovery. The case studies can be used for quality improvement discussions among practicing public health nurses and for instructing nursing students in a self-care management approach.

Acknowledgments

Source of Support: Preparation of this paper was supported by the Center for Health Outcomes and Policy Research, University of Pennsylvania School of Nursing, and the Center for Mental Health Policy and Services Research, University of Pennsylvania Department of Psychiatry. Funding support was provided by the National Institute of Nursing Research grants P30-NR-005043 ("Center for Nursing Outcomes Research," Linda H. Aiken, principal investigator), T32-NR-007104 ("Advanced Training in Nursing Outcomes Research," Linda H. Aiken, principal investigator) and R01-NR-008851 ("Nursing Intervention for HIV Regimen Adherence among SMI," Michael Blank and Linda Aiken, co-principal investigators).

Biography

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Table I

Demographic Detail (N=128)	Mean (SD) or %
Age	43.9 (6.6)
Gender	
Male	52.3%
Female	44.5%
Transgender	3.1%
Race	
African-American	81.2%
White	10.2%
Other	7.9%
Hispanic/Latino	10.2%
Education	
Less than high school	51.9%
High school or higher	48.1%
Current Employment	
Unemployed	89.1%
Competitive job	6.3%
Transitional employment	1.6%
Work training	1.6%
Work in sheltered workshop	0.8%
Other	0.8%
Marital Status	
Currently married	6.25%
Separated or divorced	27.4%
Widowed	3.9%
Never married	61.7%
Current Living Situation	
Alone	35.2%
In household with spouse	10.2%
In household with children	8.6%
In household with parents	4.7%
In household with siblings	1.6%
In household with relatives	4.7%
In household with friends	6.3%
In household with other mental health client	8.6%
In boarding home or PDR	4.7%
Substance abuse rehab	7.0%

Demographic Detail (N=128)	Mean (SD) or %
Temporary/emergency shelter	5.5%
Other	3.1%
Years Since Tested Positive	10 (5.7)

Table II

Summary of Physical, Psychological, and Social Problems	
N=126*	
Mental Health Problems	
Psychotic Disorder	57.1%
Affective Disorder	84.7%
Substance Abuse	82.7%
Risky Sex Behaviors	40.8%
Medications Adherence Problems	85.3%
Logistic problems	45.70%
Side Effects	71.10%
Major Medical Problems	72.4%
Pain	77.6%
Hospitalized for a medical problem	35.7%
Psychiatric Hospitalization	24.5%
Substance Hospitalization	13.3%
Social Problems	
Meet Poverty level	94.9%
Jailed in the last year	36.7%
Housing Problems in the last Year	32.7%

* Sample was reduced to 126 because 2 participants were ineligible for the study