

The Role of Patient Navigators in Building a Medical Home for Multiply Diagnosed HIV-Positive Homeless Populations

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ABSTRACT

Context: People living with human immunodeficiency virus (HIV) (PLWH) who are most at risk for falling out of HIV primary care and detectable viral loads include homeless and unstably housed individuals and those codiagnosed with behavioral health disorders. The patient-centered medical home (PCMH) is a model that promotes provision of comprehensive, patient-centered, accessible, coordinated, and quality care for patients. This initiative provided patient navigation to HIV-positive homeless and unstably housed individuals codiagnosed with a mental health or substance use disorder as a means to create an adapted PCMH to meet the specific needs of this population.

Objective: The purpose of this analysis was to characterize the roles and responsibilities of patient navigators as part of an effort to create a medical home for homeless and unstably housed PLWH with behavioral health comorbidities.

Design: Eighty-one in-depth interviews with clinic staff and 2 focus groups with patient navigators were conducted. Content analysis was performed to identify key roles and responsibilities of the patient navigators.

Results: Patient navigators played an important role in creating a PCMH by working with clients to schedule and complete appointments, develop comprehensive care plans, forging critical relationships with providers both within and outside of health care systems, providing holistic support to increase patient self-management, and assisting in achieving housing stability.

Conclusions: It may be necessary to adapt the traditional PCMH model to effectively meet the social, behavior health, and medical needs of homeless and unstably housed PLWH with behavioral health comorbidities. A patient navigator who can invest time in supporting and connecting these patients to needed services may be a key component in creating an effective PCMH for this population. These findings highlight the roles and tasks of patient navigators that may contribute to developing a PCMH specific to homeless and unstably housed PLWH with mental health and substance use comorbidities. Implementation of such a model has the potential to improve health outcomes (such as retention in care and viral suppression) for particularly vulnerable PLWH and thereby reduce the burden of HIV infection.

KEY WORDS: HIV, homeless, mental health, patient navigation, patient-centered medical home, substance use

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Antiretroviral therapies (ARTs) not only improve health outcomes for people living with human immunodeficiency virus (HIV) (PLWH)^{1,2} but also reduce rates of transmission.^{3,4} To maximize the benefits of ARTs, it will be critical

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to address barriers along the HIV care continuum, including linkage to care, retention, and prescription of ARTs for PLWH.⁵ Those most at risk for disengagement include homeless or unstably housed PLWH and those codiagnosed with substance use or mental health disorders.⁶ Homeless PLWH who experience co-occurring mental health and substance use disorders need access to services situated across a fragmented health care system but often lack the knowledge, resources, or skills to navigate them. In addition, the complex needs of these individuals require navigation of other social service systems for which traditional HIV case managers may not have capacity due to large caseloads or lack of training.⁷⁻⁹

The patient-centered medical home (PCMH) is a promising model that promotes provision of comprehensive, patient-centered, coordinated, accessible, and high-quality healthcare services.¹⁰ Among the general population, the PCMH model is associated with improved patient outcomes, including reduced all-cause mortality,¹¹ reduced health disparities, decreased emergency department and hospital visits,¹² and increased patient satisfaction.¹³ In HIV care, programs funded through the national Ryan White Program have been characterized as similar to PCMH in that they have a care team that addresses the comprehensive needs of the individual.¹⁴ However, there is a lack of information on characteristics of a PCMH model for PLWH. One study exploring characteristics of this model among Ryan White–funded HIV care clinics described implementation of holistic, comprehensive, and coordinated care through the use of physician-directed multidisciplinary care teams.¹⁵ The particularly complex needs of the homeless and unstably housed multiply diagnosed PLWH, however, may require an adapted kind of PCMH model. Most PCMHs provide comprehensive colocated services, but the patient must come to the facility. For PLWH who experience homelessness, having staff members who can go beyond organizational walls to provide and coordinate services may be important for reducing barriers to care.

Implementation of patient navigation in HIV care has been set forth as a strategy to facilitate such quality care delivery and coordination as a means to address barriers to needed services.⁹ Patient navigation models have been found to effectively improve quality of care and health outcomes and to reduce disparities in cancer care settings^{16,17} where they were originally utilized to support disadvantaged patients in moving through a complex and fragmented health care system.¹⁸ In this setting, patient navigators have been found to complete tasks for their patients by building a network between the patient, providers, and other actors in the health care system and community.¹⁹

A growing body of research has found that patient navigation within HIV care settings is associated with improved access to care, health care utilization, knowledge and skills, and health outcomes—particularly among disengaged PLWH.^{9,20,21} However, minimal research has been conducted to identify the key tasks and responsibilities of patient navigators in supporting PLWH. One study that investigated peer navigator responsibilities in connecting PLWH leaving jails to HIV care and other services identified key peer navigator duties as accompaniment to appointments, provision of emotional and practical support, trust and relationship building, and modeling behaviors.²² However, this intervention consisted of peer navigation-enhanced case management through a community-based organization focused on reintegrating clients into the community and engaging them in services; it did not take place within the context of building a PCMH aimed at systems integration and care coordination between behavioral health, housing, social service, and HIV primary care agencies. Furthermore, this study was not specific to homeless and unstably housed PLWH codiagnosed with behavioral health disorders. These key differences have the potential to impact the role of a patient navigator. The objective of this analysis was to describe the roles that have been undertaken by navigators across the United States in an effort to create PCMHs specifically for PLWH with behavioral health comorbidities who are experiencing housing instability. Therefore, this analysis will provide detailed descriptions of the navigator responsibilities that may be implemented or adapted in serving this population. A subsequent analysis will determine how effective such navigator tasks are within a PCMH context in improving health outcomes for this vulnerable population.

Methods

The qualitative data presented in this analysis are part of a larger national study sponsored by the Health Resources & Services Administration as a Special Project of National Significance (SPNS). Nine demonstration sites across the United States were funded to build a PCMH for multiply diagnosed homeless and unstably housed PLWH and include 2 key components: (1) systems integration with behavioral health and housing partner agencies and (2) an assigned SPNS navigator for each eligible participant.²³ Although position titles of intervention staff varied across sites (eg, network navigator, patient navigator), we will use the term “SPNS navigator” to describe all SPNS intervention staff. For this analysis, we collected qualitative data from staff across sites to identify common roles

TABLE 1
Staff Interviews (n = 81)

Administrative staff (eg, program director, medical director, program manager)	n = 21
Behavioral health staff/provider (eg, LCSW, substance use counselor, behavioral health NP, psychiatric NP)	n = 14
Case manager (eg, medical case manager, housing case manager)	n = 17
HIV primary care provider (eg, RN, MD, NP)	n = 12
SPNS navigator	n = 17

Abbreviations: HIV, human immunodeficiency virus; SPNS, Special Project of National Significance.

and responsibilities of SPNS navigators in achieving a PCMH for patients.

To increase the validity of our findings, we implemented a triangulated strategy by collecting data through both in-depth interviews and focus groups. For interviews, purposive sampling was used to recruit members of the care team and included at least one of each of the following staff from each site: behavioral health practitioner, standard-care HIV case manager, primary care provider, programmatic or administrative staff, and SPNS navigator. We worked with the SPNS project coordinator at each site to identify and inform staff members working in the previously listed capacities who provide or coordinate services for SPNS patients. Focus groups were conducted only with SPNS navigators, all of whom were invited to participate.

We developed standardized guides for both interviews and focus groups. The former was based on the principal components of PCMH; the latter focused on eliciting SPNS navigator experiences and background. Supplement Digital Content Table A (available at <http://links.lww.com/JPHMP/A268>) and Table B (available at <http://links.lww.com/JPHMP/A269>) illustrate the content areas and sample questions included in the interview and focus group guides, respectively.

All staff recruited for interviews agreed to participate (n = 81); 80 participants consented to audio-recorded interviews that were later transcribed. The interviewer took detailed notes for the one interview that was not recorded. Table 1 illustrates the number of each type of staff interviewed. SPNS navigators

from all sites were represented in the focus group sample (n = 2). All focus group participants authorized audio-recorded discussions, which were later transcribed. Table 2 describes the number of SPNS navigators, by level of training or experience, in each focus group. Focus group and interview samples were not mutually exclusive. The research team obtained approval to conduct this research from the Boston University Medical Campus institutional review board.

Analytic strategy

Each interview transcript was reviewed by 1 of 10 research team members to identify core concepts, which were then refined as a team and used to develop a preliminary coding scheme.²⁴ The preliminary scheme was implemented on a representative subset of the data (n = 26) by 6 researchers; each interview was coded by one researcher. Meetings were held to address coding inconsistencies, clarify definitions and criteria ambiguities, and add or delete codes. The final coding scheme, which consisted of 22 codes with respective definitions, was used to code the remaining interviews and subsequently for a second round of coding by 6 researchers (ie, each interview was coded by 2 researchers). To increase intercoder reliability, researchers met to discuss and resolve coding discrepancies between pairs of coders. A similar process was followed with the 2 focus group transcripts: 2 researchers conducted open coding to develop a coding scheme, which consisted of 60 codes and respective definitions. This was implemented on each transcript separately by 2 researchers who later met

TABLE 2
SPNS Navigator Focus Groups (n = 2)

	No. of Peer Participants	No. of Social Work-Trained ^a Participants	No. of Participants with Other Background or Training	Total Number of Focus Group Participants
Focus Group 1	3	2	6	11
Focus Group 2	2	3	6	11

Abbreviation: SPNS, Special Project of National Significance.

^aRefers to either BSW or MSW trained social workers.

to resolve coding inconsistencies. Thematic content analysis was conducted by reviewing coded passages to identify trends and draw conclusions. This analysis interprets findings from both interview and focus group data to increase validity of findings. Qualitative analysis software program NVIVO was used to facilitate coding and management of all qualitative data.²⁵

Results

Below, we summarize the roles and responsibilities taken on by SPNS navigators, from the staff perspective, in an effort to build a PCMH that effectively reduces barriers to engagement in continuous care for multiply diagnosed homeless and unstably housed PLWH. The results that are presented here are those tasks that were found to be present among the majority, if not all, of the 9 sites (see Supplemental Digital Content Table C, available at <http://links.lww.com/JPHMP/A270>, which includes participant quotes regarding the roles and responsibilities described in this section).

Client tracking and outreach for the out-of-care

A primary responsibility of SPNS navigators is tracking patients and conducting intensive outreach to engage them in care. Staff members described the benefit of having a team member who has time to find and follow up with out-of-care patients. Tracking refers to identifying clients who are not engaged in care, for example, by checking in with providers about which clients have missed appointments. Intensive outreach is then carried out by SPNS navigators to engage these clients using a variety of strategies, including regularly visiting “hot spots” in the community, communicating with other relevant service providers, and attempting to contact the client in various ways.

Identifying needs and barriers, and developing the care plan

SPNS navigators reported that addressing barriers to obtaining needed medical and social services constituted a considerable proportion of their workload. Among the most common barriers reported by the SPNS navigators were low literacy, distrust of service providers, illicit drug use, lack of insurance coverage or skills to enroll, and managing bureaucracies across different systems. In addition, a host of housing barriers were reported, including limited availability and affordability, housing program restrictions (eg, criminal record), and behavioral health-related issues maintaining housing (eg, illicit drug use). SPNS navigators

described using acuity tools with each client to identify social and medical needs and respective barriers. They then work collaboratively with each client and the care team to develop an individualized and holistic care plan specifying goals and identifying strategies to reduce barriers and achieve goals.

Supporting client retention in medical care

A number of key tasks were reported that support client retention in care. SPNS navigators reported considerable involvement in assisting patients to obtain, schedule, and remember upcoming medical appointments. Most notably, accompaniment to appointments both internally at the clinic and at external departments (eg, emergency departments) is particularly critical for patients with cognitive deficits or active substance use. This not only reduces barriers to getting to appointments but also provides an opportunity to improve communication and trust between clients and providers to obtain appropriate care. For patients who did not require accompaniment, coordination of transportation was reported as a valuable service that supported patients in their efforts to attend medical appointments.

Providing emotional support and encouragement

Much of the work that SPNS navigators reported doing with their clients was contingent upon trust within the patient-navigator relationship. Unsurprisingly, a significant component of the navigator role includes relationship-building, encouraging clients to complete tasks and achieve goals, coaching and education, and other strategies related to being attentive to their clients’ emotional needs.

Addressing stigma

SPNS navigators also help address issues of stigma in 2 ways. First, trust-building within the client-provider relationship helps mitigate the negative impacts of previous stigmatizing experiences within health care settings. Although this does not reduce external stigma, it does reduce the risk of stigma as a barrier to care. SPNS navigators also address the negative impacts of internalized stigma by working with clients to identify feelings of inferiority or shame and coaching clients to see their self-worth and value.

Coordinating services and educating about the service systems

SPNS navigators focus on coordinating the numerous services needed by their clients and navigating them through the various systems in which these services are situated. In fact, these are 2 areas in which

SPNS navigators seemed to take the lead (vs other team members). The amount of knowledge and time that these responsibilities require are amplified for this population. The SPNS navigators are not limited to working in health care systems; they have considerable experience working across multiple systems, including behavioral health, housing, benefits, transportation, and other social services. SPNS navigators provided insight on what “navigation” encompasses for this population: (1) educating clients on the variety of systems they need to access and (2) brainstorming with clients how to access services across these systems.

Connecting clients to behavioral health services

SPNS navigators play a critical role in connecting clients to needed mental health and substance use services. They collect information about the client that indicates need for such services and work closely with the health care team and partner agencies to assist clients in obtaining and completing referrals and adhering to treatment regimens.

Maintaining regular communication with providers

Critical to building the PCMH is that other providers recognize they do not have capacity to address all individual client needs and therefore should work closely with the SPNS navigators to do so. The other health care team members recognize that the SPNS navigators have the skills, knowledge, and flexibility to address clients’ nonmedical needs, making the care more patient-centered and reducing barriers to retention in HIV care. SPNS navigators reported frequent communication with other providers on their health care teams and at partner agencies to coordinate services for their clients. Providers also reported relying on the SPNS navigators for client updates to ensure that care is provided in a timely and appropriate manner.

Supporting patient self-management

SPNS navigators reported using a collaborative approach and motivational interviewing techniques with clients to promote self-management. Their unique role of facilitating and encouraging patient self-management is different from that of other specialized providers who promote self-management in specific areas (eg, medication adherence, managing other chronic conditions). SPNS navigators work with clients on broader self-management goals that address not only those topics but also other areas, such as documenting symptoms, understanding labs, coping strategies, skills for identifying resources, goal-setting and empowerment, and developing accountability.

Identifying, linking, and maintaining housing

SPNS navigators spend a significant amount of their time working with clients to address housing barriers in several ways: connecting clients to transitional or permanent housing resources; preparing clients for housing search and moving processes; identifying affordable housing options in the community; supporting clients in finding appropriate housing given their needs at that time; helping plan for sustainable housing; and following up regularly with housed clients to facilitate continued stability and engagement in care. This work requires relationship building with staff at local housing departments, other agencies that provide housing services (eg, housing case management), direct housing providers (eg, emergency shelters, supportive housing units), and private landlords. It also entails having a detailed understanding of clients’ needs and what they are capable of at the present time. SPNS navigators work closely with clients to determine what is needed to get on housing waiting lists (eg, paperwork, documentation), which housing options clients are eligible for, how they will pay for housing (eg, planning a budget), what services they will need once housed, how they will spend their time once they get housed, and what supplies they will need to maintain a stable living environment.

Discussion

To bridge the gaps that currently exist along the HIV care continuum, it will be critical to address the barriers faced by PLWH tenuously or not engaged in care. Homeless and unstably housed PLWH codiagnosed with substance use or mental health disorders are at a significantly higher risk of falling out of HIV care. Patient navigation within a PCMH model has the potential to reduce barriers and increase facilitators to engagement in care for this population. Adapting the PCMH model for this vulnerable population will require meaningful consideration of their complex needs and a robust understanding of the patient navigator role in addressing them. Our study identifies key responsibilities that SPNS navigators undertake to engage and retain this population in care and create a medical home for them.

Consistent with findings from other studies investigating HIV patient navigation, SPNS navigators work with each client to identify barriers to care and address them collaboratively by developing a realistic care plan with the client, primary care team, and other providers. They dedicate a significant amount of time tracking clients to keep them engaged in care; accompanying clients or coordinating transportation to medical and other appointments within

and outside of their agency of employment; assisting clients in obtaining, scheduling, and remembering needed appointments; and developing rapport with the client and providing emotional support.²² Furthermore, SPNS navigators mitigate the effects of past negative experiences in health care settings by modeling positive relationships with providers.

The results of this study are also consistent with the literature on patient navigation models in cancer care settings. We found that SPNS navigators have an intimate knowledge of, and well-established working relationships with, a network of providers and staff across the health care system, enabling them to coordinate needed services for their clients.¹⁹ In addition, it is important to highlight that SPNS navigators work with a variety of agencies that have not traditionally been considered a part of the health care system. Most notably, they work closely with staff from behavioral health agencies, housing agencies, social welfare and benefits offices, and other social service providers. We found that the SPNS navigators are the sole members of the team who have the capacity and responsibility to coordinate services across all of these systems. Not surprisingly, another key role of theirs is to educate clients about and help them plan for obtaining services from these various systems. This study also found that SPNS navigators are well-integrated into the health care team and communicate with the team consistently to ensure that all are aware of client circumstances.

Unlike findings in HIV and cancer care research, we found that SPNS navigators' approach to patient self-management is a holistic one that takes into consideration clients' overall life circumstances and needs at a given time. This may be because navigators develop strong relationships with their patients focused on gaining a deeper understanding of their clients' overall barriers and needs. It is also possible that the navigator's knowledge of and relationship with providers across a wide range of systems allow them to educate and model behaviors that clients can use to manage their variety of health care needs. While other HIV patient navigation programs have found that navigators effectively improve patient self-management, those findings have focused primarily on medication management.²¹ In this analysis, we discovered that in working with homeless and unstably housed PLWH with behavioral health comorbidities, SPNS navigators played an important role in assisting to develop self-management in areas beyond HIV medication adherence.

Finally, another unique characteristic of the SPNS patient navigator role is the considerable amount of work done with clients to obtain and maintain housing. The role of navigators in providing housing

Implications for Policy & Practice

- The traditional PCHM model may need to be adapted to effectively address the social, behavioral health, and medical needs of PLWH who are homeless or unstably housed.
- Integrating a patient navigator into the HIV care team may be an effective strategy to engage this hard-to-reach population in HIV care and treatment—and ultimately to improve their health outcomes—by accomplishing the following tasks:
 - tracking and providing outreach to disengaged patients;
 - working collaboratively to develop realistic goals and care plans;
 - supporting holistic patient self-management;
 - providing emotional support and helping reduce negative effects of stigma;
 - coordinating, connecting to, and informing the patient about services across many systems—including housing and behavioral health;
 - and keeping the health team informed about client circumstances.
- Therefore, this strategy has the potential to help cure the HIV/AIDS epidemic by closing gaps along the HIV care continuum.

assistance is critical because it provides a stability that is necessary to clients to work toward health care goals related to substance use, mental health, and HIV care. From a broader standpoint, this role may be instrumental in effectively closing the gaps across the HIV continuum of care, considering that unstable housing and behavioral comorbidities have consistently been identified as a barrier to HIV care.

By demonstrating to their clients where to access needed resources, who they can reach out to within different systems, how they are able to self-manage certain issues that arise, and what is needed to obtain and maintain housing, SPNS navigators have the potential to increase retention in care and housing among a population that is at great risk for disengagement. These navigators serve a unique role within the PCMH for multiply diagnosed homeless and unstably housed PLWH. Agencies that aim to provide services for these individuals may want to consider integrating a navigator trained and supported in the areas listed earlier into their healthcare team.

Limitations of this study included potential bias introduced by sampling restricted to Ryan White Program-funded sites, which work as part of a comprehensive team. In addition, 8 of the 9 demonstration sites are located in urban settings and therefore may have limited generalizability for HIV care providers in rural areas. We did not find any major differences

in navigator roles between urban and rural areas, but further in-depth study is warranted. Furthermore, our analysis examined navigator roles across different health systems (eg, community health centers, large university-based systems). Tasks may vary depending on the organization and team structure where a navigator works. Finally, we did not analyze navigator tasks by educational background and experience, which may impact the navigator role.

Our study illuminates key tasks that patient navigators may adopt or adapt as part of an effort to build an effective PCMH for homeless and unstably housed PLWH burdened with behavioral health comorbidities. This has the potential to improve health outcomes for a particularly vulnerable population and ultimately decrease transmission rates. Efforts are currently under way to examine the effectiveness of this model on clinical outcomes such as retention in HIV care and viral load suppression. Future research should examine the differential effects of type and amount of navigator encounters on patient outcomes for this population.

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