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Experiences of Women of Color with a Nurse Patient Navigation Program for Linkage and Engagement in HIV Care

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Abstract

Patient navigation, a patient-centered model of care coordination focused on reducing barriers to care, is an emerging strategy for linking patients to and retaining them in HIV care. The Guide to Healing Program (G2H), implemented at the Infectious Diseases Clinic at UNC Chapel Hill, provided patient navigation to women of color (WOC) new to or re-engaging in HIV care through a 'nurse guide' with mental health training and experience. The purpose of this study was to qualitatively explore patients' experiences working with the nurse guide. Twenty-one semi-structured telephone interviews with G2H participants were conducted. Interviews were transcribed and thematic analysis was utilized to identify patterns and themes in the data. Women's experiences with the nurse guide were overwhelmingly positive. They described the nurse guide teaching them critical information and skills, facilitating access to resources, and conveying authentic kindness and concern. The findings suggest that a properly trained nurse in this role can provide critical medical and psychosocial support in order to eliminate barriers to engagement in HIV care, and successfully facilitate patient HIV self-management. The nurse guide model represents a promising approach to patient navigation for WOC living with HIV.

Introduction

To achieve viral suppression and halt disease transmission, people living with HIV/AIDS (PLWHA) must be highly engaged with each step in the HIV/AIDS care continuum including diagnosis, linkage to care, retention, and, when necessary, re-engagement in care.[1,2] People of color living with HIV are consistently less likely to be engaged in HIV care than whites,[3–5] resulting in increased morbidity and mortality.[6] Additionally, women in the US are less likely than men to optimally engage in HIV care.[7] It is therefore unsurprising that women of color (WOC) have been found to have higher HIV/AIDS-related morbidity compared to all other groups.[6] Effective interventions to increase engagement in HIV care for WOC are urgently needed to address these health disparities.

Patient navigation is a patient-centered care coordination model often used with populations who are vulnerable to health disparities and poor health outcomes, focused on reducing barriers to care.[8] Patient navigators may be peers or lay health workers who are members of the community they are serving,[9–11] social workers, or nurses, depending on the level of knowledge and skills needed[8] and the funding source.[9] Patient navigation for linking and retaining PLWHA is an emerging, under-studied strategy, though initial findings are promising. Navigation for PLWHA provided by lay health workers has been found to reduce barriers to care, reduce viral loads, and increase engagement with providers and utilization of HIV primary care.[12] Peer navigators for HIV-positive individuals returning to their community after incarceration have also been successful in facilitating re-entry into HIV care and social services engagement.[9] However, few published HIV navigation programs have utilized nurses. One exception was an evaluation of community-based patient navigation provided by advanced practice nurses working with HIV-positive individuals dually diagnosed with serious mental illness which demonstrated a significant reduction in viral loads.[13,14] To our knowledge, no published studies of patient navigation for PLWHA have utilized an exclusively female sample, though HIV-positive women have been found to have treatment challenges that differ from those of men.[15]

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Introduction to Guide to Healing

The Guide to Healing Program (G2H) sought to link and retain HIV-positive WOC in HIV care. G2H was implemented at the Infectious Diseases Clinic at the UNC Health Care System in Chapel Hill, North Carolina, from January, 2011 through August, 2014. The principal component of the program was navigation, education, and autonomy support provided for up to 8 months by a licensed registered nurse (RN) with mental health training and experience known as a 'nurse guide'. Specifically, the nurse guide provided an orientation to care, care coordination, and regular phone contacts, utilizing a strengths-based perspective and motivational interviewing. The nurse guide received referrals from staff and providers of WOC newly seeking care in the clinic and those with retention in care difficulties. The purpose of this study was to qualitatively explore patients' experiences working with the nurse guide.

Methods

Study participants

Study participants were a sample of the women enrolled in the Guide to Healing Program. Women were eligible for the study if they had a minimum of one contact (phone or in-person) with the G2H nurse guide, and the first contact happened at least 8 months prior to recruitment so that there was opportunity for the patient to have completed the full nurse guide intervention. An effort was made to select a sample reflecting the clinical characteristics (length of time spent with nurse guide, current level of care engagement, and length of time since HIV diagnosis) and age of the larger cohort.

After an initial screening, eligible participants were contacted via telephone. Of the 36 women we attempted to recruit, we were unable to reach 14 (39%) of them, one (3%) refused to participate, and 21 (58%) agreed to participate in the study and were consented. Interviews were conducted by members of the Duke University evaluation team. The project received Institutional Review Board approval from both Duke University and the University of North Carolina at Chapel Hill.

Instrument development

Interview questions were developed by the research team in close collaboration with the nurse guide and clinic providers. Questions focused on experiences with the nurse guide, assessing participants' level of satisfaction and engagement with the program, quality and content of interactions, and suggestions for improvement. The semi-structured interview guide was pilot tested with three G2H participants, with minor revisions made for clarity and flow.

Data collection

Twenty-one semi-structured interviews were conducted via telephone. Prior to beginning the interview, informed consent was obtained verbally. All interviews were digitally recorded and ranged from 30 to 60 min.

Data analysis

Participant interviews were transcribed verbatim. Transcripts were compared to the audio recordings and corrected for discrepancies when necessary. Data was then managed and analyzed using QSR Nvivo® software version 10.0.[16] The analytic approach was informed by thematic analysis.[17] Researchers first familiarized themselves with the data by carefully reviewing the transcripts. Patterns in the data were then identified which informed code development. Each interview transcript was independently read and coded for content by two members of the research team at Duke University. When discrepancies emerged, researchers discussed the coding until consensus was reached. Overarching themes were identified as the relationships between the codes was explored, and relationships between conceptual categories and participant narratives were developed.

Results

Participants

All participants were African American or black (Table 1). The average age of participants was 45 years, with a range from 27 to 62. Most participants (76%) had incomes under $10,000. Respondents had varied levels of total time spent interacting with the nurse guide both in person and/or on the phone: 12 (57%) spent 90 min or more, five (24%) spent 30–90 min, and 4 (19%) spent less than 30 min. Upon beginning work with the nurse guide, nine participants were newly diagnosed, three were previously diagnosed but had never received treatment and were new to care, four had prior

Table 1. Characteristics of HIV Infected Women Receiving Care at the Infectious Disease Clinic at UNC Chapel Hill Interviewed for the Guide to Healing Evaluation ($N=21$)

Characteristic	
Age, mean no. years ± SD	44.8 ± 10.1
	n (%)
Race	
Black or African American	21 (100)
Health insurance[a]	
Private	1 (5.0)
Public	12 (60.0)
Uninsured	7 (35.0)
Annual income[a]	
Under $10,000	16 (80.0)
$10,000–$30,000	2 (10.0)
Over $30,000	2 (10.0)
Education level[a]	
Less than high school	9 (45.0)
High school	2 (10.0)
Greater than high school	9 (45.0)
Level of service with nurse guide	
Low	4 (19.1)
Medium	5 (23.8)
High	12 (57.1)
Primary patient type[a]	
New diagnosis/new to care	11 (55.0)
Prior outside care	5 (25.0)
Engaged and needing added support	3 (15.0)
Inconsistent	1 (5.0)

[a] $n=20$; data missing for one participant.

outside care and were new to the UNC clinic, three were engaged in care and referred for additional support, and one was inconsistently engaged in care.

Changes in hope and stigma

Most of the newly diagnosed patients reported having very limited knowledge about HIV prior to working with the nurse guide. Many reported previously believing their HIV diagnosis was a ''death sentence.'' For these patients, a primary lesson learned from the nurse guide was that if they adhered to antiretroviral treatment (ART), they could live a long life. This shift in perspective reduced their fear, increased their hope, and enhanced their motivation to adhere to treatment. One participant relayed:

> *(T)hat's where I was in life, you know, that I'm not going to be around for anything. That was the main focus at that time was to just get me into the mindset and the understanding that it was not a death sentence and I was not going anywhere, and as long as I took care of myself, once I got on the medication, take your medicine as you're supposed to, and everything will be fine. Once I got onto that mindset, everything started calming down and my tests were better and my CD4 levels and everything were better.*

Newly diagnosed women also expressed internalized and anticipated HIV stigma which they discussed with the nurse guide. One woman shared that an important lesson she learned from the nurse guide was that HIV was not shameful, and she should not segregate herself from her family because of it.

> *(A) lot of what I did know prior was from different things that I'd seen on TV, how the people that had gotten diagnosis that they live a segregated lifestyle because they didn't want their family or friends to know, and they separate themselves. And one of the main things that she told me was that, you know, you love your family, and your family loves you. Stay with your support group. You don't have to segregate yourself…[S]he told me to understand that there wasn't something that I should be ashamed of basically.*

Antiretroviral adherence, medication management, and laboratory test results

Respondents reported that the nurse guide stressed the importance of ART adherence and their laboratory test results. She also provided adherence support, regularly checking in with patients about their medication.

> *She would call to the house and talk to me to see how I was doing and let me know if my lab work came out bad or anything and make sure I was taking the medicines and stuff and just to see how I was doing.*

Some patients described contacting the nurse guide if they were experiencing side effects of ART, or to seek advice regarding medication interactions and safety.

> *You know, I would call her and say, hey, I've got a headache, could I take this medication, or I've got a bloated stomach, could I take that? Hey, I fell and I'm at the hospital here in town, and they want to give me this, can I take that?*

A few women reported not learning anything new about how to manage their HIV from the nurse guide because they learned what they needed from their medical provider(s).

> *Mostly those questions and answers, most of the time I asked the research and my doctor, or I really didn't get into that kind of stuff with [nurse guide]….*

Communication with providers

Numerous patients described that the nurse guide provided clarity when they were confused by information from other providers, or when other providers failed to give them needed information.

> *(W)hen I was going to the other providers before I started going to UNC, the other providers they weren't telling me what this was, what that means. Sometimes I have to go online or whatever. I don't quite understand it correctly. So she basically went through and sorted things.*

Patients also discussed learning from the nurse guide what to expect during their HIV care appointments and how to talk to their doctors and ask questions.

> *I liked the way she explained the doctors that were going to be around, how they would be and how I could talk to them. She was just very helpful.*

Another patient shared that she is now able to ask more informed questions about her health status.

> *Listen, when I go to my doctor I was told, don't be nervous, ask questions. Well, I got so now I've got little things down, I ask her [doctor] questions about my liver and my kidneys and stuff…*

Accessing resources

The nurse guide also assisted patients with accessing resources, including medication assistance, and community based services. Several patients commented on how she would go above and beyond to help them.

> *She helped me get everything that I needed in order to get me set up where I wouldn't have to pay for my pills because that was a real big problem.*

Another reported:

> *Well, she was very helpful because she helped me with resources and things here in [City], you know, to make a contact, different resources that I may need… She was—would go out of her way, well, do whatever she could do to get me whatever I may have needed…*

Relationship with the nurse guide and psychosocial support

A primary theme throughout the interviews was the patients' positive relationships with the nurse guide. Many discussed her kindness, heartfelt concern, and availability. Several mentioned that she gave them hugs. When asked what she liked best about working with the nurse guide, a patient responded,

> *Just her personality and her spirit. She is so outgoing and friendly and nice, and she let me know right out the gate that she was there for me, and just if you need a hug come here so I can hug you.*

The friendliness and concern of the nurse guide was perceived as genuine, making participants feel cared for.

I like [nurse guide] and I think she has done a lot for me because she is accessible and she has this smile on her face that doesn't make you feel like she is—you know how people just act like they care but they don't. But she does smile and she cares to help you. It is not like I am putting this phony smile on because I want you to feel cared for.

Patients reported enjoying their relationship with the nurse guide and their connection with her, particularly in the context of low social support from other sources.

[S]he is the sweetest lady and just for a person that didn't have any family here and I could call her and speak to her and tell her things. I enjoyed that a lot. Not only did I need it, I enjoyed it.

Some respondents noted the availability and reliability of the nurse guide, describing her as someone they could truly depend on.

Yeah, I had [nurse guide] on speed dial, and whenever I called she always answered…So she helped me a lot.

Several participants also appreciated the nurse guide's problem solving abilities.

She doesn't sit around and just say something to make you feel better. She actually finds a solution and I like her because of that, because a lot of times I didn't have any.

Transitioning out of G2H

Due to the time-limited nature of G2H, patients eventually had to transition out of regular contact with the nurse guide. A common theme when describing this experience was a sense of loss and sadness. A patient shared about her transition experience,

I was sad, emotional. They say she is still like in the office. I just don't get to talk to her or anything like that.

Other participants discussed being prepared for the transition and the nurse guide's continued, though limited, availability to them, which was seen as a sign of the authenticity of their relationship.

You know, she told me, and it wasn't don't call me no more, I can't help you anymore. It was, you know, this is the program that we were in, and this is what we were doing, but with the time limit that I was allotted for you I have to end that time. But if you still need me you still have my number.

While most participants were accepting of the transition out of G2H, one commented on the challenges of losing her comfortable relationship with the nurse guide, and her resistance to establishing new relationships in the clinic.

Sometimes you get started with somebody that you're comfortable with and then they'll take you to somebody else and you already got comfortable with like [nurse guide]. I already got comfortable with her so when I go there I don't want to have to see a whole lot of different people.

One respondent felt unprepared to engage in HIV care without the support of the nurse guide, and wanted to still work with her. In contrast, several women expressed a sense of readiness and autonomy surrounding their engagement in HIV care after their work with the nurse guide.

Yeah, I can honestly say I was ready at that point to not need that extra support. Because of the support that she had given me and everything, it was one of those, okay, you have to be a big girl now. You don't have that crutch to lean on any more…I was okay with it.

Another participant described owing her continued adherence to HIV treatment to her relationship with the nurse guide.

She [nurse guide] did a very good job with me. That's exactly why I'm still going to the clinic today, and I'm still taking my pills today because sorta kinda, if I don't take them, [nurse guide] makes me feel guilty, you know?

Discussion

This study explored the experiences of twenty-one HIV-positive African American and black women with a nurse guide as part of the Guide to Healing Program at the UNC Chapel Hill Infectious Disease Clinic. Findings from this study suggest that women's experiences with the nurse guide were overwhelmingly positive. Participants described their interactions with the nurse guide as increasing their hope about successfully living with HIV and providing them with the necessary knowledge, skills, and access to resources to be able to do so. Of equal importance, participants emphasized and valued the nurse guide's kindness and sincerity, and her availability as a source of emotional support. Women experienced a sense of loss when transitioning out of the program, though the vast majority expressed confidence in their ability to now successfully manage their HIV care.

Guide to Healing is, to our knowledge, the first published HIV patient navigation program designed for women utilizing a nurse in this role. Patient navigation interventions arose out of peer-based and community health worker strategies, and few early navigators had social work or nursing training.[18] HIV patient navigation interventions have largely stayed true to these roots. However, the field of oncology, where patient navigation interventions originated, has successfully embraced nurses in these roles.[19–23] Advantages of nurses serving as patient navigators include provision of enhanced patient support proportionate to a higher level of education[9] and a greater familiarity with medical conditions and treatments.[24] In this study, patients discussed the advantages of receiving their lab values directly from the nurse guide, discussing their medications and side effects with her, and the nurse guide clarifying confusing messages from other medical providers.

Nurses are recommended as patient navigators depending upon the medical complexity and needs of the patient population they are serving.[8] Women living with HIV in the United States are a group with multiple, complex needs. In the US, current research has documented the clustering of interacting epidemics of substance abuse, violence, and HIV/AIDS (known as the SAVA syndemic) among marginalized groups, including women of color.[25–28] Mental health problems and sexual risk taking/STIs are also recognized as syndemic components. The combination of a high prevalence of co-occurring health concerns and low overall levels of HIV engagement in care indicate the need for comprehensive, multifaceted interventions to promote women's sustained engagement throughout the HIV care continuum. Due to the

dual strengths of nurses to provide evidence-based medical care and psychosocial support, nurses as patient navigators may be uniquely positioned to serve in these roles. Future research should compare HIV patient navigation models to further elucidate the navigator type most effective within different patient and community contexts and include cost-benefit analyses.

Limitations of this study include potential bias introduced by the retrospective recall of participants. Additionally, though respondents were assured of confidentiality, it is possible that social desirability bias may still play a role in their responses. Changes in patient knowledge and behaviors cannot be solely attributed to their experiences in the Guide to Healing Program, due to the likelihood that patients come into contact with multiple sources of information and influence, including their medical providers and other staff in the clinic.

However, despite these limitations, this study provides important insight into the experiences of women of color with a nurse patient navigator. The findings suggest that a properly trained nurse in this role can provide critical medical and psychosocial support in order to eliminate barriers to engagement in HIV care, and successfully facilitate patient HIV self-management. The nurse guide model represents a promising approach to patient navigation for HIV-infected WOC and ultimately reducing disparities in HIV/AIDS morbidity and mortality among this group.

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Author Disclosure Statement

No competing financial interests exist.

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