HHS Public Access

Author manuscript

Health Promot Pract. Author manuscript; available in PMC 2022 February 01.

Published in final edited form as:

Health Promot Pract. 2022 January ; 23(1): 74–85. doi:10.1177/1524839920982603.

HIV patient navigation in the United States: a qualitative meta-synthesis of navigators' experiences

Katherine B. Roland, MPH [Behavioral Scientist],
Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Darrel H. Higa, PhD, MSW [Behavioral Scientist and Team Lead],
Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Carolyn A. Leighton, MA [Behavioral Scientist and Deputy Branch Chief],
Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Yuko Mizuno, PhD [Behavioral Scientist and Associate Director of Science],
Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Julia B. DeLuca, MLS [Health Communication Specialist],
Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Linda J. Koenig, PhD [Behavioral Scientist and Branch Chief]
Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Abstract

Patient navigation is increasingly used to link and (re)engage persons with HIV to care. A more holistic understanding of patient navigation can be achieved by exploring the experiences of navigators, the persons who comprise half of the navigation process. We conducted a meta-synthesis of navigator experiences with HIV patient navigation using a phenomenological approach. We identified nine relevant studies. Data were analyzed using thematic synthesis. Analysis identified two overarching themes relating to one, the breadth and depth of bidirectional relationships and functional activities that navigators undertake to connect their clients to care, and two, the inherently personal experience of delivering navigation services. From these thematic findings, we recommend that HIV patient navigators exhibit capacity and expertise in developing and maintaining interpersonal relationships with clients and healthcare systems/providers and develop self-care practices and emotional boundaries with clients. Our review seeks to advance public health research and practice by articulating key experiences and perspectives of HIV patient navigators, drawing findings and recommendations applicable to the development, implementation, and evaluation of HIV patient navigation.

Keywords

meta-synthesis; qualitative; HIV; patient navigation

Introduction

In the United States, marginalized and vulnerable groups experience higher rates of human immunodeficiency virus (HIV) infection and associated negative health outcomes when compared to the general population (Mugavero, Amico, Horn, & Thompson, 2013; Pellowski, Kalichman, Matthews, & Adler, 2013). To facilitate HIV care, interventions that address health disparities and social and structural drivers of HIV are a priority (Auerbach, Parkhurst, & Cáceres, 2011; Frieden, 2010; Frieden, Foti, & Mermin, 2015). *Patient navigation* is an intervention, or model of care, that addresses social and structural drivers of health disparities, whereby an individual helps clients navigate the healthcare system using a strengths-based orientation (Freeman & Rodriguez, 2011).

Patient navigation is increasingly used to link and retain persons with HIV (PWH) in care (Farrisi & Dietz, 2013; Thompson et al., 2012), and the evidence of positive associations with linkage, retention, and viral suppression is growing (Bradford, Coleman, & Cunningham, 2007; Mizuno et al., 2018). Still, HIV navigation services need further development (Norberg et al., 2019). Exploring the experiences of patient navigators, a perspective underrepresented in the literature (Phillips et al., 2014), can yield better understanding of the navigation process (Yosha et al., 2011). We conducted a qualitative meta-synthesis (Nye, Melendez-Torres, & Bonell, 2016; Sandelowski, Docherty, & Emden, 1997) of navigator experiences with HIV patient navigation using a phenomenological approach to inform development, implementation, and evaluation of HIV patient navigation interventions for the benefit of public health programs and practitioners (Newman, Thompson, & Roberts, 2006; Sandelowski & Leeman, 2012; Thomas & Harden, 2008; Toews et al., 2017).

Methods

We followed the American Psychological Association's Journal Article Reporting Standards recommendations for qualitative meta-syntheses to report this review (Levitt et al., 2018).

A librarian conducted searches in MEDLINE (OVID), EMBASE (OVID), PsycINFO (OVID), and CINAHL (EBSCOhost) using a combination of *HIV* or *AIDS* and *Patient Navigation* indexing and keyword terms. Supplementary database searches and a hand search of key HIV prevention journals were conducted. The search was limited to studies published and indexed from January 1, 1996 through October 19, 2020. See Appendix 1 for detailed search methods.

Peer-reviewed articles published in English, of studies conducted in the United States with PWH aged ≥18 years, reporting qualitative data on navigator perspectives and experiences with HIV navigation were included. Only studies where the patient navigator provided direct care or services to the client were eligible. Systematic reviews, book chapters, conference

abstracts and proceedings, dissertation/theses, magazine/newsletter articles, and webpages were excluded. Coauthors independently screened titles and abstracts, and then full reports to identify relevant citations. Discrepancies were resolved through discussion.

We abstracted study characteristics and assessed study quality using the Critical Appraisal Skills Programme (Butler, Hall, & Copnell, 2016; CASP Qualitative Research Checklist. [online] 2017). We used thematic synthesis (Thomas & Harden, 2008) to analyze data. A codebook was developed and piloted by the coauthors. Two coauthors independently coded secondary data (defined as researchers' interpretations and assertions of the primary data) in the results section of each article (Butler et al., 2016; Thomas & Harden, 2008; Toye et al., 2014; Zimmer, 2006). The unit of segmentation was the sentence. Discrepancies were resolved through discussion. Because of the small sample of relevant studies, we did not calculate intercoder reliability. However, with team-based coding, intercoder agreement can be achieved by relying on intensive group discussion and consensus (Harry, Sturges, & Klingner, 2005; Saldaña, 2009; Sutton & Austin, 2015).

We used NVivo 12™ (NVivo) to manage and analyze data. When coding was complete, coded data were independently reviewed by the two lead authors to confirm correct and consistent coding. Next, the lead author organized data according to frequently used codes and memos from the coding process. Data were further ordered based on similarities and relationships between codes (Sandelowski & Leeman, 2012) through a process of constant comparison (Barnett-Page & Thomas, 2009; Ryan & Bernard, 2003). Themes emerged through an inductive, iterative process of active reading, comparing findings across studies, and writing and reflection (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). All coauthors periodically reviewed and confirmed the analytic process and findings.

Results

Nine relevant studies were identified (Hallum-Montes, Morgan, Rovito, Wrisby, & Anastario, 2013; Koester et al., 2014; Maiorana, Sevelius, Keatley, & Rebchook, 2020; Maulsby et al., 2015; Parnell et al., 2017; Rajabiun, Coleman, & Drainoni, 2011; Sarango, de Groot, Hirschi, Umeh, & Rajabiun, 2017; Westergaard et al., 2017; Zamudio-Haas, Maiorana, Gomez, & Myers, 2019). Study characteristics are detailed in Tables 1 and 2. Through our analysis, we identified two overarching and interconnected themes regarding the experiences of HIV patient navigators.

Theme 1: The navigator builds supportive relationships with clients and providers/ healthcare systems that facilitate client connection to care

The first theme that emerged from our analysis is how navigators build networks of bidirectional relationships with clients and healthcare systems/providers. Through these relationships, navigators develop intimate knowledge of client needs and healthcare system options and solutions. To their encounters, they bring trust and cultural competence on behalf of the client, and skilled communication, medical literacy and holistic knowledge of systems of care on behalf of providers. These relationships foster and enable the delivery of relational and functional support necessary to link and engage clients in care. Likewise, through the effective delivery of relational and functional support, navigators build

and reinforce trust in their relationships with clients and providers. The relationships and supportive activities are not linear; rather, they are circuitous and interdependent.

Building a relationship with the client takes considerable time and effort, and is a significant component of the navigator role (Hallum-Montes et al., 2013; Koester et al., 2014; Maiorana et al., 2020; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019). Navigators develop trust and a sense of family or friendship with clients (Maiorana et al., 2020). A kind, trusting and compassionate relationship is necessary to connect clients to care and conducting outreach in the community (Koester et al., 2014; Maiorana et al., 2020; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019).

Navigators build relationships and collaborate with providers, healthcare teams, and organizations (especially that provide holistic or wrap-around services) to coordinate access to care for their clients (Maulsby et al., 2015; Rajabiun et al., 2011; Sarango et al., 2017). When navigators are integrated into a multi-disciplinary healthcare team, it facilitates comprehensive and efficient client care and can provide a network of peer support for the navigator (Rajabiun et al., 2011). When they are in the community, navigators raise awareness of navigation services, build trust and strengthen relationships with the community, and shift social norms regarding HIV stigma (Maulsby et al., 2015).

Relational support to connect clients to care—Through their relationship with the client, navigators provide psychosocial support (Maiorana et al., 2020) and attend to the client's emotional needs, providing empathy and creating a safe environment (Maulsby et al., 2015; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019). Navigators mitigate depression and social isolation though consistent, supportive communication (Westergaard et al., 2017). They address internalized stigma, homophobia, or transphobia (Maiorana et al., 2020; Sarango et al., 2017; Zamudio-Haas et al., 2019) and ease the negative impact of previous stigmatizing experiences (Sarango et al., 2017) while also building trust (Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019). Navigators also help develop the client's social support network (Rajabiun et al., 2011; Zamudio-Haas et al., 2019) to motivate them to stay connected to care (Parnell et al., 2017) and to feel part of a community (Rajabiun et al., 2011).

Through their interactions and relationships with clients, navigators provide client-centered, strengths-based care (Maiorana et al., 2020; Maulsby et al., 2015; Parnell et al., 2017; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019), building client skills and independence (Koester et al., 2014; Maiorana et al., 2020; Maulsby et al., 2015; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019). Navigators coach clients how to set goals (Maiorana et al., 2020; Parnell et al., 2017; Sarango et al., 2017), prioritize their health (Maiorana et al., 2020), develop coping strategies, accountability, and identify resources (Sarango et al., 2017). Navigators help clients see their value and worth, accept their HIV status and normalize living with HIV (Maiorana et al., 2020; Rajabiun et al., 2011; Sarango et al., 2017), develop resiliency (Zamudio-Haas et al., 2019), and reframe HIV care in the context of life goals, self-determination and empowerment (Maiorana et al., 2020). Navigators also use motivational interviewing techniques to promote self-management (Sarango et al., 2017) and use role-playing to increase client comfort during

clinical interactions (Rajabiun et al., 2011; Zamudio-Haas et al., 2019). For transgender women clients, navigators frame their work at the intersection of gender, race and stigma, and utilize a gender-affirming framework (Maiorana et al., 2020). Empowering the client (Sarango et al., 2017) through strengths-based approaches (Maulsby et al., 2015; Parnell et al., 2017), such as harm reduction, cultural competence and readiness for change (Rajabiun et al., 2011; Zamudio-Haas et al., 2019) may also contribute to an effective relationship with the client.

Facilitating communication between clients and healthcare providers is a key strength of navigation (Hallum-Montes et al., 2013) and addressing problems is crucial to clients maintaining care (Rajabiun et al., 2011). However, there is a need for a clear, standardized mechanism to facilitate regular communication between navigators and providers (Hallum-Montes et al., 2013). Navigators suggest training providers on navigator roles and responsibilities to improve communication (Hallum-Montes et al., 2013). Because of a trusting relationship with the client, navigators can identify potential barriers to treatment and adherence, and are privy to information that clients hesitate to share with providers (Hallum-Montes et al., 2013).

Functional support to connect clients to care—Outreach is an important activity to link clients to care. To locate a client who has missed appointments or fallen out of care, navigators conduct outreach in the community or through service providers, probation officers, or family members (Rajabiun et al., 2011; Sarango et al., 2017). While conducting outreach efforts, navigators are careful to respect client confidentiality (Maulsby et al., 2015).

Assessing and addressing client needs and barriers is another core navigator activity (Maiorana et al., 2020; Maulsby et al., 2015; Parnell et al., 2017; Rajabiun et al., 2011; Sarango et al., 2017; Westergaard et al., 2017; Zamudio-Haas et al., 2019) and may be the first step to engaging clients in care (Maiorana et al., 2020). Helping participants get their basic needs met is a recognition of client priorities, it is important that basic needs are met before addressing other barriers to HIV care (Maiorana et al., 2020). After assessment, care teams may create a plan to reduce identified barriers (Sarango et al., 2017). Navigators desire to be holistic in addressing client needs (Maulsby et al., 2015; Sarango et al., 2017), but recognize that they cannot address every need the client has (Maulsby et al., 2015). Addressing client needs and reorienting clients to service systems builds trust and credibility (Koester et al., 2014; Maulsby et al., 2015).

Navigators provide HIV information and education to clients (Maiorana et al., 2020; Maulsby et al., 2015; Rajabiun et al., 2011; Sarango et al., 2017; Westergaard et al., 2017; Zamudio-Haas et al., 2019), including explaining patient/consumer rights (Parnell et al., 2017), emphasizing the importance of medical monitoring of hormones, reinforcing messages from providers, providing treatment adherence tips (Maiorana et al., 2020) and how to communicate with providers (Maiorana et al., 2020; Rajabiun et al., 2011). The goals of education are to improve health outcomes (Parnell et al., 2017; Rajabiun et al., 2011; Zamudio-Haas et al., 2019), health literacy (Maiorana et al., 2020; Rajabiun et al., 2011),

clarify misconceptions, encourage behavior change, and motivate clients (Rajabiun et al., 2011).

Navigators coordinate client care that is tailored to the client (Maulsby et al., 2015), after review of the client needs assessment or health information (Sarango et al., 2017; Westergaard et al., 2017). Navigators help clients access food (Maiorana et al., 2020), transportation (Maulsby et al., 2015; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019), mental health and substance use care (Maiorana et al., 2020; Rajabiun et al., 2011; Sarango et al., 2017; Westergaard et al., 2017), housing services, and benefits programs (Maiorana et al., 2020; Rajabiun et al., 2011; Sarango et al., 2017), including health insurance (Maiorana et al., 2020; Zamudio-Haas et al., 2019), AIDS Drug Assistance programs, and legal services (Maiorana et al., 2020). Navigators make referrals to care (Maiorana et al., 2020; Rajabiun et al., 2011; Sarango et al., 2017; Zamudio-Haas et al., 2019), schedule and issue reminders about HIV appointments (Maiorana et al., 2020; Maulsby et al., 2015; Rajabiun et al., 2011; Sarango et al., 2017; Westergaard et al., 2017; Zamudio-Haas et al., 2019), explain what to expect during HIV care visits (Maulsby et al., 2015), tour medical facilities with clients (Maulsby et al., 2015), and complete paperwork (Maulsby et al., 2015; Rajabiun et al., 2011). Navigators also assist with filling prescriptions (Maiorana et al., 2020; Maulsby et al., 2015; Rajabiun et al., 2011) and supporting adherence to treatment (Rajabiun et al., 2011; Sarango et al., 2017; Westergaard et al., 2017). Navigators may visit client homes (Maulsby et al., 2015; Parnell et al., 2017; Rajabiun et al., 2011) to provide services, which is especially helpful for facilitating engagement in care (Rajabiun et al., 2011).

Accompaniment is a critical activity that helps engage clients in care. Navigators attend appointments with clients (Koester et al., 2014; Maiorana et al., 2020; Maulsby et al., 2015; Rajabiun et al., 2011; Zamudio-Haas et al., 2019) where they model how to effectively interact with providers and staff (Koester et al., 2014; Rajabiun et al., 2011; Zamudio-Haas et al., 2019), assist with translation, help orient clients to arrival and check-in procedures, schedule follow-up appointments (Zamudio-Haas et al., 2019), and advocate for gender-affirming services for transgender clients (Maiorana et al., 2020). Accompaniment reduces barriers, may improve communication and trust between clients and providers, and is particularly critical for clients with cognitive deficits or active substance use (Sarango et al., 2017).

Theme 2: Working as a navigator is an inherently personal experience, and navigators need support to develop relational boundaries and prevent emotional burnout

The second theme that emerged from this analysis relates to the inherently personal nature of the navigator position, and how the navigator experiences their work. Because navigation programs may lack clear guidance for the expectations of the navigator role, and because navigators work so extensively and intimately with medically vulnerable clients, some of whom are peers, navigators can struggle with establishing clear boundaries and therefore risk emotional burnout. Navigators need structural support from the program, providers, supervisors, and other staff to ensure their well-being.

How navigators perceive their role—Navigators believe the most important functions they perform are educating clients about service systems (Sarango et al., 2017), linking and reorienting clients to those service systems (Koester et al., 2014; Rajabiun et al., 2011; Sarango et al., 2017), and helping them learn how to communicate with providers (Rajabiun et al., 2011). Navigators also believe there are personal qualities necessary to be effective, such as being consistent and dependable, accessible, accepting, patient, honest, accountable (Rajabiun et al., 2011), empathetic, caring (Hallum-Montes et al., 2013), and non-judgmental (Koester et al., 2014; Maiorana et al., 2020; Zamudio-Haas et al., 2019). In addition, they believe that it is important to acknowledge personal biases (Rajabiun et al., 2011) and practice active listening (Parnell et al., 2017).

When navigators and clients meet, they discuss the parameters of navigation services (Parnell et al., 2017). Some programs define the type, frequency, and duration of navigator contact, but navigator-client interactions are often based on individual client needs (Parnell et al., 2017). Navigators struggle to determine when a client is self-sufficient and no longer needs support (Maulsby et al., 2015). To ease the transition out of navigation services, navigators ensure that clients are engaged in long-term case management, gradually reduce the frequency of their contact with the client (Maulsby et al., 2015), and avail themselves beyond the time limitation of the program when needed (Maulsby et al., 2015; Parnell et al., 2017). Navigators believe that supporting the client beyond the scope (linkage to and retention in HIV care) and established timeframe of the program is important (Maulsby et al., 2015).

Balancing personal and professional boundaries—Maintaining personal boundaries while simultaneously being caring and available to support the client is critical and challenging (Hallum-Montes et al., 2013; Parnell et al., 2017). It is important for navigators to refer clients who need significant emotional support to healthcare specialists (Parnell et al., 2017) and for navigators to develop resilience when dealing with adverse events such as the death of a client (Hallum-Montes et al., 2013). Navigators who are peers share similar backgrounds (e.g., transgender women of color) (Maiorana et al., 2020) or histories of substance use, incarceration (Koester et al., 2014), HIV positivity (Koester et al., 2014; Rajabiun et al., 2011; Zamudio-Haas et al., 2019) or immigration (Zamudio-Haas et al., 2019), could better identify and understand their client's life experiences (Maiorana et al., 2020). When navigators refer to their own lived experience, clients may perceive the peer navigators as equals or empowering role models (Maiorana et al., 2020), helping to normalize living with HIV (Rajabiun et al., 2011), assuage fears (Zamudio-Haas et al., 2019), build rapport and trust (Koester et al., 2014; Maiorana et al., 2020; Maulsby et al., 2015; Zamudio-Haas et al., 2019), connect clients to care (Koester et al., 2014; Maiorana et al., 2020), and enhanced client willingness to discuss personal issues (Maiorana et al., 2020).

Navigation can be overwhelming and demanding work, and navigators risk exhausting their emotional resources (Hallum-Montes et al., 2013; Maiorana et al., 2020). Navigators report that the multiple issues experienced by their clients impact them personally; they feel responsible for their clients, making it hard to set boundaries which can cause frustration and compassion fatigue (Maiorana et al., 2020). They need support, such as counseling, training, and time off to reduce turnover and foster program sustainability (Hallum-Montes

et al., 2013). Some navigators may also rely on clinical or supervisory support if necessary (Parnell et al., 2017).

Discussion

This meta-synthesis highlights the experiences and perspectives of HIV patient navigators as they deliver services to PWH. We identified the myriad interpersonal, relational and functional support and skills the navigator utilizes to connect clients to care. We also note the inherently personal experience of patient navigation for the navigator. Navigators risk emotional burnout and would benefit from social and structural support within the framework of the navigation program to establish personal and professional boundaries for the health and wellbeing of themselves and their clients. Elements of these findings have been documented in the literature. However, this meta-synthesis is comprehensive in articulating the breadth and depth of functional knowledge and relational skills required of navigators to connect clients to care, that interpersonal relationships are the crux of patient navigation, and the need to delineate expectations and boundaries regarding client-navigator relationships.

Patient navigation was designed to mediate client health disparities and poor healthcare access via two distinct pillars: functional support and relational support, with the client-navigator relationship serving as the medium through which navigator functions are enabled (Freeman & Rodriguez, 2011). Both navigators and clients cite their relationship as instrumental to the delivery of navigation services (Jean-Pierre et al., 2011; Phillips et al., 2014; Roland et al., 2020). Our analysis confirms that building a relationship with the client is a key component of navigation services, and that the relationship is a source of considerable strengths-based, client-centered psychosocial support. The analysis also contextualizes the dynamic between relational and functional support by revealing how functional support can alternately reinforce and buttress the relationship with the client. When the navigator seeks out a client in their home or their community (e.g., outreach), make inquiries about challenges the client is facing (e.g., needs assessment), shares knowledge and useful information (e.g., HIV information and education), and helps with burdensome or overwhelming tasks (e.g., coordinating care, providing transportation and accompanying clients to appointments), they are building trust and reinforcing social bonds.

To effectively carry out their duties and connect clients to care, patient navigators also develop and maintain relationships and credibility with providers and healthcare systems (Byers, 2012; Farrisi & Dietz, 2013; Phillips et al., 2014), and forge relationships with stakeholders in the community. Our analysis also highlights the importance of relationships with providers and other navigators that are cultivated through integration into healthcare teams, providing necessary social support to the navigators. We learned that the navigator-provider/healthcare system dyad is of equal consequence to the client-navigator dyad for the delivery of navigation services for PWH, and that these two dyads work synergistically to strengthen the delivery of services.

In addition to the interpersonal networks and functional responsibilities needed to connect clients to care, our analysis also reveals the personal experience of navigation. The work of an HIV navigator—managing multiple relationships while employing a complex set of functional skills—can be demanding, and the clients that a navigator supports may have shared histories of trauma including experiences of stigma, homophobia or transphobia, incarceration, HIV positivity, or substance use. Often there is insufficient guidance about how to maintain personal boundaries with clients, how to prioritize personal needs, or how to balance sincere care for clients with programmatic constraints. In some instances, navigators can become embedded within the client's social support network. These factors can lead to emotional burnout and high turnover. Managing client relationships requires substantial flexibility (Jean-Pierre et al., 2011), especially when navigation activities and services are tailored to the needs of the individual client, often extending beyond HIV-related medical services (Dutcher et al., 2011). We also found that without clear program guidance, navigators struggle with determining how long they should engage with their client. This can be especially difficult when clients are hesitant to exit the navigation program or end the relationship with their navigator (Roland et al., 2020). Navigators need to define and maintain professional boundaries (Phillips et al., 2014), and programs have an obligation to support and help navigators set boundaries and avoid burnout (Ferrante, Wu, & Dicicco-Bloom, 2011).

Limitations

This study is subject to several limitations. Our review did not define or operationalize HIV patient navigation, so our search may have inadvertently excluded potentially relevant articles that describe navigation-like interventions. However, an experienced librarian developed the search strategy and conducted the literature searches to capture articles in which the term "navigation" or a variant was used, and only studies in which navigators provided direct care and support to patients, a key feature of patient navigation, were included in the review. In addition, we did not code the methods or discussion sections of the relevant articles, and authors were conservative in determining which data were relevant to code, so we may have missed data relevant to our analysis.

Implications for practice and research

The findings from this review highlight numerous recommendations for practice. HIV patient navigators need to develop and maintain competency in three areas to be effective: establishing relationships with clients; establishing relationships with health care providers/systems of care; and establishing self-care practices and boundaries with clients. Further, clearly defined navigator roles and expectations, supervisory and peer support, integration of the navigator into the healthcare team, and clear communication between navigators and providers could help navigators achieve these competencies, process the emotional toll of their experiences, and prevent turnover or misunderstandings.

HIV patient navigation research should further evaluate the client-navigator dyad (Jean-Pierre et al., 2012), and whether there is an association between being a peer of the client, and psychosocial consequence for the navigator and client. In addition, variations in navigator qualifications, training, scope of tasks, client characteristics, duration of patient-

navigator contact, and choice of outcomes may impact the differential effectiveness of navigation services (Higa et al., 2012; Messeri, Yomogida, Ferat, Garr, & Wirth, 2020; Mizuno et al., 2018). There is a move to develop standardized training and build core proficiencies, leading to national navigator accreditation and certification (Liu et al., 2018). Standardization of training or establishment of essential skills is likely to bring further focus to the experiences and needs of navigators (including the prevention of burnout) and to encourage sustainability of navigation services. Further research on navigator experiences, activities, and essential competencies would aid the standardization and certification process.

Conclusions

Our review seeks to advance public health research and practice by articulating key experiences and perspectives of navigators, drawing findings and recommendations applicable to the development, implementation, and evaluation of HIV patient navigation. Effective interventions use a strengths-based orientation, empower clients to recognize and use their internal abilities to solve problems, and help clients navigate complex systems of care (Higa, Marks, Crepaz, Liau, & Lyles, 2012). There is a long history of personalized care and support for PWH that have addressed and mediated health disparities by providing counseling and social support, delivering health education, developing trust and forging partnerships, and empowering individuals and communities (Behforouz, Farmer, & Mukherjee, 2004; Kenya et al., 2013; Vargas & Cunningham, 2006). However, the perspective of the person delivering care and support is less understood. This review offers novel insight and dimension to the process of delivering navigation services for vulnerable PWH, findings that are applicable to any patient-centered HIV intervention.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgement

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. There are no conflicts of interest to report, or financial disclosures. This work was entirely funded by the United States Government. All authors are federal government employees and this report is not subject to copyright in the United States.

References

Auerbach JD, Parkhurst JO, & Cáceres CF (2011). Addressing social drivers of HIV/AIDS for the long-term response: conceptual and methodological considerations. Global Public Health, 6 Suppl 3, S293–309. doi:10.1080/17441692.2011.594451 [PubMed: 21745027]

Barnett-Page E, & Thomas J (2009). Methods for the synthesis of qualitative research: a critical review. BMC Medical Research Methodology, 9, 59. doi:10.1186/1471-2288-9-59 [PubMed: 19671152]

Behforouz HL, Farmer PE, & Mukherjee JS (2004). From directly observed therapy to accompagnateurs: enhancing AIDS treatment outcomes in Haiti and in Boston. Clinical Infectious Diseases, 38 Suppl 5, S429–436. doi:10.1086/421408 [PubMed: 15156434]

Bradford JB, Coleman S, & Cunningham W (2007). HIV System Navigation: an emerging model to improve HIV care access. AIDS Patient Care and STDS, 21 Suppl 1, S49–58. doi:10.1089/apc.2007.9987 [PubMed: 17563290]

Butler A, Hall H, & Copnell B (2016). A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care. Worldviews on Evidence Based Nursing, 13(3), 241–249. doi:10.1111/wvn.12134 [PubMed: 26790142]

Byers T (2012). Assessing the value of patient navigation for completing cancer screening. Cancer Epidemiology, Biomarkers, and Prevention, 21(10), 1618–1619. doi:10.1158/1055-9965.EPI-12-0964

CASP Qualitative Research Checklist. [online] (2017). Retrieved from https://casp-uk.net/casp-tools-checklists/

Dutcher MV, Phicil SN, Goldenkranz SB, Rajabiun S, Franks J, Loscher BS, & Mabachi NM (2011). "Positive Examples": a bottom-up approach to identifying best practices in HIV care and treatment based on the experiences of peer educators. AIDS Patient Care and STDS, 25(7), 403–411. doi:10.1089/apc.2010.0388 [PubMed: 21671756]

Farrisi D, & Dietz N (2013). Patient navigation is a client-centered approach that helps to engage people in HIV care. HIV Clinician, 25(1), 1–3.

Ferrante JM, Wu J, & Dicicco-Bloom B (2011). Strategies used and challenges faced by a breast cancer patient navigator in an urban underserved community. Journal of the National Medical Association, 103(8), 729–734. doi:10.1016/s0027-9684(15)30412-0 [PubMed: 22046850]

Freeman HP, & Rodriguez RL (2011). History and principles of patient navigation. Cancer, 117(15 Suppl), 3539–3542. doi:10.1002/cncr.26262 [PubMed: 21780088]

Frieden TR (2010). A framework for public health action: the health impact pyramid. American Journal of Public Health, 100(4), 590–595. doi:10.2105/AJPH.2009.185652 [PubMed: 20167880]

Frieden TR, Foti KE, & Mermin J (2015). Applying Public Health Principles to the HIV Epidemic--How Are We Doing? New England Journal of Medicine, 373(23), 2281–2287. doi:10.1056/NEJMms1513641

Hallum-Montes R, Morgan S, Rovito HM, Wrisby C, & Anastario MP (2013). Linking peers, patients, and providers: a qualitative study of a peer integration program for hard-to-reach patients living with HIV/AIDS. AIDS Care, 25(8), 968–972. doi:10.1080/09540121.2012.748869 [PubMed: 23311339]

Harry B, Sturges KM, & Klingner JK (2005). Mapping the Process: An Exemplar of Process and Challenge in Grounded Theory Analysis. Educational Researcher, 34(2), 3–13. doi:10.3102/0013189x034002003

Higa DH, Marks G, Crepaz N, Liau A, & Lyles CM (2012). Interventions to improve retention in HIV primary care: a systematic review of U.S. studies. Current HIV/AIDS Reports, 9(4), 313–325. doi:10.1007/s11904-012-0136-6 [PubMed: 22996171]

Jean-Pierre P, Fiscella K, Winters PC, Post D, Wells KJ, McKoy JM, … Patient Navigation Research Program, G. (2012). Psychometric development and reliability analysis of a patient satisfaction with interpersonal relationship with navigator measure: a multi-site patient navigation research program study. Psychooncology, 21(9), 986–992. doi:10.1002/pon.2002 [PubMed: 21681995]

Jean-Pierre P, Hendren S, Fiscella K, Loader S, Rousseau S, Schwartzbauer B, … Epstein R (2011). Understanding the processes of patient navigation to reduce disparities in cancer care: perspectives of trained navigators from the field. Journal of Cancer Education, 26(1), 111–120. doi:10.1007/s13187-010-0122-x [PubMed: 20407860]

Kenya S, Jones J, Arheart K, Kobetz E, Chida N, Baer S, … Carrasquillo O (2013). Using community health workers to improve clinical outcomes among people living with HIV: a randomized controlled trial. AIDS and Behavior, 17(9), 2927–2934. doi:10.1007/s10461-013-0440-1 [PubMed: 23515640]

Koester KA, Morewitz M, Pearson C, Weeks J, Packard R, Estes M, … Myers JJ (2014). Patient navigation facilitates medical and social services engagement among HIV-infected individuals leaving jail and returning to the community. AIDS Patient Care and STDS, 28(2), 82–90. doi:10.1089/apc.2013.0279 [PubMed: 24517539]

Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, & Suarez-Orozco C (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. American Psychologist, 73(1), 26–46. doi:10.1037/amp0000151

Liu C, Mason R, Roubal AM, Ojo E, Calhoun EA, & Patierno SR (2018). Consensus Support for the Role of Patient Navigation in the Nation's Healthcare System. In Calhoun EA & Esparza A (Eds.), Patient Navigation: Overcoming Barriers to Care (pp. 119–140). New York, NY: Springer New York.

Maiorana A, Sevelius J, Keatley J, & Rebchook G (2020). "She is Like a Sister to Me." Gender-Affirming Services and Relationships are Key to the Implementation of HIV Care Engagement Interventions with Transgender Women of Color. AIDS and Behavior. doi:10.1007/s10461-020-02777-6

Maulsby C, Kinsky S, Jain KM, Charles V, Riordan M, Positive Charge Intervention T, & Holtgrave DR (2015). Unpacking Linkage and Reengagement in HIV Care: A Day in the Life of a Positive Charge Care Coordinator. AIDS Education and Prevention, 27(5), 405–417. doi:10.1521/aeap.2015.27.5.405 [PubMed: 26485231]

Messeri P, Yomogida M, Ferat RM, Garr L, & Wirth D (2020). An HIV health plan patient navigation program: Engaging HIV positive individuals in primary medical care. Journal of HIV/AIDS & Social Services, 19(1), 55–73. doi:10.1080/15381501.2019.1699485

Mizuno Y, Higa DH, Leighton CA, Roland KB, Deluca JB, & Koenig LJ (2018). Is HIV patient navigation associated with HIV care continuum outcomes? A systematic review. AIDS. doi:10.1097/QAD.0000000000001987

Mugavero MJ, Amico KR, Horn T, & Thompson MA (2013). The state of engagement in HIV care in the United States: from cascade to continuum to control. Clinical Infectious Dieases, 57(8), 1164–1171. doi:10.1093/cid/cit420

Newman M, Thompson C, & Roberts AP (2006). Helping practitioners understand the contribution of qualitative research to evidence-based practice. Evidence-Based Nursing, 9(1), 4–7. [PubMed: 16440470]

Norberg A, Nelson J, Holly C, Jewell ST, Lieggi M, & Salmond S (2019). Experiences of HIV-infected adults and healthcare providers with healthcare delivery practices that influence engagement in US primary healthcare settings: a qualitative systematic review. JBI Database of Systematic Reviews and Implementation Reports, 17(6), 1154–1228. doi:10.11124/JBISRIR-2017-003756 [PubMed: 30994499]

Nye E, Melendez-Torres GJ, & Bonell C (2016). Origins, methods and advances in qualitative meta-synthesis. Review Of Education, 4(1), 57–79.

Parnell HE, Berger MB, Gichane MW, LeViere AF, Sullivan KA, Clymore JM, & Quinlivan EB (2017). Lost to Care and Back Again: Patient and Navigator Perspectives on HIV Care Re-engagement. AIDS and Behavior. doi:10.1007/s10461-017-1919-y

Pellowski JA, Kalichman SC, Matthews KA, & Adler N (2013). A pandemic of the poor: social disadvantage and the U.S. HIV epidemic. American Psychologist, 68(4), 197–209. doi:10.1037/a0032694

Phillips S, Nonzee N, Tom L, Murphy K, Hajjar N, Bularzik C, … Simon MA (2014). Patient navigators' reflections on the navigator-patient relationship. Journal of Cancer Education, 29(2), 337–344. doi:10.1007/s13187-014-0612-3 [PubMed: 24493636]

Rajabiun S, Coleman S, & Drainoni ML (2011). Keeping at-risk persons living with HIV/AIDS in care: A qualitative study of staff perspectives. Journal of HIV/AIDS & Social Services, .10(2), pp. doi:10.1080/15381501.2011.572736

Roland KB, Higa DH, Leighton CA, Mizuno Y, DeLuca JB, & Koenig LJ (2020). Client Perspectives and Experiences With HIV Patient Navigation in the United States: A Qualitative Meta-Synthesis. Health Promotion Practice, 21(1), 25–36. doi:10.1177/1524839919875727 [PubMed: 31597497]

Ryan GW, & Bernard HR (2003). Techniques to Identify Themes. Field methods, 15(1), 85–109.

Saldaña J (2009). The coding manual for qualitative researchers. Los Angeles, Calif.: Sage.

Sandelowski M, Docherty S, & Emden C (1997). Focus on qualitative methods. Qualitative metasynthesis: issues and techniques. Research in Nursing and Health, 20(4), 365–371. [PubMed: 9256882]

Sandelowski M, & Leeman J (2012). Writing usable qualitative health research findings. Qualitative Health Research, 22(10), 1404–1413. doi:10.1177/1049732312450368 [PubMed: 22745362]

Sarango M, de Groot A, Hirschi M, Umeh CA, & Rajabiun S (2017). The Role of Patient Navigators in Building a Medical Home for Multiply Diagnosed HIV-Positive Homeless Populations. Journal of Public Health Management and Practice, 23(3), 276–282. doi:10.1097/PHH.0000000000000512 [PubMed: 28079645]

Sutton J, & Austin Z (2015). Qualitative Research: Data Collection, Analysis, and Management. Canadian Journal of Hospital Pharmacy, 68(3), 226–231.

Thomas J, & Harden A (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8, 45. doi:10.1186/1471-2288-8-45 [PubMed: 18616818]

Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW, Gross R, … Nachega JB (2012). Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. Annals of Internal Medicine, 156(11), 817–833, W-284, W-285, W-286, W-287, W-288, W-289, W-290, W-291, W-292, W-293, W-294. doi:10.7326/0003-4819-156-11-201206050-00419 [PubMed: 22393036]

Toews I, Booth A, Berg RC, Lewin S, Glenton C, Munthe-Kaas HM, … Meerpohl JJ (2017). Further exploration of dissemination bias in qualitative research required to facilitate assessment within qualitative evidence syntheses. Journal of Clinical Epidemiology, 88, 133–139. doi:10.1016/j.jclinepi.2017.04.010 [PubMed: 28433676]

Toye F, Seers K, Allcock N, Briggs M, Carr E, & Barker K (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. BMC Medical Research Methodology, 14, 80. doi:10.1186/1471-2288-14-80 [PubMed: 24951054]

Vargas RB, & Cunningham WE (2006). Evolving trends in medical care-coordination for patients with HIV and AIDS. Current HIV/AIDS Reports, 3(4), 149–153. [PubMed: 17032573]

Westergaard RP, Genz A, Panico K, Surkan PJ, Keruly J, Hutton HE, … Kirk GD (2017). Acceptability of a mobile health intervention to enhance HIV care coordination for patients with substance use disorders. Addiction Science and Clinical Practice, 12(1), 11. doi:10.1186/s13722-017-0076-y [PubMed: 28441962]

Yosha AM, Carroll JK, Hendren S, Salamone CM, Sanders M, Fiscella K, & Epstein RM (2011). Patient navigation from the paired perspectives of cancer patients and navigators: a qualitative analysis. Patient Education and Counseling, 82(3), 396–401. doi:10.1016/j.pec.2010.12.019 [PubMed: 21255958]

Zamudio-Haas S, Maiorana A, Gomez LG, & Myers J (2019). “No Estas Solo”: Navigation Programs Support Engagement in HIV Care for Mexicans and Puerto Ricans Living in the Continental U.S. Journal of Health Care for the Poor and Underserved, 30(2), 866–887. doi:10.1353/hpu.2019.0060 [PubMed: 31130555]

Zimmer L (2006). Qualitative meta-synthesis: a question of dialoguing with texts. Journal of Advanced Nursing, 53(3), 311–318. doi:10.1111/j.1365-2648.2006.03721.x [PubMed: 16441536]

Table 1

Characteristics of studies included in the meta-synthesis

Citation	Objective	HIV care goals	Location (City, State when available)	Navigator sample size	Data collection method	Data analysis method	CASP score (range 0–10)[1]
Hallum-Montes et al., 2013	To explore successes and challenges of developing and sustaining a peer integration program in health centers, and the impact of the program on the healthcare experiences of PWH.	Recruitment and retention of hard to reach clients	3 health centers in the United States	10	"Extended period of observation" and semi-structured interviews	Grounded theory	6.5
Koester et al., 2014	To explore the strategies, roles, and responsibilities of PNs in engaging with medical and social services.	Reducing HIV transmission risk, increasing HIV medication adherence, long-term care engagement with health and social services.	San Francisco, CA	5	Field observations and in-depth interviews	Grounded theory	9
Maulsby et al., 2015	To understand strategies used by linkage to care programs, and to suggest a framework for steps in HIV linkage and reengagement in care.	Linkage and re-engagement	Chicago, IL; New York City, NY; North Carolina; Louisiana; San Francisco Bay Area	17	Semi-structured interviews	Directed content analysis	8.5
Maiorana et al., 2020	To present qualitative findings from a multi-site evaluation, examining gender-affirming services and relationships that characterized the interventions.	Engagement in care	9 demonstration sites across the Unites States (8 sites included navigation services)	26	In-depth interviews	Framework analysis	9.5
Parnell et al., 2017	To describe encounters between clients and PNs and characterize adaption and use of engagement domain components.	Strengths-based approach to link and reengage PWH lost to care	North Carolina	9	Interviews	"Iterative process"	9
Rajabiun et al., 2011	To identify direct service staff strategies and approaches to connect and retain at-risk populations in HIV care.	Engagement in care	Seattle, WA; Portland, OR; Los Angeles, CA; Detroit, MI (n=2); Washington DC; New York City, NY; Providence, RI; Boston, MA	21	Interviews	Thematic content analysis	8.75
Sarango et al., 2017	To describe the roles and responsibilities of PNs as part of an effort to create a medical home for unstably housed PWH with behavioral health comorbidities.	NR	9 demonstration sites across the United States	22	Interviews and focus groups	Thematic content analysis	9.5
Westergaard et al., 2017	To describe the development and acceptability of peer PN intervention, utilizing smart phone technology for communication.	Support HIV treatment for marginally engaged	Baltimore, MD	3	In-depth interviews	Thematic analysis	8
Zamudio-Haas et al., 2019	To explore how PN services applied a transnational framework to promote linkage	Engagement, linkage and retention	Los Angeles, CA (n=2), Chicago, IL (n=2), New York	15	In-depth interviews	Framework analysis. The	9

Health Promot Pract. Author manuscript; available in PMC 2022 February 01.

Citation	Objective	HIV care goals	Location (City, State when available)	Navigator sample size	Data collection method	Data analysis method	CASP score (range 0–10)[1]
	and retention in HIV care in programs tailored for PWH of Mexican and Puerto Rican origin.		City, NY (n=2), Charlotte-Durham, NC (n=1), Philadelphia, PA (n=1), Dallas, TX (n=1)			client -navigator relationship was the unit of analysis	

CASP= Critical Appraisal Skills Programme

[1]CASP scores range from 0–10: 9–10 indicates the article is of high quality, 7.5–8.9 indicates moderate quality, and scores <7.5 indicate low quality.

PWH= persons with HIV

PN=patient navigator

NR= not reported

Table 2

Characteristics of navigators and clients in the studies included in the meta-synthesis

Citation	Navigator title	Navigator characteristics	Navigator training for study	Client priority population	Client barriers
Hallum-Montes et al., 2013	Peer	Male and female, African American and Hispanic, PWH, some of whom worked full time at their respective health centers. Peers to the clients according to race/ethnicity and HIV status.	NR	PWH, hard-to-reach, African American and Hispanic, and MSM.	NR
Koester et al., 2014	Patient navigator	Peers (HIV + and history of incarceration) to the clients, history of service engagement, possessed good organizational and communication skills, abstinent from drugs and alcohol, and not incarcerated previous 12 months. 80% male, 20% female; 60% African American, 20% white, 20% while/Filipino; 80% 41–65 years of age. Many had not previously held jobs or had been out of the workforce for a number of years	Trained on professional behavior, confidentiality, time management, communication skills and ongoing support and clinical supervision.	PWH leaving the San Francisco jail system.	Distrust of non-peer providers, viewing the social service system as oppressive and inhumane
Maulsby et al., 2015	Care coordinator (outreach worker, community health outreach worker, peer and patient navigator, health navigator, access coordinators, per post release case managers, DIS officers)	Provided direct services to PWH.	NR	MSM (Chicago); Medicaid eligible PWH enrolled in nonprofit health plan (NYC); OOC PWH (NC); Incarcerated, newly diagnosed, and OOC (LA); homeless, incarcerated, people who use drugs, focus on women (SF).	NR
Maiorana et al., 2020	Interventionists (peer health navigator, health educator, case manager)	20 interventionists were Transgender women of color (11 African American, 9 Latina), age early 20s – late 50s. Highly motivated to help their community and often reported similar life experiences. Provided navigation services to link, retain or re-engage participants in HIV care.	Background and training varied across sites. Some were new to the work force, some had previous experience as volunteers or community organizers.	Transgender women of color living with HIV.	Low self-esteem, socially excluded, stigma, marginalization and discrimination, negative encounters with healthcare system.
Parnell et al., 2017	State Bridge Counselors	Employed as a state-level navigator. 78% female, 22% male, 56% African American, 44% white; all college graduates, median age 37 (range 29–54), 73% heterosexual, 18% gay/bisexual, 9% did not identify.	NR	PWH adult ≥18 years of age, OOC.	Distrust of the healthcare system.
Rajabiun et al., 2011	Outreach worker/ counselor, health system navigators, care coordinators, case managers, outreach nurse, peer advocate, nurse practitioner	Provide direct services to PWH. 11 male, 10 female; 5 African American, 4 Hispanic, 10 white, 2 other; 2 clinical social worker, 3 nurse or nurse practitioner, and 15 nonclinical training. Some were peer workers.	Trained in behavior change theory, stages of change and harm reduction, motivational interviewing.	At-risk PWH (never had HIV care, were currently OOC, or were in HIV care but considered dropping out).	Mental illness and being stigmatized by providers, discrimination due to sexual orientation and race, substance use, a criminal record or history of incarceration.
Sarango et al., 2017	Navigator	Provide or coordinate services for clients.	NR	PWH with behavioral health comorbidities experiencing homelessness or housing instability.	Low- or illiteracy, substance use, unstable housing, a criminal record or history of incarceration, distrust of service providers, lack of

Citation	Navigator title	Navigator characteristics	Navigator training for study	Client priority population	Client barriers
					health insurance or skills to enroll, bureaucratic systems.
Westergaard et al., 2017	Peer navigator	Familiar with the communities where participants lived, and had experience assisting patients access and utilize health and social services.	Trained on study procedures, mHealth application, counseling, motivational interviewing, deliver psychosocial and logistical support.	PWH adult ≥18 years of age, primarily African American, male, low-income, median age 49.3, viral load >1000 copies/mL, no clinic visits in previous 6 months.	
Zamudio-Haas et al., 2019	Patient navigator, outreach worker	Bilingual, native Spanish speakers, most from the same country as their clients. Half cisgender men, half cisgender women, Latinx, Age range 20–50 years. Most were trained as social workers, health educators or case managers. Some were peers with less formal training. All had salaried positions. 2–15 years of experience working with the priority population.	NR	PWH, Mexican and Puerto Rican origin, MSM and transgender women, current or former injection drug use.	Low- or illiteracy, unstable housing, undocumented or recent immigrant, lack of identification, lack of health insurance or skills to enroll.

NR= not reported

PWH = persons with HIV

MSM = men who have sex with men

OOC = out of care

NYC= New York City

NC= North Carolina

LA = Louisiana

SF= San Francisco