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Client perspectives and experiences with HIV patient navigation in the United States: a qualitative meta-synthesis

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Abstract

Patient navigation is increasingly utilized to link and (re)engage persons with HIV (PWH) to care. Understanding client experiences with HIV patient navigation can facilitate intervention design and translation of evidence to practice. We conducted a qualitative meta-synthesis of client experiences with HIV patient navigation. Data were analyzed using thematic synthesis. We identified seven relevant studies; all collected data via in-depth interviews with PWH who participated in HIV patient navigation. Four interrelated themes emerged from analysis that pertain to 1) the complexity of the health and social service environment and the holistic approaches taken by the navigator, 2) the profound significance of the client-navigator relationship, 3) client reluctance to end the navigation program, and 4) client self-efficacy and feelings of hope and psychological change as a result of their navigation experience. The unifying theme across all studies was the value and impact of the client-navigator relationship on client experience and quality of life. Programs should consider hiring navigators who possess strong relational skills and are peers of the clients, and clearly delineating the role of the navigator. Research should examine the impact of the client-navigator relationship on client outcomes, and further investigate the how participating in patient navigation impacts client self-efficacy, client resiliency, and the role of post-traumatic growth to achieve improved HIV outcomes. This review underscores the significance of the relationship within intensive, multi-level interventions for individuals and communities marginalized and isolated from health and social service systems.

Keywords

meta-synthesis; thematic synthesis; qualitative; HIV; patient navigation; relationship; social support

Background

Due to targeted prevention efforts, the incidence of human immunodeficiency virus (HIV) in the United States has decreased over time (Centers for Disease Control and Prevention, 2018a). However, disparities persist within marginalized and disenfranchised groups, due in large part to social and structural factors that drive HIV acquisition, transmission, and associated health outcomes (De Jesus and Williams, 2018; Mugavero, Amico, Horn, & Thompson, 2013; Pellowski, Kalichman, Matthews, & Adler, 2013). National HIV prevention goals direct that once diagnosed, persons with HIV (PWH) should be immediately linked and retained in care for sustained viral suppression (National HIV/AIDS Strategy for the United States, 2015). In 2015, 73% of persons in the United States with diagnosed infections were linked to HIV medical care in a timely manner, and only approximately 60% were retained in care and virally suppressed, (Centers for Disease Control and Prevention, 2018b) with even poorer linkage and retention rates for racial/ethnic minorities compared to whites (Mugavero, et al., 2013). Interventions that identify PWH, link and retain them to care with the goal of viral load suppression, while addressing key structural drivers of HIV are a priority (Auerbach, Parkhurst, & Caceres, 2011; Frieden, Foti, & Mermin, 2015).

One intervention that aims to improve linkage and retention while addressing social and structural barriers to care is *patient navigation*. Developed to address disparities in cancer care, patient navigation is a patient-centered model of care where health workers, known as patient navigators, support clients to overcome barriers and access disconnected health systems with the goal of enhanced linkage and retention (Freeman and Rodriguez, 2011). Patient navigation shares traits common to advocacy, health education, case management, and social work and is related to other historically significant HIV peer support and community-based assistance programs (Bradford, Coleman, & Cunningham, 2007; Vargas & Cunningham, 2006). Patient navigation is increasingly utilized in HIV (Bradford, et al., 2007; Farrisi and Dietz, 2013; Thompson et al., 2012), with quantitative evidence for positive associations with linkage, retention, and viral suppression (Bradford, et al., 2007; Mizuno et al., 2018).

Less is known about client experiences with navigation, how their experiences impact service engagement, and their priorities for care. (Land, Hathorn, & Ross, 2011; Peart, Lewis, Brown, & Russell, 2018; Tan, Wilson, & McConigley, 2015). To address this gap, and provide data for the development, implementation, and evaluation of HIV patient navigation interventions (Newman, Thompson, & Roberts, 2006; Sandelowski and Leeman, 2012; Thomas and Harden, 2008; Toews et al., 2017), we conducted a qualitative meta-synthesis (Nye, Melendez-Torres, & Bonell, 2016; Sandelowski, Docherty, & Emden, 1997) to understand and describe client experiences with HIV patient navigation, in order to facilitate research to practice for the benefit of public health programs and practitioners.

Methods

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

Search strategy

A librarian with expertise in building and conducting systematic literature searches developed the search methods and conducted the searches. Studies were located from 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 searches were conducted in PubMed, Scopus, and Google scholar, as well as a hand search of key HIV prevention journals and reference checks of included studies. The search was limited to studies published from January 1, 1996 through October 15, 2018 (last date search performed). Citations were uploaded to DistillerSR, a database program used for managing systematic reviews.

Determining study eligibility

Peer-review articles, published in English, of studies conducted in the United States with PWH aged ≥18 years were included in the study. Book chapters, conference abstracts, dissertation/theses, magazine/newsletter articles, webpages, and studies reporting only quantitative findings were excluded. We limited our search to studies conducted in the United States because of the unique and complex challenges PWH experience engaging with health and social systems in the United States. Two reviewers independently screened titles and abstracts, then full reports to identify relevant studies. Discrepancies were resolved through discussion.

Abstracting study characteristics and assessing study quality

For each relevant article, two reviewers independently abstracted study design, setting and recruitment; study quality; client and navigator characteristics; and intervention activities. Study quality was evaluated using the Critical Appraisal Skills Programme (CASP) qualitative checklist, (CASP Qualitative Research Checklist, [online] 2017) and scored according to Butler et al. (Butler, Hall, & Copnell, 2016). Scores range from 0-10; 9-10 indicating high quality, 7.5-9 indicating moderate quality, and <7.5 indicating low quality. Discrepancies were resolved through discussion.

Qualitative data coding and analysis

For data analysis, we used Thomas and Harden's thematic synthesis (Thomas and Harden, 2008) method, best suited for when analytic findings will be used for program practice, intervention development, and evaluation. (Nye, et al., 2016) To develop the codebook, two reviewers independently identified inductive codes from two relevant articles. Once a draft codebook was developed, all coauthors were involved in reviewing, refining, and piloting the codebook. After piloting, the codebook was revised and finalized.

For each relevant article, two reviewers independently coded data. Each reviewer highlighted segments of text (words, sentences, or paragraphs), and then assigned codes to those segments. Only researcher interpretations of primary data located within the Results section of the article were coded (Butler, et al., 2016; Toye et al., 2014; Zimmer, 2006). We did not code text in the introduction, methods, or discussion sections, or participant quotes in the results section (Thomas and Harden, 2008). The reviewers confirmed the segments of text they coded, and then within each coded segment, the codes they assigned to those segments. Discrepancies were resolved through discussion until reviewers were in agreement regarding both the segments of coded text, and assigned codes. Because of the small number of relevant studies, we did not calculate intercoder reliability. However, using a team-based approach with multiple coders, (Sutton and Austin, 2015) intercoder agreement can be achieved by relying on intensive group discussion and consensus (Harry, Sturges, & Klingner, 2005; Saldaña, 2009).

A qualitative data analysis management program, NVivo 12™ (NVivo), was used to manage data. Coded data were reviewed by the lead author to confirm coding consistency across all articles. To begin, segments of coded text were organized around the five most common codes (Ryan and Bernard, 2003). Data were further ordered based on similarities and relationships between codes, (Sandelowski and Leeman, 2012) via a process of constant comparison (Ryan and Bernard, 2003). Themes emerged through active reading of each article and noting insights, confirming and comparing findings across all studies, reevaluating organization of the data, and finally through writing and intensive editing to clarify themes (Thomas and Harden, 2008). All coauthors periodically reviewed and confirmed the analytic process and findings.

Results

Study, client, and navigator characteristics

Seven studies were identified as relevant (Broaddus, Hanna, Schumann, & Meier, 2015; Broaddus, Owczarzak, Schumann, & Koester, 2017; Fuller et al., 2018; Koester et al., 2014; Parnell et al., 2017; Sullivan et al., 2015; Westergaard et al., 2017). Primary data across all studies were collected via in-depth interviews, and data analyzed using thematic analysis (Sullivan, et al., 2015; Westergaard, et al., 2017), directed qualitative content analysis (Broaddus, et al., 2017), framework analysis (Fuller, et al., 2018), ethnographic inductive methodology and grounded theory (Koester, et al., 2014), and an unnamed systematic method (Broaddus, et al., 2015). CASP study quality scores ranged from 7.5 to 9.5/10 (mean 8.4), or moderate to high quality.

Per study eligibility, all participants were HIV-positive. Participant ages ranged from 18 to 68 years, and all studies included racial/ethnic minorities as part or all of the sample. Studies also included participants who identified as gay, bisexual or men who have sex with men (MSM), and transgender (Broaddus, et al., 2015; Parnell, et al., 2017), had a history of incarceration (Broaddus, et al., 2015; Broaddus, et al., 2017; Fuller, et al., 2018; Koester, et al., 2014; Westergaard, et al., 2017), or were incarcerated at the time of the study (Koester, et al., 2014), had a history of homelessness (Fuller, et al., 2018; Westergaard, et al., 2017), or substance use (Westergaard, et al., 2017), and were out of HIV care (Broaddus, et al., 2015; Broaddus, et al., 2017; Parnell, et al., 2017; Westergaard, et al., 2017).

Titles of the individuals functioning as navigators included linkage to care specialist (Broaddus, et al., 2015; Broaddus, et al., 2017; Fuller, et al., 2018), case manager (Fuller, et al., 2018), peer (Fuller, et al., 2018), bridge counselor (Fuller, et al., 2018; Parnell, et al., 2017), patient navigator (Koester, et al., 2014), nurse guide (Sullivan, et al., 2015), and peer navigator (Westergaard, et al., 2017). For ease in presenting the results of analysis, all titles were changed to *navigator*. Navigators were non-medical professionals (Broaddus, et al., 2015), nurses (Sullivan, et al., 2015), case managers and disease intervention specialists (Fuller, et al., 2018), and had bachelor's degrees or were clinical social workers (Broaddus, et al., 2017; Fuller, et al., 2018; Parnell, et al., 2017). Navigators sometimes shared personal characteristics with the client, such as HIV positivity, history of incarceration (Fuller, et al., 2018; Koester, et al., 2014), or familiarity with the client's community (Westergaard, et al., 2017). Length of time navigators spent with clients ranged from one 45-minute video conference (Fuller, et al., 2018), to 8 to 10 months of intensive interaction (Broaddus, et al., 2015; Broaddus, et al., 2017; Fuller, et al., 2018; Koester, et al., 2014; Sullivan, et al., 2015). Navigators communicated with clients in-person (Fuller, et al., 2018; Koester, et al., 2014; Westergaard, et al., 2017) or via video conference (Fuller, et al., 2018), phone (Fuller, et al., 2018; Sullivan, et al., 2015), or text message (Westergaard, et al., 2017).

Client experiences with HIV patient navigation

Four interrelated themes emerged from analysis that pertain to the health and social service system and care environment, the profound significance of the client-navigator relationship, client reluctance to end the navigation program, and client self-efficacy and feelings of hope and psychological change as a result of their navigation experience.

Theme 1. Navigators provide continuity and inclusive support across multiple systems of care

Systems are fragmented and the navigator provides continuity.: Navigators helped clients negotiate complex and fragmented health and social service systems, which can be burdensome for clients (Broaddus, et al., 2017). Working within and across multiple systems, navigators became "knowledge brokers," functioning as a "repository of memory," providing continuity and unifying the client experience. (Broaddus, et al., 2017) For the client, lack of clarity about the navigator role within the larger health system, or the distinction between the navigator and other service providers may cause hesitation to engage with, or confusion regarding the need to discharge from the navigator's care. (Broaddus, et al., 2017)

HIV navigators provide support for both HIV and social service needs.: Navigators acknowledged the realities of client health and social service needs beyond HIV care (Broaddus, et al., 2017; Sullivan, et al., 2015). As they introduced themselves to clients, navigators would emphasize their role in care (re)engagement and their availability to provide non-medical resources and support central tots navigating health systems (Parnell, et al., 2017).

Navigators provided HIV-specific advocacy by addressing dissatisfaction with medical care (Parnell, et al., 2017), scheduling appointments (Fuller, et al., 2018), accompanying clients to medical appointments (Parnell, et al., 2017), interpreting medical information, and educating clients about medication adherence, safety, interactions, and side effects (Sullivan, et al., 2015). While providing HIV support, navigators emphasized the relationship between the client's health and the impact to the client's family (Parnell, et al., 2017). While some clients reported not learning anything new about managing HIV because their clinician provided sufficient education (Sullivan, et al., 2015), others considered their navigator a life-saver for their assistance with accessing antiretroviral therapy (Fuller, et al., 2018). Overall, navigator support expedited client connections to care (Fuller, et al., 2018).

Clients viewed assistance with non-medical services as more important than assistance with medical services. (Fuller, et al., 2018) Non-medical assistance included navigators assessing needs, assistance with accessing food, residency, housing, mental health care, substance use treatment (Broaddus, et al., 2017), health insurance (Broaddus, et al., 2017; Parnell, et al., 2017), and job readiness programs (Fuller, et al., 2018). Navigators also provided transportation to appointments (Parnell, et al., 2017), reviewed eligibility for social programs, helped obtain and complete forms, coordinated between various support programs, and brainstormed solutions to problems (Broaddus, et al., 2017).

Theme 2. The relationship with the navigator is fundamental to the client experience—Clients attributed the success of the navigation program to the dimensions of the relationship with their navigator (Broaddus, et al., 2017).

The relationship is comfortable and familial.: Clients described the relationship as comfortable, sometimes depicting the navigator as a member of the family (Broaddus, et al., 2015). Clients reported enjoying spending time with the navigator during home visits (Parnell, et al., 2017).

Clients appreciate a personable, encouraging, and genuine navigator.: Clients viewed navigators as proactively checking on their well-being and facilitating access to resources (Broaddus, et al., 2017). They noted their navigator's kindness, reliability, and affection (Sullivan, et al., 2015), and appreciated when they listened and provided non-judgmental encouragement (Westergaard, et al., 2017). Navigator earnestness to listen made it easier for clients to share their experiences. (Parnell, et al., 2017) The availability of the navigator was seen as a sign of the relationship's authenticity. (Sullivan, et al., 2015) Clients described navigators as motivating and helping (Broaddus, et al., 2017), providing assistance beyond their navigator duties, or being available after hours to talk (Broaddus, et al., 2017; Sullivan, et al., 2015). Clients appreciated the navigator's problem solving abilities (Parnell, et al., 2017; Sullivan, et al., 2015), and their persistence in addressing client dissatisfaction with medical care, which often motivated clients to return to care (Parnell, et al., 2017). For some clients, perceptions of the navigators evolved over time, learning that the navigator was a resource to help, rather than a monitor of their behavior (Broaddus, et al., 2017).

The presence of the navigator is evidence someone cares.: Clients appreciated having a person designated to help them, and found it comforting to be able to contact the navigator after the intervention ended (Fuller, et al., 2018). The genuine friendliness and heartfelt concern of the navigator gave clients a feeling they were cared for (Sullivan, et al., 2015), as did the navigator's patience and flexibility to help the client engage in care (Parnell, et al., 2017). For incarcerated clients, contact from the navigator before release was proof that someone on the outside cared for them (Fuller, et al., 2018). Likewise, for clients who were separated or estranged from family, the navigator provided a sense that someone cared (Broaddus, et al., 2017).

The value of shared experiences and empathy.: Clients valued the presence of a peer (Westergaard, et al., 2017); the relationship with a navigator who is a peer was different and potentially more meaningful for clients (Koester, et al., 2014). When clients knew the navigator understood or shared their priorities, it enhanced their interest in returning to HIV care (Parnell, et al., 2017), and brought value to their interactions with services (Koester, et al., 2014). Shared experiences served as a motivating factor to follow the navigator's advice; some clients were not as willing to take advice from someone without similar life experiences (Koester, et al., 2014).

Psychosocial support is an important component of the relationship.: Navigators provided emotional support and social connection (Broaddus, et al., 2017; Parnell, et al., 2017). They increased comfort with an HIV diagnosis (Broaddus, et al., 2015), and clients believed the social support and encouragement they received facilitated their engagement in HIV care (Parnell, et al., 2017; Westergaard, et al., 2017). Clients consistently endorsed the navigator's support, regardless of whether they had strong or limited social support networks. For clients with strong ties to friends and family or other networks, the navigator provided additional encouragement (Fuller, et al., 2018). For clients without stable sources of support, navigators may have been the primary source of support (Fuller, et al., 2018), in which a personal connection was especially important and fulfilling (Broaddus, et al., 2015; Broaddus, et al., 2017; Fuller, et al., 2018; Sullivan, et al., 2015). For incarcerated clients, the navigator and the program addressed gaps in supportive networks that may have deteriorated while clients were incarcerated (Broaddus, et al., 2017). Compared to other service providers, navigators provided more support and paid closer attention to their needs (Broaddus, et al., 2017).

The relationship functions as a buffer against stigma.: The relationship with the navigator was cited as a buffer against client perceptions and experiences of HIV stigma and shame, which may have kept them from engaging in care (Broaddus, et al., 2015), or with their family (Broaddus, et al., 2017; Sullivan, et al., 2015).

The relationship leads to care engagement.: Clients noted the relationship with their navigator as motivation to prioritize engagement in care (Broaddus, et al., 2015), and as the reason for continued adherence to HIV treatment (Sullivan, et al., 2015).

Theme 3. Clients are reluctant to end the navigation program—Clients reported feelings of loss and sadness when describing the experience of ending the navigation program (Westergaard, et al., 2017). Even for clients who understood the program was time-limited and were prepared to manage their own care, some were anxious about leaving the program (Broaddus, et al., 2017).

Unprepared to leave and/or need more assistance.: Clients wanted to continue working with their navigator because they felt unprepared to engage in HIV care (Sullivan, et al., 2015). Some incarcerated clients needed continued assistance navigating nonmedical support services to facilitate transition into the community and minimize potential barriers (Fuller, et al., 2018).

The desire to maintain a relationship with their navigator.: Clients were reluctant to end the intervention, especially when they formed close bonds with the navigator (Fuller, et al., 2018). Clients wanted to maintain their relationship for as long as possible (Broaddus, et al., 2017) and some intended to keep in contact if they encountered barriers to care, or simply to touch base (Broaddus, et al., 2015).

Burden of starting over.: Clients expressed anxiety about transitioning out of the program because they viewed their relationship as an investment (Broaddus, et al., 2015; Broaddus, et al., 2017). They may be resistant to establishing new relationships (Sullivan, et al., 2015) with their next care provider because of the emotional burden of continuing to disclose their story to people over and over again (Broaddus, et al., 2015; Broaddus, et al., 2017).

Theme 4. Participation in a navigation program can instill hope and transform lives

Working with the navigator engendered hope.: Working with the navigator and participating in the navigation program gave clients a feeling of meaning, worth, hope, and desire (Broaddus, et al., 2017; Fuller, et al., 2018). Learning from their navigator that adhering to their medication meant they could live a long life increased their sense of hope (Sullivan, et al., 2015).

Navigator models positive behaviors and self-efficacy.: Clients regarded their navigator as a role model, or embodiment of a goal (Koester, et al., 2014), and motivational speaker (Broaddus, et al., 2017). Navigators motivated clients to be more accountable for their health (Broaddus, et al., 2015), and reinforced skills that enabled clients to manage their care with increasing independence (Broaddus, et al., 2017; Fuller, et al., 2018; Sullivan, et al., 2015). Clients intended to continue engaging in HIV care after the end of the program (Broaddus, et al., 2017; Sullivan, et al., 2015), and expressed confidence in their ability to do so (Fuller, et al., 2018; Parnell, et al., 2017).

Clients experience personal reflection and psychological change.: The support and insight that the navigators offered helped clients feel optimistic about the future, which for some was a significant shift in perspective (Sullivan, et al., 2015). Clients described the timing of the navigator coming into their lives as inspired or ordained, the navigator “finding them when they needed to be found” (Broaddus, et al., 2017). When clients shared life experiences and common values with their navigator, the navigator became a personification of transformation with which the client could easily identify (Koester, et al., 2014).

Discussion

This meta-synthesis of the experiences of PWH participating in HIV patient navigation elucidates the complexity of the client environment within which navigation occurs, the significance of the client-navigator relationship to the client navigation experience, the reluctance to end the program, and the learned skills and hope engendered as a result of their navigation experiences. The first theme regarding fractured care systems and the holistic social service and medical care support provided by navigators is consistent with our understanding of barriers to social services and healthcare. Client feelings of hope, empowerment, and self-efficacy as a byproduct of participation in navigation emerged during the final stage of analysis as a notable outcome of the navigation process. The value and significance of the client-navigator relationship and the reluctance to leave the navigation program were primary themes across most of the studies, and over the course of our analysis, the relationship clearly emerged as the most salient and overarching theme of the client experience, uniting the studies.

Patient navigation is most often associated with functional aspects of care such as coordinating services and addressing barriers (Bradford, et al., 2007; Freeman and Rodriguez, 2011). However, the navigation process also provides critical relational support (Cook, Canidate, Ennis, & Cook, 2018), instrumental in improving client psychosocial wellbeing and adherence to care (DiMatteo, 2004). A relationship is a feeling or sense of emotional bonding with another person - feeling that one is recognized, appreciated, cared about, understood, and in union with another (Perlman, 1979). The relationship between a navigator and client can provide emotional support and facilitate trust, and can be much stronger than the typical relationship between a patient and service provider (Davis et al., 2017). Our analysis indicated that clients overwhelmingly endorsed the presence of the navigator in their lives, valued the navigator’s empathy and support of their emotional concerns, considered their navigators as friends and confidants, and they felt they were not alone in their HIV experience. When the navigator was a peer, shared life experiences established trust and respect, which facilitated uptake of care and deepened the relationship. Other research has found that clients prefer peers to deliver emotional support and linkage to care (Cook, et al., 2018). In the context of patient-centered care, when a patient feels they are “known as a person” by a clinician, it is significantly and independently associated with improved HIV outcomes (Beach, Keruly, & Moore, 2006).

The client-navigator relationship is not an independent function of navigation, but rather, the relationship is the foundation of and medium through which navigator functions are enabled and services delivered (Freeman and Rodriguez, 2011; Phillips et al., 2014). In our analysis, one of the more significant functions of the relationship was the provision of social support. Social support is defined as the network structure of relationships, functional support (emotional, psychological, tangible or informational) offered, perceived adequacy of this support, and is often operationalized by measures of perceived support (Green, 1993). This review found navigators offering all aspects of functional support, and perceived support was evident across the data. The relationship also facilitated engagement in care, and served as a buffer against stigma, outcomes identified in other literature (Burgoyne, 2005; McLeroy, Bibeau, Steckler, & Glanz, 1988; Wohl et al., 2010). In some cases, the client came to see the navigator as a personification of their goals, as a model of health and achievement. These opportunities for personal reflection and transformation, increased self-efficacy, and feelings of hope and personal worth were secondary outcomes of the relationship and participation in the navigation program. Patient empowerment and activation is a natural outcome of navigation due to the patient-centered, strengths-based approach to care coordination and relational support (Carroll et al., 2010; Yosha et al., 2011).

Implications for Practice and Research

The findings from this review highlight a number of recommendations for practice. Regarding navigator training and preparation for practice, strong interpersonal skills may be equally as important as knowledge of medical and social service systems. Programs may consider including or enhancing basic relationship-building skills such as demonstrating empathy, active listening, and communicating care for the client in the navigator training curriculum. It may also be beneficial to hire navigators who are peers of their clients or have shared life experiences. In addition, the program should clearly delineate the role of the navigator, and the navigator should inform the client of the parameters of their relationship, including the time-limitation. Intentional planning around phasing the client out of the navigation program may be especially important for clients without immediate, stable social support networks and social capital, including those with a history of incarceration. Finally, continuity across service providers and systems of care is critical when considering developing and implementing an HIV navigation program. Programs should be holistic in design and approach, and able to address client needs beyond HIV care. Programs should also consider emphasizing a strengths-based approach to client care and practice, acknowledging the self-determination of the client.

There are a number of research questions identified for future inquiry. Five of the seven studies included a partial or full sample of PWH with a history of incarceration. The current analysis did not intentionally disaggregate the experiences of those with and without a history of incarceration; however, anecdotally we found that clients receiving navigation during their transition from jail into the community may have experienced heightened feelings of personal growth, and further exploration on this topic should be considered. It is also worth exploring whether the amount of time the client spends developing a relationship with their navigator has an impact on HIV-related health outcomes. Likewise, how long beyond the intervention do the impacts of the client-navigator relationship last, and do outcomes change or decrease? Further, are benefits amplified by particular aspects of the relationship between the navigator and client, and more broadly, what are the essential components of interpersonal relationships for public health intervention? Finally, as we identified, navigation can facilitate personal growth, hope, and self-efficacy, which has potential downstream benefits for the client and health system. Future research should consider role of client resiliency and post-traumatic growth in HIV care.

Strengths and Limitations

As the field of HIV patient navigation and care coordination evolves, there is continued need for clearer definitions of models of care. Our review did not define or operationalize HIV patient navigation, as such our search may have inadvertently excluded potentially relevant articles. However, an experienced librarian conducted the literature searches and ensured our search methods were sound. Five of the seven primary studies were funded under the U.S. Department of Health and Human Services, Health Resources Services Administration, Special Projects of National Significance grant, and among those studies, there are common study locations and dates of data collection. It is unclear whether findings from these studies are independent of one another. It is increasingly common to assess study quality in meta-synthesis (Lewin et al., 2015), and the moderate to high quality of the primary studies lends credibility to our analysis. The method used to synthesize data in this review, thematic synthesis, was developed specifically to assess intervention need, appropriateness and acceptability (Barnett-Page & Thomas, 2009), and for the practical application of those findings for theory development, program, and research (Nye, et al., 2016) which should appeal to programs seeking to implement patient navigation.

To date, no systematic review has been conducted of PWH experiences with HIV patient navigation in the United States. Our review seeks to advance public health research and practice by articulating key experiences and perspectives of PWH, and drawing recommendations that can be applied to the development, implementation, and evaluation of HIV patient navigation intervention and programs. Patient navigation is a systems-level intervention where a fundamental mechanism for action is the interpersonal relationship. The lived experiences of PWH are complex and varied, yet this analysis found that almost universally, the client-navigator relationship was central to their navigation experience and broader quality of life. This review underscores the importance of the relationship within patient-centered approaches for PWH, and provides insight into the interpersonal dynamics between a client and navigator. Intensive, multi-level interventions, such as HIV patient navigation are not the brief, easily replicable interventions preferred in public health (Frieden, 2010; Kaufman, Cornish, Zimmerman, & Johnson, 2014). Yet, as long as individuals and communities are marginalized and isolated from health and social service systems, patient-centered interventions such as HIV patient navigation may be a necessary public health strategy to engage and retain the most underserved and vulnerable in HIV care.

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References

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

Beach MC, Keruly J, & Moore RD (2006). Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? J Gen Intern Med, 21(6), pp. 661–665. [PubMed: 16808754]

Barnett-Page E, & Thomas J (2009). Methods for the synthesis of qualitative research: a critical review. BMC Med Res Methodol, 9, p 59. [PubMed: 19671152]

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

Broaddus MR, Hanna CR, Schumann C, & Meier A (2015). “She makes me feel that I’m not alone”: linkage to Care Specialists provide social support to people living with HIV. AIDS Care, 27(9), pp. 1104–1107. [PubMed: 25854534]

Broaddus MR, Owczarzak J, Schumann C, & Koester KA (2017). Fostering a “Feeling of Worth” Among Vulnerable HIV Populations: The Role of Linkage to Care Specialists. AIDS Patient Care STDS, 31(10), pp. 438–446. [PubMed: 28981336]

Burgoyne RW (2005). Exploring direction of causation between social support and clinical outcome for HIV-positive adults in the context of highly active antiretroviral therapy. AIDS Care, 17(1), pp. 111–124. [PubMed: 15832838]

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 Evid Based Nurs, 13(3), pp. 241–249. [PubMed: 26790142]

Carroll JK, Humiston SG, Meldrum SC, Salamone CM, Jean-Pierre P, Epstein RM, & Fiscella K (2010). Patients’ experiences with navigation for cancer care. Patient Educ Conns, 80(2), pp. 241–247.

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

Centers for Disease Control and Prevention, (2018a). HIV Surveillance Report, 2017 http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html Published November 2018 Accessed 5/21/2019.

Centers for Disease Control and Prevention., (2018b). Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2016. HIV Surveillance Supplemental Report 2018;23(No. 4). http://www.cdc.gov/hiv/librarv/reports/hiv-surveillance.html Published June 2018 Accessed 5/21/2019.

Cook CL, Canidate S, Ennis N, & Cook RL (2018). Types and delivery of emotional support to promote linkage and engagement in HIV care. Patient Prefer Adherence, 12, pp. 45–52. [PubMed: 29343948]

Davis DA, Aguilar JM, Arandi CG, Northbrook S, Loya-Montiel ML, Morales-Miranda S, & Barrington C (2017). “Oh, I’m Not Alone”: Experiences of HIV-Positive Men Who Have Sex With Men in a Health Navigation Program to Promote Timely Linkage to Care in Guatemala City. AIDS Ednc Prev, 29(6), pp. 554–566.

De Jesus M, & Williams DR (2018). The Care and Prevention in the United States Demonstration Project: A Call for More Focus on the Social Determinants of HIV/AIDS. Public Health Rep, 733(2_suppl), pp. 28S–33S.

DiMatteo MR (2004). Social support and patient adherence to medical treatment: a meta-analysis. Health Psychol, 23(2), pp. 207–218. [PubMed: 15008666]

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

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

Frieden TR (2010). A framework for public health action: the health impact pyramid. Am J Public Health, 100(4), pp. 590–595. [PubMed: 20167880]

Frieden TR, Foti KE, & Mermin J (2015). Applying Public Health Principles to the HIV Epidemic--How Are We Doing? N Engl J Med, 373(23), pp. 2281–2287. [PubMed: 26624243]

Fuller SM, Koester KA, Maiorana A, Steward WT, Broaddus MR, Lass K, … Myers JJ (2018). “I don’t have to do this all by myself’: Systems Navigation to Ensure Continuity of HIV Care for Persons Leaving Prison. AIDS Behav

Green G (1993). Social support and HIV. AIDS Care, 5(1), pp. 87–104. [PubMed: 8461365]

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

Kaufman MR, Cornish F, Zimmerman RS, & Johnson BT (2014). Health behavior change models for HIV prevention and AIDS care: practical recommendations for a multi-level approach. J Acquir Immune Defic Syndr, 66 Suppl 3, pp. S250–258. [PubMed: 25007194]

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 STDS, 28(2), pp. 82–90. [PubMed: 24517539]

Land L, Hathorn E, & Ross JDC (2011). Using patient experience to measure the quality of HIV care. 22(7), pp. 366–367.

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. Am Psychol, 73(1), pp. 26–46. [PubMed: 29345485]

Lewin S, Glenton C, Munthe-Kaas H, Carlsen B, Colvin CJ, Gulmezoglu M, … Rashidian A (2015). Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). PLoS Med, 12(10), p e1001895. [PubMed: 26506244]

McLeroy KR, Bibeau D, Steckler A, & Glanz K (1988). An ecological perspective on health promotion programs. Health Educ Q, 15(4), pp. 351–377. [PubMed: 3068205]

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 2018 11 13;32(17):2557–2571. [PubMed: 30102661]

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. Clin Infect Dis, 57(8), pp. 1164–1171. [PubMed: 23797289]

National HIV/AIDS Strategy for the United States: Updated to 2020 (7 2015). https://files.hiv.gov/s3fs-public/nhas-update.pdf Retrieved 5/22/2019.

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

Nye E, Melendez-Torres GI, & Bonell C (2016). Origins, methods and advances in qualitative meta-synthesis. Review Of Education, 4(1), pp. 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 Behav2019 1;23(Suppl 1):61–69.

Peart A, Lewis V, Brown T, & Russell G (2018). Patient navigators facilitating access to primary care: a scoping review. BMJ Open, 5(3), p e019252.

Pellowski JA, Kalichman SC, Matthews KA, & Adler N (2013). A pandemic of the poor: social disadvantage and the U.S. HIV epidemic. Am Psychol, 65(4), pp. 197–209.

Perlman H (1979). Relationship. The heart of helping people.: University of Chicago Press.

Phillips S, Nonzee N, Tom L, Murphy K, Hajjar N, Bularzik C, … Simon MA (2014). Patient navigators' reflections on the navigator-patient relationship. J Cancer Educ, 29(2), pp. 337–344. [PubMed: 24493636]

Ryan GW, & Bernard HR (2003). Techniques to Identify Themes. Field methods, 75(1), pp. 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. Res Nurs Health, 20(4), pp. 365–371. [PubMed: 9256882]

Sandelowski M, & Leeman J (2012). Writing usable qualitative health research findings, (dual Health Res, 22(10), pp. 1404–1413.

Sullivan KA, Schultz K, Ramaiya M, Berger M, Parnell H, & Quinlivan EB (2015). Experiences of women of color with a nurse patient navigation program for linkage and engagement in HIV care. AIDS Patient Care STDS, 29 Suppl 1, pp. S49–54. [PubMed: 25457920]

Sutton J, & Austin Z (2015). Qualitative Research: Data Collection, Analysis, and Management. Can J Hosp Pharm, 68(3), pp. 226–231. [PubMed: 26157184]

Tan CH, Wilson S, & McConigley R (2015). Experiences of cancer patients in a patient navigation program: a qualitative systematic review. JBI Database System Rev Implement Rep, 13(2), pp. 136–168.

Thomas J, & Harden A (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol, 8, p 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. Ann Intern Med, 156(11), pp. 817–833, W-284, W-285, W-286, W-287, W-288, W-289, W-290, W-291, W-292, W-293, W-294. [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. J Clin Epidemiol, 88, pp. 133–139. [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 Med Res Methodol, 14, p 80. [PubMed: 24951054]

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. Addict Sci Clin Pract, 12(1), p 11. [PubMed: 28441962]

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

Wohl AR, Galvan FH, Myers HF, Garland W, George S, Witt M, … Carpio F (2010). Social support, stress and social network characteristics among HIV-positive Latino and African American women and men who have sex with men. AIDS Behav, 14(5), pp. 1149–1158. [PubMed: 20107888]

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 Educ Couns, 82(3), pp. 396–401. [PubMed: 21255958]

Zimmer L (2006). Qualitative meta-synthesis: a question of dialoguing with texts. J Adv Nurs, 53(3), pp. 311–318. [PubMed: 16441536]

Table 1:

Study characteristics of relevant studies reviewed (n=7)

Study (Year)	Objective	Location	Design	Data collection method	Data collection dates	Data analysis method	CASP score (0-10)	Funding source
Broaddus, Hanna, Schumann, & Meier (2015)	To describe client barriers to care, how navigators decrease barriers, and client perspectives on the study.	Wisconsin	Intervention study (pilot phase) with qualitative data results	Interview	February to August 2013	Cited “systematic methods,” but no specific analytical approach identified	7.5	DHHS/HRSA Special Projects of National Significance Initiative, Systems Linkages and Access to Care, grant number H97HA22698
Broaddus, Owczarzak, Schumann, & Koester (2017)	To contribute generalizable knowledge and understand experiences of clients who participated in the study.	Wisconsin (Madison and Milwaukee)	Intervention study with qualitative data results	Interview	Winter 2013 to Spring 2014	“Directed qualitative content analysis”	9	DHHS/HRSA, Special Projects of National Significance Initiative, Systems Linkages and Access to Care, grant number H97HA22698
Fuller, et al., (2018)	To understand the experiences of clients who participated in the study.	Louisiana, Massachusetts, Wisconsin, North Carolina	Intervention study with qualitative data results	Interview	January to April 2015	Framework analysis	9.5	DHHS/HRSA, Special Projects of National Significance Initiative, Systems Linkages and Access to Care, grant number U90HA22702
Koester et al., (2014)	To examine the interactions between navigators and their clients in order to understand how the patient-navigator model worked in practice.	San Francisco, CA	Ethnographic, supplemental qualitative data collection	Interview	December to October 2011	Grounded theory	8.5	National Institute on Drug Abuse Grant R01DA027209
Parnell et al., (2017)	To describe encounters between clients and navigators, and characterize adaption and use of engagement domain components.	North Carolina	Intervention study with qualitative data results	Interview	2014	Cited an “iterative process” but no specific analytical approach identified	9	DHHS/HRSA, Special Projects of National Significance Initiative, Systems Linkages and Access to Care, grant number H97HA22695
Sullivan, et al., (2015)	To explore experiences of clients who participated in the study.	Chapel Hill, NC	Intervention study with qualitative data results	Interview (via telephone)	Not reported (study dates January 2011 to August 2014)	Thematic analysis	9.5	DHHS/HRSA Special Projects of National Significance Initiative, Systems Linkages and Access to Care, grant number H97HA15148
Westergaard et al., (2017)	To evaluate a mobile health and peer support intervention.	Baltimore, MD	Intervention study with qualitative data results	Interview	September to November 2014	Thematic analysis	7.5	National Institutes of Health/ National Institute on Drug Abuse Grants R34DA033181, U01DA036297 and K23DA032306

CASP = Critical Appraisal Skills Programme

Table 2:

Client characteristics of relevant studies reviewed (n=7)

Study (Year)	Sample size (n)	Study population	Recruitment process	Inclusion/exclusion to be interviewed	Age min/max and mean/ median	Sex/gender	Race/ethnicity	Other notable characteristics
Broaddus, Hanna, Schumann, & Meier (2015)	n=16	PWH, primarily black MSM	Participant names were generated from the navigator client list	Participated in the intervention	18/68, mean 33.7	11 male, 3 female, 2 TG (MTF)	13 African American, 2 Hispanic, 1 white	3 had history of incarceration, 8 were out of care
Broaddus, Owczarzak, Schumann, & Koester (2017)	n=30	Newly HIV+ and initiating HIV care for the first time, out of care for 60 days, or at risk of falling out of care, history of incarceration	Navigators referred clients for invitation to participate in interviews	Participated in the intervention	22/68, mean 39.7	12 male, 8 female, (missing 10 records)	16 African American, 9 white, 3 Latino, 1 African, 1 Indian	3 interviews conducted in Spanish, 9 had history of incarceration
Fuller, et al., (2018)	24 (LA n=14, MA n=1, NC n=1, WI n=8)	PWH recently released from prison	Intervention staff set up times and locations for the investigators to meet study participants.	Intervention participant, provided verbal consent, released from prison in previous 18 months, and expressed interest in participating in interviews	25/59, mean 45.9	21 male, 3 female	18 African American, 6 white	3 Some college, 12 HS/GED, 7 some HS, 1 <8th grade; 3 homeless; all have history of incarceration (mean 6.7 years)
Koester et al., (2014)	n=31	PWH leaving the San Francisco jail system	Participants were selected by convenience sample, approached and asked to participate.	Had >2 contacts with navigator and completed 2, 6 and 12 month post-release assessments.	18/65 (71% were 41-65)	25 male, 6 female	15 African American, 13 white, 2 Latino, 1 more than 1	All have history of incarceration (9 incarcerated 1-10 times, 5 incarcerated 11-20 times, 4 incarcerated 21+ times)
Parnell et al., (2017)	n=11	PWH out of care (6-9 months since last doctor appointment)	Purpose sampling technique. Clients approached by their navigator, obtained verbal consent, referred to research team for formal consent and data collection.	PWH, >18 years, speak English, worked with a navigator for care engagement, willing to participate in an interview.	24/57, median 39	5 male, 5 female, 1 TG	8 African American, 2 white, 1 Other	8 Heterosexual, 2 gay/ bisexual, 1 did not identify. 4 some HS, 3 HS, 4 some college
Sullivan, et al., (2015)	n=21	PWH women of color	Women who participated in the intervention were screened for eligibility to participate in interviews, and then were contacted via phone and invited to participate.	1 contact with nurse guide 8 months prior to interview (intervention completed)	27/62, mean 44.8	All participants were female	All participants were African American	9 < HS, 2 HS, 9 > HS; annual income 16 <$10,000, 2 $10-30,000, 2 >$30,000; 1 private insurance, 12 public insurance, 7 uninsured
Westergaard et al., (2017)	n=12	PWH, predominantly Black, male and low-income.	Clinic electronic medical record produced list of those lapsed in HIV care. Clinic staff contacted	> 18 years, PWH, >10000mL copies, no visit with HIV provider in 6 months,	$^{\wedge}$49.3 median (interquartile	$^{\wedge}$12 males	$^{\wedge}$17 African American	$^{\wedge}$ Use 6 months prior to enrollment: 14 cigarette, 10 marijuana, 4 heroin, 8

Study (Year)	Sample size (n)	Study population	Recruitment process	Inclusion/exclusion to be interviewed	Age min/max and mean/ median	Sex/gender	Race/ethnicity	Other notable characteristics
			patients by phone and invited to participate in the intervention. Interviews were conducted with the first 12 participants.	and willing to attend 1 visit. Excluded medical or psychiatric conditions.	range 45.0-54.6)			alcohol, 3 cocaine, 3 injection drug use; 14 high school GED; 8 annual income <$5,000; 7 hepatitis C seropositive; 5 ever homeless, 9 history of incarceration

PWH = People with HIV

MSM = Men who have sex with men

TG = Transgender, MTF =Male to female

HS=high school

GED=General Educational Development

LA Louisiana, MA=Massachusetts, NC=North Carolina, WI=Wisconsin

^ out of 19 randomized into the intervention