



Published in final edited form as:

AIDS Care. 2011 January ; 23(1): 79–90. doi:10.1080/09540121.2010.496847.

Improving HIV/AIDS care through treatment advocacy: going beyond client education to empowerment by facilitating client–provider relationships

Matt G. Mutchler^{a,b,*}, Glenn Wagner^c, Burt O. Cowgill^d, Tara McKay^{b,e}, Brian Risley^f, and Laura M. Bogart^g

^aDepartment of Sociology, California State University, Dominguez Hills, Carson, CA, USA

^bCommunity Based Research, AIDS Project Los Angeles, Los Angeles, CA, USA

^cRAND, Santa Monica, CA, USA

^dUCLA/RAND Center for Adolescent Health Promotion, University of California, Los Angeles, Los Angeles, CA, USA

^eDepartment of Sociology, University of California, Los Angeles, Los Angeles, CA, USA

^fTreatment Education, AIDS Project Los Angeles, Los Angeles, CA, USA

^gChildren’s Hospital Boston, Division of Pediatrics, Harvard Medical School, Boston, MA, USA

Abstract

Treatment advocacy (TA) programs have been implemented by AIDS service organizations (ASOs) and primary care clinics across the USA to help engage clients with HIV into care and support their adherence to antiretroviral therapy (ART). TA aims to empower people with HIV through education and client-centered counseling regarding HIV, ART, and other health issues; advocate on behalf of patients with providers; and make referrals to healthcare services and clinical trials. However, relatively little is known about the impact TA has on clients’ healthcare experiences. The present study’s objectives included exploring how TA services help clients engage in HIV care, initiate ART, and adhere to HIV medications. We conducted 25 semi-structured qualitative open-ended interviews with clients living with HIV/AIDS recruited from AIDS Project Los Angeles (APLA); four HIV medical providers; and two TA staff at APLA. Of the 25 clients interviewed, 92% were male and 8% were female. The average age was 43 years (SD = 9). About 60% were African-American, 20% were White, 12% were other or multiracial, 4% were Latino, and 4% were Asian/Pacific Islander. Five interconnected themes consistently emerged across clients, TAs, and providers. TAs helped clients understand treatments and supported adherence within a holistic context. Further, TAs acted as a bridge to providers and helped clients build self-advocacy skills. Our data show that TA services go beyond traditional areas of education and treatment adherence. TA services within an ASO also provide a safe place to discuss initial HIV diagnoses and other health issues in a more comprehensive manner. TA services complemented medical and other social services by preparing clients with HIV to be

*Corresponding author : mmutchler@csudh.edu.

better consumers of healthcare services. Future quantitative research examining the effectiveness of TA on improving clients' engagement in care and adherence is a critical next step.

Keywords

HIV care; treatment advocacy; adherence; antiretroviral therapy; ancillary services

Introduction

Many people living with HIV/AIDS (PLWHA) are not receiving antiretroviral therapy (ART) and are not engaged in care. Gardner and colleagues (2005) found that 40% of newly diagnosed individuals with passive referrals had not initiated HIV medical care within 6 months of diagnosis. Krentz, Auld, and Gill (2004) found that 39% of patients presenting for initial HIV care had CD4 counts <200, despite the standard of care recommendation that patients begin ART if their CD4 counts are less than 350. Teshale et al. (2005) estimate that only 60% of PLWHA in the USA are engaged in HIV care (Perkins, Meyerson, Klinkenberg, & Iaffoon, 2008; Samet et al., 2001); 56% of those eligible for treatment are receiving ART. Many on ART do not successfully adhere at high enough levels (i.e., 90–95% of prescribed doses) for optimal treatment benefit (Arnsten et al., 2001; Bangsberg, Hecht, Charlebois, Chesney, & Moss, 2001; Bangsberg et al., 2006; Gardner, Burman, Steiner, Anderson, & Bangsberg, 2009; Holzemer et al., 2006; Howard et al., 2002; Liu et al., 2001).

Ancillary services have arisen to facilitate access to care for PLWHA, including those funded by the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act: case management, drug reimbursement, home healthcare, transportation and food assistance, mental health and substance abuse treatment, as well as treatment education/treatment advocacy (TA), the present study's focus. Receipt of ancillary services has been associated with primary care entry (Gardner et al., 2005; Messeri, Abramson, Aidala, Lee, & Lee, 2002), ART use and adherence (Katz et al., 2001; Magnus et al., 2001), treatment retention (Ashman, Conviser, & Pounds, 2002; Chan, Absher, & Sabatier, 2002; Convisier & Pounds, 2002; Lo, MacGovern, & Bradford, 2002; Sherer et al., 2002), care services utilization (Soto, Bell, & Pillen, 2004), and HIV health literacy (van Servellen et al., 2005).

Few studies have explored the process by which ancillary care programs may facilitate improved provider–patient relationships. Ancillary services may facilitate greater rapport between patients and providers and promote engagement in care (Mallinson, Rajabian, & Coleman, 2007) through active outreach (Cabral et al., 2007), especially for those with comorbid substance use or mental health disorders (Calsyn, Klinkenberg, Morse, Miller, & Cruthis, 2004).

We explored how one type of ancillary care service – TA – might improve engagement in care, ART initiation, and ART adherence. TA programs represent feasible and potentially cost-effective interventions that have been sustained across the US AIDS service organizations (ASOs). TA aims to empower patients through education and client-centered counseling regarding HIV, ART initiation and adherence, and other health issues;

advocating on behalf of patients with providers; and making referrals to access healthcare services and clinical trials. TA also seeks to link PLWHA into effective and timely care, by facilitating navigation through the medical care system and adherence. We conducted a qualitative process evaluation of one well-established TA program at a large ASO, with the following research questions: (1) How does TA help engage PLWHA in care? (2) How does TA help PLWHA initiate ART when appropriate? and (3) How does TA help PLWHA improve adherence?

Methods

Study setting

The present study was conducted at AIDS Project Los Angeles (APLA), an ASO with the mission of improving the lives of PLWHA, reducing HIV incidence, and advocating for fair and effective HIV-related public policy. APLA provides direct, bilingual services to >7500 men, women, and children with HIV/AIDS in Los Angeles (LA) County annually. Clients are 37% Latino, 36% White, and 23% African-American; ~90% are male and 9% female. Client racial/ethnic and gender distributions are similar to those for PLWHA in LA County (HIV Epidemiology Program, Los Angeles County Department of Public Health, 2008): 37% Latino, 36% White, and 23% African-American; ~90% are male.

We used community-based participatory research (CBPR), in which community members and researchers are joint contributors on every study aspect (Bogart & Uyeda, 2009; Israel, Eng, Schulz, & Parker, 2005; Viswanathan, Ammerman, Eng, Garlehner, Lohr, & Griffith, 2004). APLA research and TA program staff partnered with researchers at RAND, UCLA, California State University, Dominguez Hills, and Harvard Medical School. The impetus for the study originated in discussions with APLA staff, who approached the researchers to partner on a TA program evaluation. APLA's ongoing TA Community Advisory Board (CAB) – composed of APLA clients in TA, treatment advocates, and a medical provider – provided a forum for idea exchange and community input at every stage of the project. APLA's and RAND's human subjects review boards both approved the study.

Treatment advocacy (TA) components

TAs aim to increase the understanding of HIV pathogenesis, treatment options, co-infection (e.g., hepatitis), side effects, lab results, nutrition, and healthcare; and to provide client-centered health and treatment counseling, referrals to treatment and services, advocacy to healthcare providers, and community education forums. Both TAs had university degrees in health-related sciences and completed three-day trainings to certify in treatment education. TAs were required to demonstrate extensive knowledge in HIV transmission, testing, pathogenesis, human immune system, disease states, and HIV treatment options. One of the TAs was female and bilingual (English and Spanish).

TAs and clients jointly develop an Individual Service Plan (ISP). TAs assess clients' treatment needs, health issues, healthcare access, disease indicators, medication status, adherence (if applicable), substance use, depression, and HIV knowledge. TAs then help clients set goals; provide referrals for any needed medical care, clinical trials, mental health

services, and social services, and offer advocacy with healthcare providers, in which TAs may contact clients' HIV care providers to discuss clients' situation and possible solutions. The amount of time clients worked with TAs varied between one initial intake to over a year.

Participant recruitment

We conducted interviews with 25 TA clients, two TAs, and four HIV providers who managed the care of APLA's TA clients. Qualitative researchers have found that 25–30 participants are sufficient to reach saturation (i.e., new themes are no longer emerging) across several domains (Morse, 1994; Strauss, 1987), and five participants are needed to understand the essence of a particular sub-group experience (Rice & Ezzy, 1999; Strauss, 1987). We offered the study to all clients in TA at the time of the study and interviewed the first 25 clients who responded. To supplement client perspectives, we interviewed all of the TAs and providers directly involved with the TA program at the ASO. We recruited less than five TAs and medical providers, because we were constrained to those who worked directly with the program. TA clients were recruited via study fliers and screened for eligibility. Clients were eligible if they spoke English or Spanish, and were 18 years old. We used the screener to recruit purposively by care and treatment situation: 12 participants were engaged in care (visited an HIV medical care provider at least once in the last six months), were taking ART, and reported perfect adherence in the last three days; eight were engaged in care and on ART but missed at least one dose in the last three days; two were engaged in care, had CD4 counts <350 and had been recommended to start ART but had not; two were engaged in care, had CD4 counts >350 and were not taking ART; and one had not seen a medical provider in the last six months. HIV providers who worked with TA clients were contacted by TAs about their willingness to participate.

Qualitative protocol

Semi-structured qualitative interviews were used to explore TA's influence on treatment and care. The protocol elicited information about HIV diagnosis, help-seeking after diagnosis, medical care decisions, adherence, and experiences with TA. Tables 1–3 show the client, provider, and TA protocols. Interviews were audio taped and transcribed.

Data analysis

Qualitative analysis was conducted using the program Atlas.ti. Content analysis was conducted using inductive and deductive techniques, which allows for a full range of themes and subthemes to emerge, including those not anticipated. We created a set of thematic-based codes, applied the codes systematically to the narratives, and tested reliability between coders (Bernard, 2002). The first and last authors initially read through a sample of transcripts to identify the presence of text related to TA experiences. Coders were given basic operational definitions of TA-related issues, derived in part from descriptions of APLA's program and current HIV treatment.

Coders identified text related to five themes and related subthemes (described below) (Bernard, 2002; Lincoln & Guba, 1985). The first and last authors resolved discrepancies between coders. Subthemes were mutually exclusive and exhaustive (Bernard, 2002;

Spradley, 1979). Kappas (Cohen, 1960) showed good to excellent consistency between coders (ranging = 0.74–0.92) (Bakeman & Gottman, 1986; Landis & Koch, 1977). We calculated for the number of times each theme was coded; these counts showed the relative depth of each theme (Mutchler, 2000): almost all = theme emerged in almost every interview ($n = 27–31$); most = theme emerged in majority ($n = 20–26$); about half = theme emerged in ~50% ($n = 13–19$); some = theme emerged in a substantial minority ($n = 6–12$); a few = theme emerged in a small number ($n = 1–5$).

Results

Sample

Of the 25 clients interviewed, nearly all (92%) were male. The average age was 42.9 years old (SD = 9.05 years); 60% were African-American, 20% White, 12% other or multiracial, 4% Latino, and 4% Asian/Pacific Islander. Five interconnected themes consistently emerged across clients, TAs, and providers (discussed below and listed with relevant quotes in Table 4).

Understanding treatments

Comprehensive education—Almost all participants mentioned that TA provides comprehensive education about HIV and treatment in a unique way that does not duplicate basic information from healthcare providers. TAs provided detailed information about ways in which medications affected HIV across its reproductive cycle, medication side effects, consequences of non-adherence, and reasons for adherence (Quote 1). Participants sought out TAs to confirm and validate treatment information. Participants felt that TA influenced clients' engagement in HIV medical care and decisions to initiate ART.

Support for newly diagnosed clients—Understanding HIV and treatment options was viewed as particularly useful for newly diagnosed clients (Quote 2). For example, one newly diagnosed participant felt that discussing treatment with a TA helped him to initiate ART earlier than he would have (Quote 3). Overall, clients were able to gain a deep understanding of treatments through conversations with TAs.

Treatment Advocates (TAs) unique perspective outside of the medical establishment—Clients frequently had doubts about treatment but felt that they did not have time or feel comfortable discussing concerns with medical providers. Clients often sought TAs instead of medical providers to confirm or validate treatment information (Quote 4). Many clients used TA to seek a second opinion outside of the healthcare setting (Quote 5).

Treatment Advocates (TAs) as accessible and knowledgeable—Clients valued TAs' availability, convenience, and treatment knowledge. Though TAs – like doctors – often scheduled appointments with clients, TAs were available for drop-in visits. Some participants perceived TAs as being more accessible and better able to address questions and issues than their medical provider (Quote 6). Clients felt TAs possessed a great deal of knowledge about HIV treatments. Clients felt more comfortable bringing up an array of

concerns and questions about treatment experiences with TAs compared to medical providers due to a sense that doctors did not have sufficient time to answer all of their questions.

Supporting adherence

About half of participants mentioned that TA provided education about the importance of adherence in a way that clients could understand (Quote 7), and worked with clients to determine appropriate strategies for supporting adherence, such as pill boxes or pill trays. TAs provided positive reinforcement and a support system for adherence. TAs regularly checked in with clients (e.g., to ask whether they were taking their medications). Clients viewed this simple check-in as a powerful support (Quote 8). TAs also worked with clients and other service providers, such as social services benefits counselors, to ensure clients had access to a steady supply of medications.

Holistic care

Taking into account the life situation of each client—Most clients mentioned that TA offered services within a holistic care model. Because TAs were aware of clients' background and life circumstances (e.g., mental health issues, substance abuse, homelessness, incarceration), they were able to identify key areas of need in clients' lives that might influence medication taking, and then provide appropriate referrals (Quote 9). Further, TAs took clients' life context into account when determining which medication would be best (Quote 10). TAs' complete picture of clients' healthcare and social services needs allowed them to make well-informed recommendations and referrals regarding care and treatment.

Taking into account comorbid conditions—Many clients had comorbidity concerns. In a few rare cases, TAs directly helped to coordinate multiple mental health, social, and medical services for clients. For example, a TA who was aware of a client's "myocardial issues" was able to bring it to the attention of the client's HIV specialist, who had prescribed a protease inhibitor with a history of aggravating myocardial symptoms. Another PLWHA, who suffered from several comorbid conditions, including narcolepsy, cognitive impairments, and a pain disorder, experienced complications in his medical care (Quote 11). He had difficulty filling prescriptions because they were provided through numerous specialists, some requiring regular appointments to reauthorize restricted medications (e.g., narcotics). Gradually the confusion of managing different providers and medications became an obstacle to his HIV medication adherence, and thus the client and his multiple providers (the TA, medical provider, and others such as his psychiatrist) met in person to coordinate his treatment. Although this kind of meeting was exceptional, TAs did frequently go beyond their formal roles as treatment educators to address clients' other service needs and, as discussed below, served as intermediaries between clients and medical providers.

Bridge to providers

Engagement in care—Most participants said that TAs connected them to medical providers. This included finding different provider options available through insurance, dealing with a lack of insurance, or enrolling clients into a clinical trial. Because TAs were

knowledgeable about specific local providers, they were able to match clients with appropriate providers that fit their needs, personality, and insurance situation (Quotes 12 and 13).

Interfacing with providers—TAs acted as a liaison to medical providers. TAs exchanged critical information with providers and sometimes offered important recommendations based on their unique understandings of clients' non-medical issues. For example, TAs often emailed or talked to medical providers to discuss clients' diagnosis, medication regimen, and treatment options. In some cases, TAs suggested alternative regimens that they felt might fit better with clients' life situation (Quote 14). Although rare, TAs also accompanied the clients to provider visits.

Providers felt that TAs helped clients understand medication regimens in a way that supported adherence (Quote 15). Providers also recognized that including TAs in discussions of the clients' treatment were valuable to provider–patient communication. TAs and providers alike felt that direct communication among all three individuals could counteract clients' misconceptions about the healthcare system and providers. Providers valued the presence of the TA as an intermediary, acknowledging that TAs have a holistic view and thus can provide information that can make a significant difference to the client's treatment plan and overall healthcare (Quote 16).

Building self-advocacy

Empowering clients to be active medical consumers—Clients, providers, and TAs shared ways in which TAs empowered clients through information, skills, and tools to advocate for their own healthcare. TAs saw their primary role as working with clients directly to build self-advocacy skills and foster empowerment to ask questions of providers, to change regimens, or to change providers (Quote 17). TAs' provision of information about treatments, regimens, adherence, and the patient–provider relationship helped many clients discuss treatment concerns with doctors (Quote 18). TAs encouraged clients to become active consumers of healthcare by preparing them for medical appointments and anticipating issues (Quotes 19 and 20). TA also assisted clients with problems they encountered with their providers. For instance, one client worked with the TA to write a letter of complaint about medical services he received (Quote 21).

The work provided by TAs often goes beyond traditional conceptions of TA services to include client empowerment, such that clients may learn skills they need to advocate for better healthcare for themselves. With TAs' guidance, clients became more knowledgeable about treatment issues, more able to research relevant treatment information, more skillful in anticipating and asking questions of healthcare providers, and more able to assert their needs in the healthcare setting (Quote 22). Clients not only gained information through TA, but also skills needed to continue to find information (Quote 23).

Discussion

In this study, TA clients and medical providers said TA contributed to client engagement in care, use of ART, and treatment adherence. TAs' unique services, which are not available to

clients through other programs, include providing holistic care, being a bridge to providers, advocating for clients, and building self-empowerment. Participants viewed TAs as accessible and knowledgeable about treatment issues and the landscape of local HIV care, allowing them to match clients and providers based on clients' holistic needs. Because of their focus on treatment issues, TAs had a deep understanding of the contextual issues affecting clients' treatment experiences. In addition to reaching out to clients, TA plays a unique role in the HIV care system by actively supporting the relationship between client and provider through education and advocacy. TAs were able to empower clients to learn how to become better consumers of their own care. Because TA was embedded within an ASO, clients could seek advice, validate information, and gain skills for their own self-advocacy relatively free from concerns or mistrust about the medical establishment.

The objective of TA is to help clients understand and adhere to appropriate treatment regimens. Since healthcare providers may be too busy to answer questions or explain HIV treatment options (Harman, Amico, & Johnson, 2005), TA fills an important gap. TAs provide information about HIV and treatments that validate provider recommendations or offer alternative options that may better address clients' needs. TAs can help clients develop strategies for supporting adherence. Education that helps support beliefs about the importance of adherence can improve adherence (Schneider, Kaplan, Greenfield, Li, & Wilson, 2004).

TAs are able to incorporate a holistic view, taking the time to understand clients' treatment issues in the context of their whole lives; they can work with clients to develop a deeper relationship in which psycho-social and other comorbidity issues related to care and treatment can be addressed. In addition, TA provides a critical component in quality of care. TAs are able to pay attention to individual circumstances and make appropriate referrals to a variety of social and medical services.

The TA program builds a unique relationship among clients, TAs, and providers, allowing for a broader approach to HIV/AIDS care and treatment. Although other adjunct services may increase linkage to primary care providers (Craw et al., 2008; Katz et al., 2001; Sherer et al., 2002), TA is focused primarily on HIV/AIDS treatment education and advocacy. Unlike other ancillary social services, TA is necessarily staffed by professionals who have specific expertise in HIV/AIDS virology, pathogenesis, and treatment therapies and strategies. TAs help clients to have positive experiences with healthcare by educating clients about the healthcare system and matching them with appropriate providers. These positive experiences appear to facilitate better rapport with providers, which may ultimately improve engagement in care and adherence (Mallinson et al., 2007; Schneider et al., 2004).

This study had several limitations. Participants were recruited from one ASO; findings may not generalize to TA experiences in other organizations, and TAs' and providers' views may not represent providers outside of this agency. Consistent with qualitative methodology, our purpose was not to seek a representative sample, but instead to elicit the range of experiences at a particular TA program. Because APLA's TA program immediately connects clients with care, we could not elicit perspectives of PLWHA who were not in care. Findings could have been affected by a social desirability bias: clients may have felt

compelled to provide positive comments about the program. However, interviewers stressed that responses were kept confidential, research staff were not associated with the TA program, and participation would not affect their standing in TA. Future research should attempt to explore a fuller range of clients served by TA, especially female clients who may have child-care issues and monolingual Spanish speaking clients. We did not randomize clients to TA, so we do not know if their satisfaction with TA, and perceptions of TA's effectiveness, were due to selection bias. Next steps for research include the need for randomized controlled trials to test the effects of TA on engagement in care and adherence over time.

There are several key recommendations for developing or improving TA services that can be gleaned from our results. TA services were seen as particularly valuable because they empower clients to advocate for their own medical needs in addition to providing comprehensive treatment information. In this way, TAs may help those who have little power in the provider-patient relationship to become better advocates for themselves. The providers in this study appreciated TA since they often do not have time to educate patients and find that more educated clients meet treatment goals more efficiently. The TA-client-provider relationship is important to foster since it goes beyond the provision of education and adherence training; providing TA services in a social service setting may help by filling a critical gap in traditional medical and ancillary social services provided for PLWHA.

Acknowledgments

This study was supported by the National Institute of Nursing Research (NINR) and the grant is (R21 NR010284, PI: Bogart). The development of this manuscript was also supported by the Centers for Disease Control and Prevention (CDC) grant number (U48/DP000056, PI: Kaplan). The authors wish to acknowledge the study participants, the members of the treatment advocacy community advisory board (CAB), and the many interns and volunteers who helped support this project, including Philicia Castillo, Caleigh Douglass, Chassity Griffin, Matthew Louie, Vaidehi Mahadev, Jessie Tang, and Lynnea Waters. We would also like to thank Jacinta Elijah, Jennifer Patch, and Alexa Rabin for coding and Bryce McDavitt for his thoughtful contributions to the study and review of this paper.

References

- Arnsten J, Demas P, Farzadegan H, Grant R, Gourevitch M, Chang C, Schoenbaum E. Antiretroviral therapy adherence and viral suppression in HIV-infected drug users: Comparison of self-report and electronic monitoring. *Clinical Infectious Diseases*. 2001; 33:1417-1423. [PubMed: 11550118]
- Ashman JJ, Conviser R, Pounds MB. Associations between HIV-positive individuals' receipt of ancillary services and medical care receipt and retention. *AIDS Care*. 2002; 14(Suppl 1):109-118.
- Bakeman, R.; Gottman, JM. *Observing interaction: An introduction to sequential analysis*. New York: Cambridge University Press; 1986.
- Bangsberg D, Acosta E, Gupta R, Guzman D, Riley E, Harrigan P, Deeks S. Adherence-resistance relationships for protease and non-nucleoside reverse transcriptase inhibitors explained by virologic fitness. *AIDS*. 2006; 20(2):223-231. [PubMed: 16511415]
- Bangsberg DR, Hecht FM, Charlebois ED, Chesney M, Moss A. Comparing objective measures of adherence to HIV antiretroviral therapy: Electronic medication monitors and unannounced pill counts. *AIDS & Behavior*. 2001; 5:272-281.
- Bernard, H. *Research methods in anthropology: Qualitative and quantitative approaches*. 3. Thousand Oaks, CA: Sage; 2002.

- Bogart LM, Uyeda K. Community-based participatory research: Partnering with communities for effective and sustainable behavioral health interventions. *Health Psychology*. 2009; 28:391–393. [PubMed: 19594261]
- Cabral HJ, Tobias C, Rajabiun S, Sohler N, Cunningham C, Wong M, Cunningham W. Outreach program contacts: Do they increase the likelihood of engagement and retention in HIV primary care for hard-to-reach patients? *AIDS Patient Care and STDs*. 2007; 21(Suppl 1):S59–S67. [PubMed: 17563291]
- Calsyn RJ, Klinkenberg D, Morse GA, Miller J, Cruthis R. Recruitment, engagement, and retention of people living with HIV and co-occurring mental health and substance use disorders. *AIDS Care*. 2004; 16(1):56–70.
- Chan D, Absher D, Sabatier S. Recipients in need of ancillary services and their receipt of HIV medical care in California. *AIDS Care*. 2002; 14(Suppl 1):73–83.
- Cohen J. A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*. 1960; 20(1):37–46.
- Convisier R, Pounds MB. The role of ancillary services in client-centred systems of care. *AIDS Care*. 2002; 14(Suppl 1):119–131.
- Craw JA, Gardner LI, Marks G, Rapp RC, Bosshart J, Duffus WA, Schmitt K. Brief strengths-based care management promotes entry into HIV medical care. *Journal of Acquired Immune Deficiency Syndromes*. 2008; 47(5):597–606. [PubMed: 18285714]
- Gardner E, Burman W, Steiner J, Anderson P, Bangsberg D. Antiretroviral medication adherence and the development of class-specific antiretroviral resistance. *AIDS*. 2009; 23(9):1035–1046. [PubMed: 19381075]
- Gardner LI, Metsch LR, Anderson-Mahoney P, Loughlin AM, del Rio C, Strathdee S. Anti-retroviral Treatment Access Study Group. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*. 2005; 19(4):423–431. [PubMed: 15750396]
- Harman JJ, Amico KR, Johnson BT. Standard of care: Promoting antiretroviral adherence in clinical care. *AIDS Care*. 2005; 17(2):237–251. [PubMed: 15763717]
- HIV Epidemiology Program, Los Angeles County Department of Public Health. HIV/AIDS Surveillance Summary, July 2008. Los Angeles: County Department of Public Health; 2008.
- Holzemer W, Bakken S, Portillo C, Grimes R, Welch J, Wantland D, Mullan J. Testing a nurse-tailored HIV medication adherence intervention. *Nursing Research*. 2006; 55(3):189–197. [PubMed: 16708043]
- Howard AA, Arnsten JH, Lo Y, Vlahov D, Rich JD, Schuman P. HER Study Group. A prospective study of adherence and viral load in a large multi-center cohort of HIV-infected women. *AIDS*. 2002; 16(16):2175–2182. [PubMed: 12409739]
- Israel, B.; Eng, E.; Schulz, A.; Parker, E. *Methods in community-based participatory research for health*. San Francisco, CA: Jossey-Bass; 2005.
- Katz M, Cunningham W, Fleishman J, Andersen R, Kellogg T, Bozzette S, Shapiro M. Effect of case management on unmet needs and utilization of medical care and medications among HIV-infected persons. *Annals of Internal Medicine*. 2001; 135:557–565. [PubMed: 11601927]
- Krentz HB, Auld MC, Gill MJ. The high cost of medical care for patients who present late (CD4<200 cells/ μ L) with HIV infection. *HIV Medicine*. 2004; 5(2):93–98. [PubMed: 15012648]
- Landis J, Koch G. Measurement of observer agreement for categorical data. *Biometrics*. 1977; 33:159–174. [PubMed: 843571]
- Lincoln, Y.; Guba, E. *Naturalistic inquiry*. Newbury Park, CA: Sage; 1985.
- Liu H, Golin CE, Miller LG, Hays RD, Beck CK, Sanandaji S, Wenger N. A comparison study of multiple measures of adherence to HIV protease inhibitors. *Annals of Internal Medicine*. 2001; 134(10):968–977. [PubMed: 11352698]
- Lo W, MacGovern T, Bradford J. Association of ancillary services with primary care utilization and retention for patients with HIV/AIDS. *AIDS Care*. 2002; 14(Suppl 1):S45–S57. [PubMed: 12204141]
- Magnus M, Schmidt N, Kirkhart K, Schieffelin C, Fuchs N, Brown B, Kissinger P. Association between ancillary services and clinical and behavioral outcomes among HIV-infected women. *AIDS Patient Care and STDs*. 2001; 15(3):137–145. [PubMed: 11313026]

- Mallinson K, Rajabiun S, Coleman S. The provider role in client engagement in HIV care. *AIDS Patient Care*. 2007; 21(Suppl 1):77–84.
- Messeri PA, Abramson DM, Aidala AA, Lee F, Lee G. The impact of ancillary HIV services on engagement in medical care in New York City. *AIDS Care*. 2002; 14(Suppl 1):15–29.
- Morse, J. Designing qualitative research. In: Denzin, N.; Lincoln, Y., editors. *Handbook of qualitative research*. Thousand Oaks, CA: Sage; 1994. p. 220-235.
- Mutchler M. Young gay men’s stories in the states: Scripts, sex and safety in the time of AIDS. *Sexualities*. 2000; 3(1):31–54.
- Perkins D, Meyerson B, Klinkenberg D, Iaffoon B. Assessing HIV care and unmet need: Eight data bases and a bit of perseverance. *AIDS Care*. 2008; 20:318–326. [PubMed: 18351479]
- Rice, PL.; Ezzy, D. *Qualitative research methods: A health focus*. Victoria, Canada: Oxford University Press; 1999.
- Samet J, Freedberg K, Savetsky J, Sullivan L, Stein M. Understanding delay to medical care for HIV infection: The long-term non-presenter. *AIDS*. 2001; 15:77–85. [PubMed: 11192871]
- Schneider J, Kaplan SH, Greenfield S, Li W, Wilson IB. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *Journal of General Internal Medicine*. 2004; 19:1096–1103. [PubMed: 15566438]
- Sherer R, Stieglitz K, Narra J, Jasek J, Green L, Moore B, Shott S, Cohen M. HIV multidisciplinary teams work: Support services improve access to and retention in HIV primary care. *AIDS Care*. 2002; 14(Suppl 1):31–44.
- Soto TA, Bell J, Pillen MB. Literature on integrated HIV care: A review. *AIDS Care*. 2004; 16(Suppl 1):43–55.
- Spradley, J. *The ethnographic interview*. New York: Holt, Rinehart and Winston; 1979.
- Strauss, A. *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press; 1987.
- Teshale, E.; Kamimoto, L.; Harris, N.; Li, J.; Want, H.; McKenna, M. Estimated number of HIV-infected persons eligible for and receiving HIV antiretroviral therapy, 2003 – United States. Paper presented at 12th conference on retroviruses and opportunistic infections; Boston, MA. 2005 Feb.
- van Servellen G, Nyamathi A, Carpio F, Pearce D, Garcia-Teague L, Herrera G, Lombardi E. Effects of a treatment adherence enhancement program on health literacy, patient–provider relationships, and adherence to HAART among low-income HIV-positive Spanish-speaking Latinos. *AIDS Patient Care and STDs*. 2005; 19(11):745–759. [PubMed: 16283835]
- Viswanathan, M.; Ammerman, A.; Eng, E.; Garlehner, G.; Lohr, K.; Griffith, D. *Community-based participatory research: Assessing the evidence (Evidence Report/Technology Assessment No. 99, AHRQ Publication 04-E022-2)*. Rockville, MD: Agency for Healthcare Research and Quality; 2004.

Table 1Protocol for client interviews ($n = 25$).

Protocol topic	In-depth questions
HIV diagnosis	<ul style="list-style-type: none"> • Tell me about the time you tested positive. • When did you first test HIV-positive? • What kind of help did you get? • What roadblocks or barriers did you encounter? • Are you receiving services from any AIDS service organization? If yes, which organization?
Decisions and involvement in HIV medical care	<ul style="list-style-type: none"> • Do you have a doctor for your HIV care? If no, why not? • If yes, describe your doctor and your relationship with him/her. • How did you come to seek HIV care regularly?
Antiretroviral therapy (ART)	<ul style="list-style-type: none"> • Have you had any blood work done to determine your CD4 count or your viral load? • If yes, what were your latest results, when and where were these tests taken? • Are you currently on ART? If no, have you ever been? What would it take for you to be on it? • If yes, when did you first start? Is this your first ART regimen? • Describe a typical day of medications and how they affect you. • Do you ever miss a dose? Do you find it difficult to take the medication exactly as prescribed?
Experiences with APLA's TA program	<ul style="list-style-type: none"> • How did you learn about the TA program? • Did you take to a treatment advocate before or after your medical care? • What was your reason for seeking TA services? How long have you been receiving services? • What type of services do you receive from the program, how often do you use these services?
How the TA program has influenced management of HIV care and treatment	<ul style="list-style-type: none"> • For clients not engaged in care: How has it influenced your decision to not access HIV medical care? • For clients engaged in care: How has it influenced your decision to access HIV medical care? • Has it had any influence on your decision to start or remain on ART? • For clients on ART: How has it influenced how you manage your ART regimen?
Overall impressions of the TA program	<ul style="list-style-type: none"> • Are there any services that you were hoping to see that this program does not offer? • Have you considered, or would you consider referring other clients to the program? • What is most helpful about the program? What is least helpful? • What advice could you offer to improve the program?

Table 2Protocol for provider interviews ($n = 4$).

Protocol topic	In-depth questions
Experiences as an HIV provider	<ul style="list-style-type: none"> • How long have you been providing HIV care? • How many patients are you currently treating? • In what type of clinical setting are you providing HIV care?
Experiences with APLA's TA program	<ul style="list-style-type: none"> • How many of your clients have received services from APLA's treatment advocacy program? • How many clients have received services from organizations other than APLA? • What is your understanding of the treatment advocate's role with your patients? • Have you referred any clients to APLA's TA program? Why or why not?
Experiences with APLA treatment advocates	<ul style="list-style-type: none"> • Who initiates these interactions usually? How do the interactions usually take place (email, phone, and in-person)? • What are the goals and content of these interactions? • What components of APLA's TA program seem to be the most/least helpful? • What is your overall impression of the TA program in helping clients start ART? • What is your overall impression of the TA program in helping clients with adherence? • Optimally, what role would you like the TA program to play in helping clients manage their HIV? • What kind of changes do you think would be most beneficial to APLA's TA program?

Table 3Protocol for treatment advocate interviews ($n = 2$).

Protocol topic	In-depth questions
For the director of the TA program	<ul style="list-style-type: none"> • Provide a brief description of the TA program here at APLA. • Have you assessed patient satisfaction with the program? Has this changed over time? • How do you monitor quality of TA service provision?
For all treatment advocates	<ul style="list-style-type: none"> • When did you first get involved in the program and why? • What qualifications or training is required to be TA at APLA? • Which services are you involved in providing? Which services are you not involved in?
Client referrals	<ul style="list-style-type: none"> • How are clients referred to the program? • Are referrals from outside the program encouraged or promoted by the program? • Do you see a pattern in the type of providers who refer patients to your program? • How can referrals from providers be improved? • What kind of patient feedback do you give providers?
Experience with TA clients	<ul style="list-style-type: none"> • Describe your client population. • How do you determine what services to offer to clients that are seeking help? • For clients not engaged in care, <ul style="list-style-type: none"> – What types of services will you offer them to get them into care? – What are the easiest and most difficult interactions you have had with them? • For clients but not on ART despite low CD4, <ul style="list-style-type: none"> – What types of services do you offer to these clients? – Please describe clients of this type and the easiest and most difficult interactions you have had with them. • For clients who are on ART but are struggling with non-adherence, <ul style="list-style-type: none"> – What services do you typically offer them? • Describe this type of client and the easiest and most difficult interactions you have had with them.
Effectiveness of the TA program	<ul style="list-style-type: none"> • How have providers of the clients receiving TA services responded to the program? • Are the TA services living up to what you expected? If not, how can they be improved? • Please discuss other programs outside of APLA that you know and your opinions regarding their effectiveness and success. • What barriers to success has the TA program faced?

Table 4

Representative quotes of key themes in treatment advocacy process evaluation interviews among 25 clients, two treatment advocates, and four medical providers.

Theme	Source	Representative quote
Understanding treatments		
Comprehensive education	C	(1) It's not that much telling me about the meds, but showing me how the meds work on the virus. . . how they actually work in your body; like this med does this and this, and that's why you take this with this and this. . . I'm not so apprehensive now that I'm being more informed about being on meds.
Support for newly diagnosed clients	C	(2) If you're a new client, like I was. . . [the TA] gives you information, and knowledge is power. There's so much misinformation going on out there with everybody. . . at least [the TA] knows what's factual.
TAs' unique perspective outside of the medical establishment	C	(3) I think I got into [treatment] a little earlier. . . The medication scared me more than the disease, believe it or not. (4) Meeting [the TA] was very helpful because I got to find out. . . a lot of information. . . because I, when I made the appointment I was wondering, "Well is Atripla right for me?" Because my doctor. . . just said, "Well, here's the prescription," and I didn't know what questions to ask. . . so I kind of got to have that dialog with [the TA] and after I left I was very confident that that was a good choice for me.
TA's as accessible and knowledgeable	C	(5) I can always come to [the TA] as a second opinion for looking at things and just the fact that he's telling me things are good and my doctor's telling me that things are good. . .
Supporting adherence	C	(6) Sometimes you don't. . . wanna go through your doctor. 'Cause like they're so busy and to talk to them personally one-on-one is just, and it's hard to open [up]... sometimes it's good to have someone outside the medical [establishment]. . . [the TA] is not a doctor. But he's educated. . . he knows about this. (7) I would sometimes miss a whole week. . . [the TA] explained it to me like this, that when you have been missing all these doses it makes the virus itself become resistant, and then it can be resistant too many times or something like that because there's only so many antiviral drugs of therapy that if you use up all of them, you won't have nothing to fall back on.
Holistic care	C	(8) They always ask me the same thing. Are you taking your medication?... Have you missed any pills?
Taking into account the life situation of each client	C	(9) [I talk with the TA about]. . . my situation, my living situation, other resources and stuff I've been accessing (10) I certainly make better decisions as a result of [the TAs] because they help me understand the context of the decision I'm trying to make.
Taking into account comorbid conditions	P	(11) Things really started to fall apart [for a client with several comorbid conditions]. [The TA] contacted us and said that the client is under the impression that you're not willing to help him get his prescriptions filled. . . we scheduled a meeting. we all met here. um with a variety of people, including some of the other sub specialists like our psychiatrist, [the TA]. . . somebody else from [an ASO], [the medical provider], the nurse practitioner, the client and sort of worked through it.
Bridge to providers	TA	(12) By the time they leave me, they actually have an appointment to see a care provider. I'm not just leaving it up in the air that they might access it. I want to know they have an appointment.
Engagement in care	C	(13) If you're having a problem with your treatment, [the TA] is the person who you can go to and have mediate between you and your healthcare professional if necessary, 'cause he will do that. He plays a role in letting you know what's available, what's cutting edge, what's working and what's not.
Interfacing with providers	C	(14) At first I was having such a problem taking them [the pills] twice a day and. . . keeping them down. . . [the TA] was telling me that they have another way that you can take them. You know you can take all of them once a day but you have to ask your doctors if it's OK. At first my doctor didn't want to do it, but then [the TA] talked to him and ever since it's like candy, taking candy.

Theme	Source	Representative quote
	P	(15) [The TA] reassures them about side effects, and talks to them about what regimens have been recommended and why this may be okay or why this may not be okay. Next thing we know, the patient comes back to us and is either ready to start therapy or is now taking the therapy more consistently, and we're thrilled.
	P	(16) I communicate back to the treatment advocate rather than directly to the patient, that might make our next meeting between me and the patient more efficient or better. The client may be unhappy. . . about having HIV and sort of blaming it on the doctor. I think the treatment advocate has the unique role of being the only person who's around who could both go with the client [to the doctor's appointment] and potentially know the system enough to help the client make a change.
Building self-advocacy	TA	(17) I don't want to just be in the middle. . . I want them to learn how to deal with providers, to fight for their health, to know how to speak, to know everything. . . Only if they really need me, you know, if they cannot do it for cognitive issues or psychological things, or anything that. . . so if it's not [cognitive issues], I try, 'Ok, you go first. You're an adult. You know how to deal with that. I gave you a tour.'
Empowering clients to be active medical consumers	C	(18) [The TA] started telling me. . . about how the medication will work. And he told me about some different medications to talk to my doctor about.
	C	(19) [TA helped me with] being more aggressive with my doctor. . . and not just be so passively involved in my medical care.
	C	(20) Well with this information I have choices. Especially when we talk about. . . how that medicine and other medicine are a combination of medicine. . . So. . . I can see why the doctor would order this particular or this particular meds, instead of just being in the. . . blind. . . but at least I will have some information why I am taking it.
	C	(21) I was really mad, and [the TA] helped me put together a letter- to compose a letter to complain about the services to make note that they needed more intensive services to help us to take care of our needs. And so it was a difficult letter to write. . . and that's not a priority for [the TA] to do but [the TA] made time for me and made sure it was done. And that's a special thing for me.
	P	(22) [The TA] may be able to identify that there may be a particular regimen that's better for the client, in which case the client may bring that to us directly. . . so none of that necessarily required [the TA] connecting with us.
	P	(23) I think [the TA] assists in helping them to advocate for their healthcare. Which is not something I would necessarily see a direct impact on it, but he tells them you know who to look for, what kind of doctors to get, how you can work with your doctors, what you can expect from your HIV provider, so they come out empowered. . . Um, knowing what they're supposed to get, what to expect.

Note: C, client; TA, treatment advocate; P, medical provider.