Patients' Perspectives on Informal Caregiver Involvement in HIV Health Care Appointments

Katie E. Mosack, Ph.D.^{1,2} and Andrew Petroll, M.D., M.S.^{2,3}

Abstract

HIV treatment advances have had a major impact on disease-related morbidity and mortality. However, not all HIV-positive persons are experiencing improved health outcomes. In the United States in particular, patient nonadherence and prescription bias may explain some health disparities. To address these factors, researchers and practitioners may benefit from enlisting support from an underutilized resource: patients' families and significant or supportive others. Little is known about informal caregiver involvement in treatment planning or how such involvement might affect health care delivery and receipt. The purpose of this study was to investigate patient perspectives on informal caregiver involvement in treatment planning, including the perceived consequences of others' involvement. Forty-two predominantly African American HIV-positive adults who were partnered at the time of diagnosis were recruited in 2005 from infectious disease clinics in Milwaukee, Wisconsin. Participants took part in individual semistructured interviews. They were asked questions pertaining to their diagnosis, treatment planning, and informal caregiver involvement at medical appointments. Data were recorded, transcribed, and coded for themes using NVivo 7 qualitative software. A minority of those interviewed were accompanied to medical appointments. Still, participants overwhelmingly identified more potential benefits than disadvantages to others' involvement. Benefits categories include improved information communication, the development of stronger relationships, improved family health, and successful treatment outcomes. Disadvantages of involvement included negative emotional and behavioral consequences for the patient and disrupted patient-provider communication. Recommendations for health care providers are discussed.

Introduction

OVER THE PAST 25 YEARS of the HIV epidemic, treatment advances have changed the nature of HIV from a disease in which death was imminent to one that is considered a manageable, chronic condition. Resource-rich regions, such as North America and Western Europe have experienced a marked decrease in the number of people who die from HIV, particularly over the past decade. The development of potent antiretroviral medications, known as highly active antiretroviral therapy (HAART) has been essential in decreasing HIV-related morbidity and mortality.¹⁻⁴ For example, between 1996 and 2000, the number of deaths in people with AIDS declined considerably. Since 2000, however, the decrease in deaths has leveled off.⁵ Poor adherence, which can lead to inadequate virologic suppression and increased likelihood of developing treatment-resistant mutations, may be primarily responsible for the slowed decline in the mortality

rate.⁶⁻¹⁰ Unfortunately, HAART therapies are often complex and can result in significant side effects. Because of this complexity, adherence can be difficult even under the most ideal circumstances. However, HIV disproportionately affects those with fewer economic resources, people who belong to certain ethnic and sexual minority groups, and those with drug or alcohol addictions.¹¹ HIV-positive individuals who simultaneously confront challenges such as racism, stigma and isolation, and economic depravity might well have an even more difficult time maintaining strict medication adherence because HIV is likely just one of many stressors they are facing.¹² As a result of such challenges and the serious life-threatening implications of nonadherence, clinicians routinely avoid prescribing HAART to those whom they believe are at high risk for nonadherence,^{13,14} including people with a history of drug use, homelessness, and depression.^{8,9} Evidence also suggests that racial stereotyping and patient-provider racial discordance contribute to negative adherence assessments

¹Department of Psychology, University of Wisconsin-Milwaukee, Milwaukee, Wisconsin.

²Department of Psychiatry and Behavioral Medicine, ³Division of Infectious Diseases, Center for AIDS Intervention Research, Medical College of Wisconsin, Milwaukee, Wisconsin.

and health care disparities.^{14–19} Moreover, providers are not good at predicting patient adherence and some patients do not get life-saving treatment when providers underestimate their ability to adhere.^{19–22}

Social support provided by informal caregivers (i.e., friends, parents, partners, or significant others)²³ has been found to improve medication adherence among HIV-positive people.^{24–27} In addition to providing emotional support, informal caregivers can contribute to successful medication-taking behavior by directly administering medication, reminding patients to take medication, and setting up subsequent medical appointments.²⁸ Less is known, however, about the degree to which informal caregiving in the health care context might influence treatment planning considerations, including provider willingness to prescribe HAART. Ideally, providers could enlist informal caregivers to help explain medication regimens, underscore the importance of adherence, and ultimately, improve patient-provider communication.

Before we can determine the effects of supportive others' involvement in HIV treatment planning, we must establish information about the nature and degree of such involvement in the health care context. Research is warranted in order to consider whether others' involvement in the health care setting could have a positive effect in improving patient adherence, patient-provider communication, and ultimately, health care outcomes. The purpose of this study, then, is to examine the extent to which others are present at medical appointments, the nature of their involvement, and patient perspectives on the perceived consequences of such involvement. For those who have not had others present, we want to investigate the barriers to their involvement, the reason for which others have been excluded, and how not having someone present might have affected their medical care. An understanding of patients' perspectives on the role informal caregivers should or should not take in their HIV care can have important implications for systemic health care delivery and ultimately, health outcomes.

Methods

Participants and procedures

Institutional Review Board (IRB) approval was secured through the Medical College of Wisconsin. Potential participants for this study were recruited from March to June 2005 from two primary locations: a private nonprofit AIDS service organization's medical clinic and an infectious disease clinic affiliated with a medical college in Milwaukee, Wisconsin. Fliers were posted that provided cursory information about the study and a telephone number that potential participants could call to receive additional information. Research staff screened callers to determine eligibility for the study. To be eligible, individuals had to report being at least 18 years of age at the time of screening, being diagnosed with HIV after 1997, having had at least one initial treatment planning appointment after the date of their diagnosis, and being involved in a "committed, romantic relationship" at the time of diagnosis. We recruited only those participants diagnosed after 1997 in order to ensure a homogenous cohort that could have potentially been offered the latest generation of drug treatments, i.e., HAART. Likewise, we wanted to include participants who likely had at least one supportive person who could have attended a treatment planning appointment, which is why we

limited the sample to those with a primary partner at the time of diagnosis. As the results reveal, this criterion did not have the intended effect on the sample composition and we began oversampling for individuals who actually had someone present in the treatment planning session(s) after roughly half the sample was successfully recruited.

Individual qualitative data elicitation interviews were conducted at our research offices by three research staff members who were trained in qualitative interviewing techniques. The semistructured interviews were audio taped and generally lasted between 1 and 2 hours. Topics covered during the interviews included diagnosis, treatment planning, and the involvement of informal caregivers in medical appointments. At the conclusion of each interview, a short survey was administered to collect basic demographic information, including age, gender, ethnic identity, educational attainment, HIV status, and date of HIV diagnosis. Participants were paid \$30 for their participation.

Semistructured interview protocol

The interview covered questions related to diagnosis, initial treatment planning, and end-of-life care discussions. For each of these topics, interviewers asked participants questions related to informal caregiver involvement. For example, interviewers initially asked who, if anyone, attended the first treatment planning appointment with the doctor. If a participant reported having someone present during one or more medical appointments, then we asked additional probing questions related to the decision to include others; satisfaction with others' involvement; and the effects of involvement on the participants' relationships with the involved individual and the provider, the treatment planning process, and adherence. We also asked those participants who were accompanied at appointments questions related to how they believe their HIV treatment planning might have been different had informal caregivers not been involved. If a partner or family member did not attend any medical appointments, we asked about the decision not to include one's partner in the process, and the effects they believe that decision might have had on their relationship. We also asked how the other's absence might have affected the treatment planning process and the participant's ability to comply with medical recommendations. We then asked them to consider how treatment planning might have been different if they had they been accompanied.

Data analysis

Descriptive statistics were calculated for participant demographic and disease-related variables. Information pertaining to partners' gender and HIV status, informal caregivers' involvement in the health care context, and the nature of others' involvement was coded and calculated from interview data. Interviews were transcribed verbatim by research staff or professional transcribers then verified by a second individual. When possible, original interviewers were asked to review the transcriptions for accuracy. The transcripts were analyzed using NVivo 7.0 qualitative software.²⁹

The current study's analysis reflects a conceptual/thematic description using principles of grounded theory³⁰ and interpretative phenomenological analysis (IPA).^{31,32} The goal of

grounded theory is to develop a theory of a phenomenon that emerges from the data rather than examining preconceived hypotheses.³⁰ The goal of IPA is to explore insiders' thoughts and beliefs related to their subjective experiences of a particular phenomenon.³³ Using the latter strategy, both manifest and latent themes are identified and considered to be direct representations of the phenomena under study.³⁴ Such an approach privileges social cognitions and assumes that one's interpretations of his or her experiences reflect the "true" nature of the phenomena, which in this case, is the experience of including family in HIV treatment planning.³⁵

Guided by these two approaches, a coding team consisting of the first author and undergraduate and graduate research staff independently coded the transcripts. We initiated our analysis by independently reviewing the first transcript and making exhaustive notes regarding preliminary topics, themes, or relationships. This analytic strategy was then repeated for all transcripts. Next, we met and discussed our independent list of codes and developed a master list. We then discussed the validity of the codes of the final list in order to arrive at consistent coding labels and definitions.³⁶ We subsequently considered how well these topics clustered together into emergent themes. A hierarchical coding structure emerged from these discussions.

Once the coding scheme was determined, the coding team independently reviewed all transcripts a second time and coded each in its entirety according to the newly developed coding scheme. Coding discrepancies were discussed until consensus about the appropriate code was obtained. The coding team discussed new themes that did not appear to fit into the original codebook and modifications were made as appropriate. At this point, codes were dropped if they did not fit well within the emerging thematic structure or if sufficient evidence of the themes was not found across transcripts. We also discussed new topics that did not appear to fit into the original codebook and modifications were made as appropriate. Furthermore, when suggested by associations, overlap, or diversions in the data, thematic categories were refined, merged, or subdivided. Decision trails were documented to assure that interpretations were supported by the data.^{36,37} Themes related to informal caregiver involvement in treatment planning sessions were examined for the purposes of this article. The results presented here contain the conceptualization deemed to provide the most parsimonious representation of the data.

Results

Participant demographics

One hundred ninety-four individuals were screened for participation in the study; 147 were deemed ineligible. The primary reasons for ineligibility included a date of diagnosis earlier than 1997 and not having a primary partner at time of diagnosis. About halfway through data collection, we also decided to exclude participants with incarcerated partners in order to obtain an adequate sample of participants who could feasibly invite a partner to health care appointments. In the end, 47 participants were interviewed. However, only data from 42 interviews were used for this study. (Four recordings were of poor quality; data from one participant were not included in the analysis because he reported being diagnosed in 1989 at the time of the interview, which should have rendered

him ineligible for the current study). Participant socio-demographic and disease data are presented in Table 1.

Amount and type of informal caregiver involvement

Although most individuals received a diagnosis days or weeks after initial HIV testing, 73% of individuals indicated that "no one" was physically present with them at the time of diagnosis. Those who were present at the time of diagnosis included partners or ex-partners (for 7 participants), friends (for 4 participants), and family members (for 3 participants). Even after diagnosis, few people had others present with them at the time of their initial treatment planning appointments. Just 15 participants reported that someone accompanied them to medical appointments. Those who attended included partners or ex-partners, friends, family members, and for one individual, a case manager.

Benefits of informal caregiver involvement

Regardless of whether participants reported having informal caregivers present at the time of the interview, we asked

TABLE 1. PARTICIPANTS' SOCIODEMOGRAPHIC AND DISEASE DATA

Variable	Range, Arithmetic Mean Number	SD Percentage ^a
Age	23–61, 41.7	8.0
Gender		
Female	14	32.6
Male	28	65.1
MTF transgender	1	2.3
Ethnic identity		
African American	39	90.7
Other	4	9.3
Educational attainment		
Less than HS degree	13	30.2
High school degree or equivalent	13	30.2
Training beyond high school	17	39.5
HIV Status		
HIV-positive; no AIDS diagnosis	32	74.4
HIV-positive; AIDS diagnosis	11	25.6
Year of Diagnosis		
1999	1	2.4
2000	9	21.4
2001	8	19.0
2002	7	16.7
2003	9	21.4
2004	3	7.1
2005	5	11.9
Primary partner's gender ^b		
Male	31	73.8
Female	11	26.2
Primary partner's HIV status ^b		
Believed to be HIV-positive	24	57.1
Believed to be HIV-negative	15	35.7
Unsure about status	3	7.1

^aRounding errors in some cases resulted in categorical percentages not equaling 100.

^bPartner data is from date of diagnosis as reported retrospectively by participants.

MTF, male to female.

them about the perceived effects of others' involvement. No contradictions were identified between those who had others present and those who did not with regard to either benefits or disadvantages. Thus, for ease of reading, we have framed the categories as actual rather than hypothesized benefits and disadvantages. Participants overwhelmingly identified many more and a greater diversity of benefits than disadvantages to involvement. Perceived benefits clustered around four major thematic categories. These include improved information communication, the development of stronger relationships, improved family health, and successful treatment outcomes. Each benefit category will be discussed in turn and the relationships that emerged between them will then be enumerated.

Improved information communication. One clear benefit involved the improvement of communication that occurred as a result of involvement. Better communication was believed to benefit the patient, the caregivers, and the health care providers. Respondents reported that caregivers often contribute to the discussion at the health care appointment by asking questions the patient forgets to ask, correcting patient information or providing relevant information to the physician that patient fails to provide, and interpreting medical information for the patient. As illustrated by this quote, informal caregivers can provide instrumental support in the form of capturing important information that might have otherwise been overlooked: "I kinda let my brother do all the listening because I was still (in) kind of like a shock stage" (47-year-old man whose brother and sister have attended appointments).

Improved information communication benefitted caregivers, as well. For example, some became better educated about the patient's prognosis or HIV transmission, including sexual risks and myths related to transmission from casual contact. One 27-year-old man whose partner attended the first appointment was asked about whether he would appreciate other family members' presence in treatment planning appointments. He responded, "Actually, I would be kind of happy, especially if my sister's with me 'cause she can learn more about it. And she probably can understand why some days I do get tired." Others reported a sense of relief that caregivers could get their questions answered and that they did not have to serve as the family's HIV expert:

I wanted the doctor to talk with them, you know, answer any questions that they may have because they were part of me, part of my life. I just wanted them to share in the information... and ask questions that I may not have been able to answer. (48-year-old man whose sister and HIV-positive partner attended initial appointment)

Development of stronger relationships. A second major theme involved the development of stronger relationships as a result of partner or informal caregiver involvement. Participants found that caregivers were better able to empathize with them. This was particularly relevant with regard to the stigma that they felt related to caregivers' fear of contagion. Some noted that after attending medical appointments, caregivers started to treat the participant with more concern and respect. Likewise, they noticed an improvement in the quality of emotional and instrumental support that they were able to garner from caregivers who attended. Support was both HIV-

related, such as help with filling prescriptions and scheduling appointments, as well as non-HIV-related, such as when the other runs errands, helps with housework, or spends time with the patient. Finally, stronger relationships were developed as the patients and their informal caregivers engaged in more honest communication. Specifically, one participant discussed a teamwork mentality that the pair developed in which HIV was the shared enemy. Within the context of a seroconcordant relationship, one 35-year-old man reported, "Going to the doctor's together, that's helpful for couples, I think. Because it allows us to be honest with each other now, instead of versus... 'Oh, the doctor said this,' which might not be true."

Improved family health. Finally, participants framed others' involvement in terms of how it affected family health. Specifically, seronegative partners were more likely to be tested when they were involved and partners seemed to be making the conscientious decision to use condoms consistently. Furthermore, family members were supportive of and began contributing to healthy dietary changes. In one case, a seropositive partner who had not been receiving regular medical care began to seek his own treatment as a result of involvement in the participant's medical appointments.

Successful treatment outcomes. The data demonstrated a relationship between these perceived benefits categories (Fig. 1). Both improved information communication and the development of stronger relationships were considered to contribute to improved family health. Thus, for example, the more educated about HIV and the more involved in HIV care, the more likely informal caregivers (and family members in particular) were to engage in other positive changes. Ultimately, the benefits were perceived as relating directly or indirectly to some key treatment outcomes. The most commonly reported benefit involved improved treatment plan compliance including consistent appointment attendance and medication adherence. Some participants acknowledged an improved ability to manage drug or alcohol addictions by entering treatment or limiting drug and alcohol use. An example of the importance of family involvement is provided by a 36-year-old man who had been accompanied to appointments by his mother:

Interviewer: If she was not involved... how would that be different?

Participant: I guess to this day I probably wouldn't have took it seriously right away. I probably would have kept going, and the pills probably would have sat there until I got ready to take them... I would (not) have taken it to heart as fast if she wasn't involved.

A 35-year-old woman, who was accompanied by her HIV-negative partner to appointments, concurred, "He was concerned. I appreciated that he wanted to learn... He wanted to learn so he could stay on me, you know! 'Cause as a matter of fact, he's the reason why I'm still taking medication."

Disadvantages of informal caregiver involvement

Although participants overwhelmingly indicated that others' involvement has been or would be beneficial, they cited salient disadvantages, as well. One clear disadvantage was related to family members' inappropriate or unhelpful behavior within the clinical context. Accounts of others

FIG. 1. Benefits of family involvement: a model.

dominating the discussion and overbearing or angry family members disrupting the appointment were provided. Partners or parents' expressions of anger, which were generally related to the mode of transmission, sometimes obstructed the discussion. For example, accounts were given in which tension related to sexual infidelity or same-sex relationships directly affected patient-provider communication.

Some disadvantages related more to the participants' emotional response to others' involvement than to others' actual reactions. Participants reported being less honest or less willing to discuss certain topics, including sexual behavior or infidelity. Other concerns related to how involvement would affect the relationship outside the medical context. For example, participants reported not wanting to be nagged about treatment compliance and lifestyle choices related to sexuality, alcohol or drug use, and choice of friends. Furthermore, one 38-year-old woman reported being involved in an abusive relationship and that her partner assaulted her in response to information he overheard during a particular office visit. Her HIV-positive partner attended all of her appointments and she did not have a choice related to his involvement:

Interviewer: And how was it decided that that he would go with you to that first visit?

Participant: Because he would never let me out of his sight. He was a very abusive man.

Interviewer: How did his presence affect your relationship with your doctor?

Participant: I didn't feel as comfortable talking when he was there. Because I was always afraid of getting in trouble after we left the doctor's office...

Facilitators to involvement

Participants revealed information related to those factors that facilitate others' involvement. The themes that emerged

can be arranged according to personal, relationship and family, or structural factors. The primary personal factor related to others' involvement was the decision to disclose one's HIV status. That is, disclosure generally preceded others' involvement in treatment planning. Patients' ability to take the initiative in including others was also an important factor. For example, some participants were proactive in involving others in the medical appointment. As one 36-year-old man revealed:

I said (to the doctor), "Well, can my mom come in?" He was like, "Yeah, sure she can come in." She wanted to come in. She didn't want to sit out there. I guess because she had tons of questions. Stuff I didn't even know to ask.

Participants in stable, supportive relationships and those with seroconcordant partners frequently mentioned that their partners were present at medical appointments. Participants' willingness to educate their family members either facilitated others' involvement or increased the likelihood that they would invite others to their clinic appointments. Structural facilitators included informal caregivers' availability during clinic office hours, i.e., daytime availability, and having had physicians, nurses, and/or caseworkers inviting others to appointments.

Barriers to involvement

Despite our targeting sampling plan in which we attempted to oversample those with primary partners, the vast majority of those sampled had not had anyone present at their appointments. What got in the way of others' involvement? First, there were important individual-level barriers. The most salient issue was disclosure. Optimally, patients visit with a provider to discuss treatment planning within a short time after receiving an HIV diagnosis. Patients may, therefore,

initiate treatment prior to telling important people about their diagnosis. Despite greater public awareness about HIV, it remains a much stigmatized disease. Concerns about privacy were prevalent, particularly during the time period of diagnosis. Often, they were either not ready to disclose or feared consequences of disclosing their illness to significant others or family members.

Second, participants were concerned about burdening others. This concern may have arisen through the belief that they should be self-reliant, as one woman indicated that she believed she should "stand up, be a woman, (and) get myself through it." Likewise, some resisted the idea that the diagnosis warranted others' concern or involvement. One man who had a seronegative female partner discussed his family's lack of involvement:

Well, they don't have no involvement because I don't run to them, you know. I'm 47 years old, and I don't go to them for every little bitty thing! I have to be really, like I said, really sick, you know, to do that... But we're a close family—I have a close family.

In addition to individual-level barriers, there were relationship barriers, as well. Perhaps the most common barrier with partner involvement (aside from nondisclosure) was relationship ambivalence or instability resulting from the diagnosis. Again, to be eligible for the study, individuals must have had a partner at the time of diagnosis. Given the nature of HIV transmission, participants or their partners were sometimes embroiled in anger over transmission, infidelity, and previous disease nondisclosure. In other cases, family members learned of the participants' gay or bisexual orientation or homosexual involvement. In situations in which the relationship was unable to survive or the patient did not want to deal with others' anger at the medical appointment, they were not invited to the appointment. Furthermore, one participant indicated that his mother was too anxious about the medical context to attend appointments.

Finally, structural barriers impeded informal caregiver involvement. Structural barriers, by definition, can be either systemic or a part of policy over which the individual has limited influence. Examples of such barriers are when clinic staff do not invite informal caregivers to appointments, incarceration (of participants or their partners), geographic constraints, and conflicting work schedules. Particularly among this sample, incarceration was an especially salient issue. Although we did not specifically probe for information related to incarceration, 14 of the participants indicated that either they or their partners had been incarcerated either at the time of diagnosis or during the course of their medical treatment.

Discussion

These data indicate that there are many perceived benefits to others' involvement in treatment planning, although caregiver involvement occurred in a minority of cases. These included Improved Information communication, the development of stronger relationships, improved family health, and successful treatment outcomes. Perhaps the most salient disadvantage of and barrier to involvement related to the feared or actual relational consequences of disclosure. Despite efforts to educate the population at large and attempts to diminish HIV-related stigma, newly diagnosed patients often

fear the social repercussions of disclosure. These concerns are not unfounded as participants reported varying reactions from others in the face of the diagnosis, including anger, blame, and emotional abandonment. In effect, some of these reactions lead to emotional upset and violence during and in response to the information that is exchanged during medical appointments. Besides nondisclosure, other barriers to family participation included relationship instability resulting from the HIV-positive person's anger that the partner had infected him or her, a health care culture that does not actively encourage family participation, and incarceration.

Because of the importance of adherence, health care providers frequently discuss strategies to enable the patient to achieve high levels of adherence. These strategies include taking personal circumstances and daily schedules into account when planning a medication regimen and assessing patients' tolerance for medications' side effects. In addition to helping the patient remember to take medications, an informal caregiver could help identify salient environmental cues that the patient could use to remember to take medications. For example, a mother might be aware that her son takes his dog for a walk at certain times of the day and might suggest that he take his medication right before the walk. The presence of a family member may help the provider more fully understand the patient's life circumstances and the circumstances which might create barriers to optimal adherence. In some cases, informal caregivers could emphasize medication dosing requirements, dispense medications into pill boxes, or provide injections.

Besides influencing patient behavior, informal caregivers could potentially influence provider behavior. On the one hand, having a loved one at the health care appointment who advocates for the patient could reduce the likelihood that a provider fails to offer HAART to patients. There has been no research to date on this question; however, informal caregivers might be more likely than the patient to challenge providers' decision to withhold HAART, or they might be elicited to provide support so that the patient successfully initiates and adheres to HAART regimens. Thus, informal caregivers might make a provider more comfortable prescribing HAART which could ultimately benefit the patient. Of course, a family member's opinion could also convince a provider to withhold HAART, such as if a family member provides evidence that the patient would have difficulty complying with treatment recommendations. Such information (assuming that it is accurate) could be critical when making medication-related decisions.

In addition, if informal caregivers help to improve and strengthen the relationship between a provider and a patient, the patient may become more adherent. In fact, studies have shown that HIV-positive patients who are more engaged with their health care provider and those who believe their provider "knows them as a person," demonstrate greater adherence.^{38–41} Although adherence is highly correlated with virologic suppression, the relationships between family involvement in the treatment planning context and adherence and disease progression need further research attention.

Limitations

We investigated the perspectives of patients who have already been through the experience of treatment planning with

their HIV care providers. As such, this study was retrospective in nature. Participant perspectives may have changed over time. It may not be feasible to ask people to examine their experience with collaborative treatment planning soon after becoming diagnosed with HIV. Some have even argued that participants are unable to provide meaningful reflections without the separation of time between the traumatic event and the interview.⁴¹ For these reasons, we did not focus our recruitment efforts on the recently diagnosed. This sample consists of those who reported having a primary partner at the time of HIV diagnosis and therefore may not represent the experiences of those in other situations and particularly those for who do not have the benefit of another's social support. Lack of representativeness tends to be a greater concern in quantitative research, however, where the goal is to make inferences from a sample to the larger population. This is generally not a concern in qualitative research because the goal is to identify salient themes within a particular sample. Still, it warrants highlighting that by virtue of simply having a significant other's support, our participants might have financial, instrumental, and emotional resources not afforded to others. The benefits of positive sources of social support on emotional well-being and risk-avoidant and medication-taking behaviors among those with HIV are clear.⁴²⁻⁴⁶ More research is needed to investigate ways in which other family members and friends play supportive roles, as well as the way in which health care professionals can facilitate the development of supportive networks for those with HIV in order to improve health care experiences and treatment outcomes.

Practice-related recommendations

For providers, there are a number of strategies that can be employed to redress barriers to others' involvement. For example, providers should consider routinely inviting informal caregivers to health care appointments. For example, as a matter of protocol, the provider could meet privately with patients at the first appointment and discuss their available support system. They could then explicitly invite patients to include a supportive other in subsequent appointments. During such private conversations, the provider should carefully screen for abuse and discuss the topics which might be off limits when others are involved. As an additional protection related to confidentiality and HIPAA, providers could routinely have patients sign releases of information prior to commencing an appointment with another person present if they believed this to be necessary.

Alternatively, social or case workers could meet with patients prior to their health care appointments. During that meeting, they could screen for abuse, and help patients brainstorm about individuals who might be enlisted to join them at health care appointments. If no appropriate person is available, having a caseworker who could attend initial treatment planning appointments could potentially improve the likelihood of getting the patient engaged in treatment and more likely to comply with medical recommendations.

On a related note, although the benefits of having informal caregivers present during treatment planning are overwhelmingly apparent, many patients do not have such support available to them early in their diagnosis. However, volunteer or clinic-sponsored programs could be established in which a non-related treatment advocate or mentor who is

also HIV positive attends one or more initial appointments. A patient advocate may provide many of the same benefits described of the informal caregivers without some of the disadvantages that were found when including family in this context.

A final recommendation is to schedule evening or weekend appointments for initial treatment planning appointments. Although this would require greater effort and resources, securing others' support early on in treatment planning and prior to the commencement of a medication protocol could yield important dividends, particularly in terms of adherence and secondary prevention.

Acknowledgments

We would like to acknowledge Geri Cotrell-Wynn, Cheri Treffinger, Cheryl (Caz) Sitzler, Jean Gust, and Leah Przedwiecki for their assistance with data collection and transcription. We would also like to thank Jamie Esser for coding support and members of the CAIR Developmental Core for their assistance in the preparation for this study. Finally, we thank the participants for their willingness to participate and make this research possible.

This research was conducted in part while Dr. Mosack was a postdoctoral fellow at the Center for AIDS Intervention Research (CAIR) at the Medical College of Wisconsin and was funded in part by center grant P30-MH52776 from the National Institute of Mental Health, NRSA postdoctoral training grant T32-MH19985, and a CAIR Developmental Core grant.

Author Disclosure Statement

No competing financial interests exist.

References

1. Fang CT, Chang YY, Hsu HM, et al. Life expectancy of patients with newly-diagnosed HIV infection in the era of highly active antiretroviral therapy. *Q J Med* 2007;100:97-105.
2. King JT, Justice AC, Roberts MS, Chang CH, Fusco JS. Long term HIV/AIDS survival estimation in the highly active antiretroviral therapy era. *Med Decis Making* 2003;23:9-20.
3. Lohse N, Hansen A-BN, Pedersen G, et al. Survival of persons with and without HIV Infection in Denmark, 1995-2005. *Ann Intern Med* 2007;146:87-95.
4. Paterson DL, Swindells S, Mohr J, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med* 2000;133:21-30.
5. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report Rockville, MD: Centers for Disease Control and Prevention, 2005.
6. Garcia de Olalla P, Knobel H, Carmona A, Guelar A, Lopez-Colomes JL, Cayla JA. Impact of adherence and highly active antiretroviral therapy on survival in HIV-infected patients. *J Acquir Immune Defic Syndr* 2002;30:105-110.
7. Hogg RS, Heath K, Bangsberg D, et al. Intermittent use of triple-combination therapy is predictive of mortality at baseline and after 1 year of follow-up. *AIDS* 2002;16:1051-1058.
8. Maisels L, Steinberg J, Tobias C. An investigation of why eligible patients do not receive HAART. *AIDS Patient Care STDs* 2001;15:185-191.

9. Sollitto S, Mehlman M, Youngner S, Lederman MM. Should physicians withhold highly active antiretroviral therapies from HIV/AIDS patients who are thought to be poorly adherent to treatment? *AIDS* 2001;15:153–159.
10. Bangsberg DR. Less than 95% adherence to nonnucleoside reverse-transcriptase inhibitor therapy can lead to viral suppression. *Clin Infect Dis* 2006;43:939–941.
11. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2007. Vol. 19. Atlanta: U.S. Department of Health and Human Services, Center for Disease Control and Prevention, 2009. www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf (Last accessed September 19, 2009).
12. Mosack KE, Abbott M, Singer M, Weeks MR, Rohena L. (2005). If I didn't have HIV, I'd be dead now: Illness narratives of drug users living with HIV/AIDS. *Qual Health Res* 2005;15:586–605.
13. Gerbet B, Bronstone A, Clanon K, Abercrombie P, Bangsberg D. Combination of antiretroviral therapy: Health care providers confront emerging dilemmas. *AIDS Care* 2000;12:409–421.
14. Wong MD, Cunningham WE, Shapiro MF, et al. Disparities in HIV treatment and physician attitudes about delaying protease inhibitors for nonadherent patients. *J Gen Intern Med* 2004;19:366–374.
15. King WD, Wong MD, Shapiro MF, Landon BE, Cunningham WE. Does racial concordance between HIV-positive patients and their physicians affect the time to receipt of protease inhibitors? *J Gen Intern Med* 2004;19:1146–1153.
16. Bogart LM, Catz SL, Kelly JA, Benotsch EG. Factors influencing physicians' judgments of adherence and treatment decisions for patients with HIV disease. *Med Decis Making* 2001;21:28–36.
17. Burgess DJ, Fu SS, van Ryn M. Why do providers contribute to disparities and what can be done about it? *J Gen Intern Med* 2004;19:1154–1159.
18. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient–physician communication during medical visits. *Am J Public Health* 2004;94:2084–2090.
19. Stone VE. Physician contributions to disparities in HIV/AIDS care: The role of provider perceptions regarding adherence. *Curr HIV/AIDS Rep* 2005;2:189–193.
20. Bangsberg DR, Hecht FM, Clague H, Charlebois ED, Ciccarone D, Chesney M, Moss A. Provider assessment of adherence to HIV antiretroviral therapy. *J Acquir Immune Defic Syndr* 2001;26:435–442.
21. Gross R, Bilker WB, Friedman HM, Coyne JC, Strom BL. Provider inaccuracy in assessing adherence and outcomes with newly initiated antiretroviral therapy. *AIDS* 2002;16:1835–1837.
22. Lerner BH, Gulikc RM, Dubler NN. Rethinking non-adherence: Historical perspectives on triple-drug therapy for HIV disease. *Ann Intern Med* 1998;129:573–578.
23. Prachakul W, Grant JS. Informal caregivers of persons with HIV/AIDS: A review and analysis. *J Assoc Nurses AIDS Care* 2003;14:55–71.
24. Johnson MO, Catz SL, Remien RH, et al. Theory-guided, empirically supported avenues for intervention of HIV medication non-adherence: Findings from the Healthy Living Project. *AIDS Patient Care STDs* 2003;17:645–656.
25. Knowlton AR, Arnsten JH, Gourevitch, MN, et al. Micro-social environmental influences on highly active antiretroviral therapy outcomes among active injection drug users: The role of informal caregiving and household factors. *J Acquir Immune Defic Syndr* 2007;46: S110–119.
26. Power R, Koopman C, Volk J, et al. Social support, substance use, and denial in relationship to antiretroviral treatment adherence among HIV-infected persons. *AIDS Patient Care STDs* 2003;17:245–252.
27. Remien RH, Hirkay AE, Johnson MO, et al. Adherence to medication treatment: A qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four U.S. cities. *AIDS Behav.* 2003;7:61–72.
28. Mosack KE. The involvement of family in HIV treatment planning discussions: Barriers and facilitators. Paper presented at the NIMH Annual International Research Conference on the Role of Families in Preventing and Adapting to HIV/AIDS. San Juan, Puerto Rico: July 2006.
29. QSR International. NVivo Qualitative Data Analysis Software; Version 7. 2006.
30. Strauss A, Corbin J. *Grounded Theory in Practice*. Thousand Oaks, CA: Sage, 1997.
31. Sandelowski M, Barroso J. Classifying the findings in qualitative studies. *Qual Health Res* 2003;13:905–923.
32. Smith JA, Osborn M, Osborn M. 1999. Doing interpretative phenomenological analysis. In: Murray M, Chamberlain K, eds. *Qualitative Health Psychology: Theories & Methods*. London: Sage, 1999:218–240.
33. Bogdan RC, Biklen SK. *Qualitative Research for Education: An Introduction to Theories and Methods*, 4th ed. New York: Allyn & Bacon, 2003.
34. Joffe H, Yardley L. Content and thematic analysis. In: Marks DF, Yardley L, eds. *Research Methods for Clinical and Health Psychology*. London: Sage, 2004:56–68.
35. Gubrium JF, Holstein JA. Analyzing interpretative performance. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*, 2nd ed. Thousand Oaks, CA: Sage, 2005: 487–508.
36. Sandelowski M. The problem of rigor in qualitative research. *Adv Nurs Sci* 1986;8:27–37.
37. Hall J, Stevens P. Rigor in feminist research. *Adv Nurs Sci* 1991;13:16–29.
38. Bakken S, Holzemer WL, Brown M-A, et al. Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care STDs* 2000;14:189–197.
39. Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med* 2006;21:661–665.
40. Heckman BD, Catz SL, Heckman TG, Miller JG, Kalichman SC. Adherence to antiretroviral therapy in rural persons living with HIV disease in the United States. *AIDS Care STDs* 2004;16:219.
41. Schneider J, Kaplan SH, Greenfield S, et al. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *J Gen Intern Med* 2004;19:1096–1103.
42. Zukoski AP, Thorburn S. Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: A qualitative analysis. *AIDS Patient Care STDs* 2009;23:267–276.
43. Kang SY, Goldstein MF, Deren S. Gender differences in health status and care among HIV-infected minority drug users. *AIDS Care* 2008;20:1146–1151.

44. Rothman G, Anderson BJ, Stein MD. Gender, drug use, and perceived social support among HIV positive patients. *AIDS Behav* 2008;12:695–704.
45. Malta M, Strathdee SA, Magnanini MM, Bastos FI. Adherence to antiretroviral therapy for human immunodeficiency virus/acquired immune deficiency syndrome among drug users: A systematic review. *Addiction* 2008;103:1242–1257.
46. Wrubel J, Stumbo S, Johnson MO. Antiretroviral medication support practices among partners of men who have sex with men: A qualitative study. *AIDS Patient Care STDS* 2008;22:851–858.

Address correspondence to:
Katie E. Mosack, Ph.D.
Department of Psychology
University of Wisconsin-Milwaukee
P.O. Box 413
Milwaukee, WI 53201
E-mail: kemosack@uwm.edu