Health Care Provider Perspectives on Informal Supporters' Involvement in HIV Care

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Abstract

Positive social support has been associated with medication adherence and slowed disease progression among people living with HIV. The nature of support within the medical context itself has not been adequately investigated, however. The purpose of our study was to describe HIV health care providers' perspectives on informal supporter-oriented health care and whether and how the involvement of patients' adult informal supporters in health care and health care decision making is helpful or beneficial. We conducted in-depth qualitative interviews with 11 HIV specialists between March and September, 2005. Using directed qualitative content analysis, we first describe the frequency and course of others' involvement and the type of support provided. We then situate these findings within the context of role theory and consider the meaning they have in terms of the negotiated relationships among and between patients, providers, and informal supporters. Finally, we provide research and clinical recommendations based on these findings that are designed to improve patient care.

> There [are] some times where a significant other or family member is really the only person willing to actively participate in the care plan of the patient . . . so that [patients'] support system may truly be their connection to survival. (Physician participant)

Informal social support from partners, friends, and family has been associated with improved mental and physical health in HIV-positive persons (Douaihy & Singh, 2001; Serovich, Kimberly, Mosack, & Lewis, 2001; Simoni, Pantalone, Plummer, & Huang, 2007). Likewise, such support contributes to improved medication adherence and slowed

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disease progression among people living with HIV (Ammassari et al., 2002; DiMatteo, 2004; Leserman et al., 2002), although the mechanisms by which social support contribute to adherence outcomes are not entirely clear. HIV-related social support has most commonly been studied using quantitative methods in which the focus is on social network size or density, type of support, or satisfaction with support (Ashton et al., 2005; Knowlton, Hua, & Latkin, 2005; Murphy, Marelich, Hoffman, & Steers, 2004; Serovich et al.). Few researchers have investigated the qualitative nature of enacted support by informal supporters in the health care setting, or in relation to medical decision making (Beals, Wright, Aneshensel, Murphy, & Miller-Martinez, 2006; Wrubel, Stumbo, & Johnson, 2008). As a result, little is known about how, when, and in what contexts informal social support might affect adherence and health outcomes in people living with HIV, or why social support is not universally helpful (Johnson et al., 2003; Murphy et al.). One way to examine informal support provider involvement in health care settings and with HIV medical decision making is to interview health care providers who serve this patient population.

Although we have some understanding of patients' preferences regarding the involvement of informal supporters (Mosack & Petroll, 2009) and informal supporters' perspectives on caring for ill loved ones (James, Andershed, & Ternestedt, 2009; Wuest & Hodgins, 2011), health care professionals' perspectives on informal supporters' involvement in the health care context has not received adequate research attention. For example, a recent search of PsychINFO, Medline, and the Web of Science using the combination of key words *HIV/ AIDS*, *health care delivery/health care*, *social support*, and *family* resulted in just one published article addressing health care providers' perspectives on informal supporters' involvement in planning medical treatment for persons with HIV (Aujoulat, Libion, Bois, Martin, & Deccache, 2002). Aujoulat and her colleagues highlighted concerns related to family member–provider communication but did not directly address other considerations related to informal support provider involvement in the health care context, such as the barriers impeding involvement, how providers enlisted the support of these individuals, or the situations in which such support was perceived as being more or less helpful. This gap in the literature is important because providers are in a unique position to encourage or dissuade informal supporters' health care involvement. In effect, their attitudes toward informal supporters' involvement could influence whether patients enlist others' help in coping with the diagnosis and symptoms, making treatment-related decisions, and creating realistic plans to adhere to treatment protocols.

If we consider social support in the health care context from the perspective of role theory, support could be framed as a set of behaviors that are elicited, enacted, and procured by patients, providers, and members of patients' social networks. Both structuralist and symbolic interactionist perspectives inform our understanding of the roles actors create or enact in the health care setting (Heiss, 1990). For example, according to a structuralist perspective, specific roles result in certain behaviors or scripts for social conduct (Biddle, 1986). Indeed, one might expect that principal roles, such as that of health care provider and patient, are quite well defined. The roles of others who are intimately involved and who participate in the medical journey with an HIV-infected individual (i.e., informal supporters) have not been as clearly delineated, however, and are not as well understood. Because of

this, we would expect the actors in such roles to adhere less to a set of social norms and behavioral expectations and more to the demands of the situation and to the other actors (i.e., providers and patients) occupying that space. According to a symbolic-interactionist perspective, then, this role-making process is a self-conscious one, and the conduct in which one engages is a consequence of the goal one has in a particular setting (Hewitt, 1976; Hewitt & Shulman, 2011). In the health care context, one can presume that the roles informal supporters make depend on each actor's agenda. Likewise, the roles providers take in relation to informal supporters emerge in response to the demands the supporters' presence creates within the situation (Heiss). Both theoretical perspectives inform our understanding of and the meanings we attribute to the roles actors take in the patient social system.

The primary purpose of our study was to describe HIV health care providers' perspectives on the involvement of informal supporters in their patients' HIV health care and health care decision making. Given the need for basic information about the qualities of informal supporter involvement, we investigated health care providers' perspectives on episodes in which informal supporter involvement did and did not go well, when such involvement would be indicated or contraindicated, and what effects such involvement might have on patient mental and physical health outcomes, risk behaviors, and treatment adherence. We used directed qualitative content analysis to analyze the data and have framed our key findings in terms of role theory.

Methods

Health care providers (including physicians, physician assistants, and nurse practitioners) who were identified as HIV specialists in the Milwaukee metropolitan area were targeted for this study. Potential participants were invited to participate in a project designed to better understand provider perspectives on collaborative health care and informal supporter involvement in HIV health care planning. Providers were recruited through announcements made at HIV clinics, letters to those who self-identified as infectious disease specialists in medical service directories and on hospital and clinic Web sites, and word of mouth from other providers who had participated in the study. Interested providers were asked to contact project staff to be screened for inclusion in the study. To be eligible for the study, providers must have had an active clinical practice in which they treated newly diagnosed HIV-positive patients, and at least 50% of their practice must have been devoted to the treatment of HIV-positive patients. All providers who were screened were enrolled in the study. Recruitment for the study continued until no additional responses to our requests for participation were received during the funding period (March 2005 to March 2006).

The semistructured, qualitative interviews took place between March 2005 and September 2005, and were conducted by the first author and two other members of the research team who had been trained in qualitative interviewing techniques. The interview protocol and informed consent procedures were approved by the Institutional Review Board at the Medical College of Wisconsin in accordance with the American Psychological Association's ethical principles for research (American Psychological Associaion [APA], 2002). Each interview generally lasted 1 to 1.5 hours, and participants were paid $50 for

their time. Participants were asked questions pertaining to the training they had received related to discussing life-threatening diagnoses and end-of-life care, the typical first-visit protocol for HIV-positive patients, and the way in which they managed adult informal supporter involvement in health care and health care decision making. For the purposes of this study, only data related to informal supporter involvement in HIV health care were analyzed. Examples of questions or prompts that were used to discuss informal supporter involvement in care included: "Can you give me an example of a situation in which a partner or other family member was present in the examination room or office?" "What were the lessons learned from that experience?" "In what situations would family or supportive other involvement be contraindicated?" We attempted to elicit information about both positive and negative experiences with informal supporter involvement through the use of detailed prompts. At the conclusion of each interview, basic demographic and practice-related information was also gathered.

Data were analyzed according to the directed approach to qualitative content analysis (Hsieh & Shannon, 2005), in which thematic categories are developed from the data with theoretical frameworks directing the analytic approach. This approach is particularly useful when there is an incomplete understanding of the phenomena under study and when validation or extension of a conceptual framework or theory is the goal. Thus, researchers can use directed content analysis to examine the applicability of a theory or conceptual framework in a new context or with a new sample to gain a greater understanding of the concepts of interest and to assess the degree to which the theory is supported under the new conditions (Hsieh & Shannon).

All interviews were recorded via tape recorder, transcribed, and analyzed for themes using NVivo 7 (QSR International, 2006) qualitative data management computer software. We initiated our analysis by reading all of the transcripts in their entirety. Next, we independently reviewed the first transcript by conducting open coding, analyzing the interview transcript line by line for relevant themes pertaining to our research question. This analytic strategy was then repeated for all transcripts. Then, we discussed our independent list of codes and developed a master list. In so doing, we considered how well these codes clustered together into emergent categories. A hierarchical coding structure emerged from these discussions, in which several of these categories were collapsed into higher-level categories, whereas other categories were subdivided. Finally, we reexamined each code on the master list to ensure that each was explicitly represented within the transcripts. At this point, codes were dropped if they did not fit well within the emerging coding scheme or if sufficient evidence for these categories was not found across transcripts.

Once the coding scheme was determined, we independently reviewed all transcripts a second time and coded each in its entirety according to the newly developed coding scheme. To ensure coding reliability, we met to discuss our coding interpretations. Coding discrepancies were discussed until consensus about the appropriate code was obtained. Decision trails were documented to ensure that interpretations were supported by the data (Hall & Stevens, 1991; Sandelowski, 1986). We also discussed new topics that did not appear to fit into the original codebook, and modifications were made as appropriate. The

results presented here contain the conceptualization deemed to provide the most parsimonious representation of the data.

Results

Participants in this study were 11 health care professionals who specialize in the care of HIV-positive patients, including 7 physicians, 3 nurse practitioners, and 1 registered nurse. Five men and six women were interviewed, and their ages ranged from 32 to 57 years (mean = 45 years; SD = 7.6 years). The majority (n = 9) were White, and none reported being HIV positive. Providers reported being specialists in the treatment of HIV-positive persons for between 2 and 20 years (mean = 10.6 years; SD = 6.9 years). Their total patient load ranged from 40 to 1,800 patients, although most reported having between 100 and 200 active HIV-positive patients on their caseload. They had between three and 20 appointments per day (mean = 9.3 appointments; SD = 4.3 appointments), and practiced at a major nonprofit medical center dedicated to the needs of HIV-positive people, hospital clinics, and private practice offices. Providers generally reported meeting with patients approximately once per week at the beginning of treatment, or when concerns about suboptimal adherence or health status arose. Otherwise, patients who were on established antiretroviral medication regimens were generally seen approximately once every 3 months.

Superordinate codes emerged from the data in relation to the frequency and course of others' involvement, the type of involvement, and the roles that supporters and providers played in relation to the patients at the center of the health care relationship. In the following sections, we provide a descriptive analysis of informal supporters' involvement in the health care context. We next discuss our interpretations of the roles that were ascribed to supporters. Finally, we discuss providers' key roles in relation to the patient–supporter system in the health care context.

Descriptive Analysis of Informal Supporters' Involvement

We asked providers about who tends to be present at medical appointments. The majority of those involved were partners, although others included mothers, siblings, children, and even clergy. Length of time in a partnership did not necessarily predict which partners attended sessions. Some patients attended with long-term partners, whereas others came in with new partners after being newly diagnosed. Moreover, seroconcordant partners (i.e., those who are also HIV positive) were more likely to attend appointments. Providers were then asked about the frequency with which patients included someone close to them at health care appointments and the type of support provided by that other person. Generally, their experiences indicated that although supporters attend health care appointments, it was not the norm. For example, a nurse practitioner explained, "Sometimes people come in because they want to help give medications, or help take care of patients, or help be a part of their lives. But it doesn't happen often." Family members, in particular, were more likely to be directly involved with medical care, either immediately after a patient's HIV diagnosis or near the end of life. Rarely did significant others or adult family members attend appointments throughout a patient's course of treatment unless they were HIV-positive partners. As one physician indicated, "As soon as [patients] get to undetectable and their

numbers look good and they are tolerating the meds [medications], it may be one other visit, and then [family members] back off." Informal social support seemed to be particularly crucial when the patients simultaneously struggled with mental illness or when they were in the advanced stages of illness. Informational, emotional, and practical or instrumental types of support were provided at various times. However, supporters demonstrated unhelpful behaviors, as well, which are described below.

Key Informal Supporter Roles

Four primary supporter roles were derived from the data. Each role we identified reflected specific behavioral constellations that could be and often were perceived as helpful in some contexts and less helpful in others; some were less helpful when provided in excess. These four informal supporter roles included information communicator, emotional conductor, medical executor, and personal agenda driver. A summary of each role (and subroles, as appropriate) is provided in Table 1.

Information communicator—The information communicator is someone who serves as an intermediary between the provider and the patient and can transform patient–provider communication by influencing the way that information is shared between the two people. Two subroles were identified within this supercategory: the interpreter and the reporter. The interpreter is someone who helps the patient by explaining what was discussed in the appointment, how HIV works, what the providers' expectations are, and how the patient can best take care of him- or herself. By listening to the information given by the provider, informal supporters are able to help patients recall information (e.g., pill-taking recommendations) from the appointment. As one nurse practitioner reported, "Patients may not hear everything I say, but the partner may hear something that the patient misses." To that end, this role was attributed to better adherence. As a physician illustrated, "I would say something techno-garble and [the informal supporter] would say it in their language." Another physician voiced a similar sentiment:

> Because sometimes when physicians or medical providers speak, we don't realize that sometimes we might be saying things that might be going over their head, and so, if there are other people listening who are involved with the patient's medical care, then they could repeat it or break it down.

There are times, though, when others misinterpret information, which can have serious consequences. Several participants discussed disadvantages of involvement when significant others give poor advice, or recommendations that could negatively impact treatment. A physician described this, stating,

> Sometimes the partner may not understand the proper use of a medication, and so even though they're trying to be helpful, they're actually giving bad advice, bad recommendations. [An example of poor advice would be], "If you're supposed to take one of these pills twice a day, it would probably be even better to take two twice a day," so they're actually overdoing it.

A nurse practitioner corroborated that sentiment:

> [My patient's mother] is of the belief that it's not good to take a lot of medicine, but she was all into health food drinks, so she would . . . be making potions and concoctions that interfere with the HIV medicines. . . . I think when we're all on the same page it's okay . . . but in this particular situation . . . half of the stuff that was going into these shakes could very easily be lowering the levels of the HIV medicine.

Within the context of the medical appointment, a reporter provides details that the patient fails to provide. From providers' perspectives, sometimes this information had been lost to recall; other times it had been willfully withheld, as in the case of medication nonadherence. A physician explained the importance of having partners or other family members at the appointment and using their unique role and perspectives to enhance care, stating,

> I think it's important to have more than one person there . . . if the patient or families have questions for [me]. Sometimes other people have a different perspective on care for the patient, sometimes they've taken care of the patients in a different level, and they can add something.

Just as there are serious consequences when an interpreter misinterprets information, reporters who exaggerate or falsify information, or those who "spill the beans" can cause psychological harm. For example, patients' perceptions of their health status or treatment options can be disastrously skewed by informal supporters who minimize HIV-related stressors, or if they are too positive about the patient's health or prognosis. Likewise, supporters can under- or overestimate symptom experiences, as one physician described:

> In some ways they're destructive to the care. . . . They like to exaggerate all the bad things, like if the patient said, "Oh, I had a little bit of diarrhea." And the patient is trying to deal with it. And the partner is saying, "Yeah, it was horrible . . . and we had to leave the store," and making everything worse than the patient, who's trying their best to . . . stick with it. That's not helping.

Another physician recounted how a reporter can engender negativity within a medical appointment:

> Physician (P): I can think of a lot of negative [situations], especially when [informal supporters] are overbearing and fussing at their partner. "And you didn't tell [the physician] about this." You know, "You've been doing this. Why don't you tell her about that?"

> Interviewer: So that's not useful at all to you?

> P: No. It just makes them mad at each other, and then they are sitting there—pick, pick, pick.

Emotional conductor—Those occupying the role of emotional conductor can have a positive or negative influence on the emotional well-being of the patient. Invariably, someone enacting an emotionally supportive role encourages the patient, validates and responds to his or her emotional needs, and maintains a positive outlook. A physician explained:

> They can [be] a cheerleader for the person early on, when it can be more difficult to get going on the medications during that first initial period, where side effects are more common. So, they can be supportive in a number of ways by kind of helping the person get through with it and continue to remember to take their doses and be encouraging and praising of them doing that.

Another physician indicated, "They can act as a reinforcer of the advantages of the medicine. They can help with side effects in terms of [the] treatment of them, or trying to keep side effects in perspective with the overall advantages." In this way, then, supporters can assist the provider in underscoring the benefits of life-extending medications. One physician reported how he made sure to discuss how well a patient was adhering to his medication protocol in front of the patient's partner so as to reinforce the patient's efforts and bolster the sense of teamwork. Informal supporters' presence was attributed to improved mental health and coping, because their very presence communicates acceptance of patients who have been diagnosed with a stigmatizing disease. Finally, as one physician offered, those who are emotionally present can provide a refuge: "If [patients] were to get really sick, someone would take care of them; that if they were in a particularly depressed mood, they could just go somewhere and be taken care of."

Those who are emotionally engaged in the patient's health care decision making but who are destructive in their behaviors take the role of emotional abusers. Providers gave accounts of abusive partners who attended appointments as a means of controlling or denigrating the patient. For example, a physician discussed his sense that a partner seemed to enjoy occupying a more powerful position that resulted from the patient being debilitated by the disease. In such instances, the abusive or otherwise harmful nature of a relationship might only come to light after the partner has been involved in treatment with the patient. Indeed, a nurse practitioner acknowledged that only after having seen a couple together was she informed by the patient that he did not want his partner in the room. In abusive relationships, domineering or controlling partners might be concerned that the patient will disclose maltreatment to the provider. Negative treatment outcomes were attributed to involvement from abusive partners, supporters who engage in destructive behaviors such as drug abuse, or those who hold negative views toward medication. For example, one physician saw a patient's poor adherence as a direct consequence of the partner's focus on the medication's debilitating side effects.

Medical executor—When a person occupies the medical executor role, he or she appears to be as involved in the medical care context as the patient is. Two subtypes, both of which have positive consequences, are the treatment manager and the health buddy. The treatment manager is someone whose focus is on providing emotional or instrumental support to the patient. In contrast to the emotional supporter, the treatment manager role is enacted for the express purpose of improving health care outcomes. The treatment manager is often highly involved in patient–provider communication. For example, he or she might remind the patient of questions he or she wanted to ask. Other role-associated behaviors include helping with the administration of medication, reminding the patient to take his or her medication, setting up subsequent medical appointments, and reinforcing the importance of lifestyle changes. Inasmuch as the treatment manager takes over medical responsibilities, the health

buddy shares the burden of the illness with the patient by participating in lifestyle changes (e.g., diet, sleep regimen, exercise). One physician discussed how an informal supporter's skills and resources can complement a patient's needs:

> I think when it's positive is that if you have a patient who's not sure that they can remember to take the medication or whether they're nervous about it and . . . [the informal supporter will] say, . . . "I'm not going to let you forget that because you know we're doing this [at] this time, and this at this time." And so that's kind of, that's like the ideal thing is when the partner has a strength that the patient is kind of deficient in.

Such support can extend to joining the patient in activities the provider has recommended. For example, a physician was discussing situations in which she talks to patients' family members without the patient being present. She recounted how her patient's partner agreed to start walking with the patient because the provider had talked to him about how important it was for the patient to lose weight and lower his lipid levels.

Others who are highly involved in the health care context but who have a negative influence have been identified as treatment obstructionists. In contrast to the role of emotional abuser, treatment obstructionists are perceived as directly and adversely affecting the provider's ability to develop rapport or communicate effectively with the patient, which in turn has negative consequences on the provider's health care agenda. The behavior of a treatment obstructionist takes two primary forms: voicing skepticism or opposition to provider treatment recommendations and engaging in conflicted communication with patients during the appointment. For example, a seemingly routine appointment can devolve if the supporter and the provider have a substantial difference of opinion, or if the supporter calls the provider's treatment plan or general competence into question. For example, a physician explained:

> I make a big deal the first time I see people about how this isn't the 1990s anymore, where people die from AIDS. "I want you to take your medication and you'll live a long time." At the same time, somebody else in the room is saying, "Well, how do you know that's true? That isn't necessarily true; people still die from AIDS." They're not being helpful in terms of trying to think positive.

Personal agenda driver—Those who play the personal agenda driver role use the appointment as an opportunity to pursue their own objectives. For example, providers discussed how supporters sometimes attend medical appointments to receive rather than provide support. Such support seeking also manifests itself through questions about the patient's prognosis or how the supporter might avoid secondary infection. In such cases, the education informal supporters receive can reassure them (e.g., "He's going to be fine. He's doing good. He can do this!") or lead to important behavioral responses such as their own HIV testing and risk-reduction planning. Whether a particular personal agenda driver was viewed positively depended upon whether the provider was involved in the decision to include him or her in the appointment and the reasons for which the informal supporter took this role. For example, providers spoke more positively of personal agenda drivers whose involvement they encouraged and whose motives seem to be related to improving patient

health outcomes. In certain situations, supporters do not drive the agenda, per se, but the agenda becomes about the supporter at the behest of the patient. For example, some patients bring loved ones to medical appointments to facilitate disclosure of their serostatus. In these cases, the appointment, understandably, becomes focused on the supporter rather than on the patient. Even when supporters' involvement is warranted or encouraged, providers indicated that their presence can create additional challenges. For example, a physician admitted, "We try to make this a positive, welcoming environment, and we address issues and bring in family members and their support system. . . . Taking that approach—it's time consuming."

The personal agenda driver might engage in destructive behaviors such as interrupting, distracting, and not letting the patient answer for him- or herself. These behaviors, in turn, interfere with patient–provider communication. In contrast to treatment obstructionists, personal agenda drivers who hijack appointments do not necessarily position themselves in opposition to the provider. In the context of discussing how she manages family member involvement, one nurse practitioner acknowledged how such a role can be problematic:

> If a partner comes [in and is] . . . one of those people who is answering all the questions, you know, "[The patient] needs this or that." You know, I'm starting to get the feeling that this person is way too domineering. I'll try to figure out a way to get them out of there.

Demonstrations of anger or contempt toward the patient, especially during the initial phases of care and when the informal supporters are coming to terms with the reality of how the patient became infected (e.g., sexual infidelity), can also derail an appointment. An example of this was given by a physician: "When [a] partner repeatedly interrupted the session, saying, 'Well, this is your [the patient's] fault. What did you think? What do you expect?'" Under these types of circumstances, providers or patients commonly ask these individuals to leave the examination room.

Key Provider Roles

Although the intent of this research was to better understand provider perspectives on informal supporter involvement in patient health care, providers also enacted discreet roles in relation to patient–informal supporter systems. Their narratives reflected identification with two specific key roles, the social support facilitator and the gatekeeper. In the following paragraphs, we discuss these key roles and how they might contribute to providers' sense of ambivalence regarding others' health care involvement. Table 2 summarizes these two key roles.

Social support facilitator—All of the providers interviewed identified benefits to involving informal supporters in patient care. However, they differed in terms of how explicitly they discussed involving informal supporters with their patients. For example, some discussed how they merely responded or reacted to situations in which a patient brought another person into the examination room rather than having directly encouraged or invited others to attend appointments. Others actively encouraged informal supporters' involvement and considered them an invaluable part of the treatment team. These providers were more likely to have conversations with patients about this issue and/or actively

encounter supporters to become involved. One such provider, a physician, seemed to suggest that the decision to not involve key members of patients' support networks might be ethically irresponsible:

> One reason I would like the patient to bring the primary partner, if it is the sexual partner . . . so that they are hearing the preventive information from us, rather than filtering through somebody who might have some other perspective on it or misunderstanding. It always makes me a little uncomfortable when I [ask], "What does your partner know about your HIV, and what are you doing sexually, or changing?" I think, "Okay, what do we really know about what that other person knows, and to what extent does our responsibility extend to making sure that the partner is in on it?" . . . Once I have told the partner, in [front] of the patient . . . I feel a lot better about it that we have done all that we can do about keeping that partner in the loop, and usually the partner is getting accurate information.

Gatekeeper—How welcome informal supporters' involvement was depended on how helpful providers perceived the enacted roles to be. Although all providers reported benefits to supporters' involvement, some placed a greater emphasis on the importance of protecting patients and their confidentiality. Those providers enacting the role of gatekeeper carefully consider the effects informal supporter involvement has on their patient's well-being and their own treatment objectives, and when warranted, they take steps to reduce others' involvement or minimize the degree of communication they themselves have with these individuals. Although providers consistently indicated that patients could decide who and under what conditions others might be involved with medical decision making, a few providers seemed to exercise more caution and maintain more rigid boundaries with respect to informal supporter health care participation. For example, one physician made it his practice to "always ask the other person to leave unless the patient says, 'Oh, no. They can stay. It's okay.'"

Within the context of discussing behavior that was consistent with the gatekeeper role, providers shed light on the motivations to enact such a role. In some cases, providers enact the gatekeeper role to improve efficiency within the medical appointment. For example, participants emphasized the difficulty of explaining and helping both the patients and their informal supporters to understand treatment information or available care options. One physician commented,

> [Having another person in the room during an appointment] is a little bit harder to do because you have to . . . get someone to buy in to what you were saying and to, like, grab on. You have to do it then to two people, and you know any two people don't see an issue the same way, so sometimes you have to cover it or describe it in two different ways so that . . . they both understand.

In other cases, providers play the gatekeeper role to protect patient privacy. For example, when patients want to share information about members of their social networks, or if they want to discuss or disclose sensitive information such as sexual infidelity or drug-using behaviors to the provider, providers are in a position to restrict others' access to the examination room. Playing the role of gatekeeper also ensures that those who are incapable

of providing specific types of support are not empowered to try to do so. For example, a physician illustrated his concern about overwhelming supporters with limited competency:

> It's always a risk to put a partner in [the position of helping] because it's really asking a lot of a person, and sometimes it's inappropriate because they don't have the personal or educational experience or resources to do what you're asking them to do.

Provider Role-Taking Decision Making

For the most part, providers did not exclusively occupy either the social support facilitator or gatekeeper role. Although some made it more of a practice to encourage others' involvement, the data suggest that providers take supporter characteristics and the patient–supporter relationship into account and conduct a "cost–benefit" analysis to determine whether they take one role or the other in any particular patient's case. They also evaluate who the informal supporter is, and what the nature of the relationship is, and only then draw a conclusion about what information is acceptable to discuss in his or her presence. A physician recounted,

> We'll have . . . encounters where someone comes with the patient, but the patient doesn't really want that to happen, and that's part of what we try to do: we try to ascertain how comfortable the patient [is with] having the significant other there.

Providers sometimes take the role of gatekeeper not in relation to a specific patient–supporter system but rather in consideration of the goals of any particular health care appointment. For example, when providers plan to broach sensitive topics such as drug use or sexual risk-taking behaviors, they invariably attempt to speak privately with their patients. To that end, they reported learning to avoid assumptions about the nature of the relationship (e.g., whether the person accompanying the patient is a partner, friend, or other family member), or even whether that individual knows of the patient's HIV diagnosis. To be sure, there seems to be a fairly complex process of determining whether to facilitate or impede others' involvement, and determining the appropriateness of one's involvement is not a one-time or all-encompassing decision. As one physician noted, "I have a patient whose sister keeps riding me, asking me things. So I have to go back [to the patient] each time and make sure it's okay to give specific details."

Aside from considering the nature of the patient– supporter relationship in terms of the relationship type (e.g., romantic, familial) and the relative degree of support the patient derives from the relationship, health care providers sometimes need to make a decision about whether to treat partners who are both HIV positive. Although some providers avoid treating both patients in the relationship, others welcome the opportunity to utilize the relationship to encourage mutual support and treatment adherence. In these cases, however, it can be difficult to determine what information is protected from the other. One particular physician, who makes it a practice not to see "two people in the same relationship," was asked to discuss why seeing a couple can be problematic. To this, he responded,

> You end up knowing things about the other one, and it's sort of your natural tendency to make reference to things that one person might have said. You know,

> "Oh, [partner] said you were doing this." Well, it's really inappropriate, [but] it's
> sort of just something that tumbles out of your mouth sometimes. . . . It's hard even
> if you don't do that to sort of not be mad at one of them for something.

Another physician treats both members of a couple but does so separately. She makes casual references about her patients' partners:

> When I see this one married couple, I don't talk to her about his T-cell count, but I
> will ask her, "How is so and so [spouse] doing? Is he out of town again?" And I
> will ask him, "How is so and so doing? Is she back at work? How is your son?" or
> whatever. Medical information? Never.

If others are present at the medical appointment but the provider decides to play the gatekeeper role, removing the others from the room can be accomplished through the use of established norms of appropriate levels of personal privacy. For example, toward the end of the first medical appointment, the provider might announce that he or she is going to perform a physical exam and request others to leave the examination room. Having supporters out of the room then affords the provider the opportunity to get more information about the relationship so that "the next time they come, I know how much I can say and how open I can be." It also allows the provider to assess for abuse, although a provider acknowledged that abusive partners are likely to find ways to stay with the partner so that no disclosure can occur.

Discussion

In this study, we investigated HIV health care providers' perspectives on informal supporter-oriented health care and the involvement of patients' informal supporters in HIV health care appointments. A discussion of the role HIV-positive patients' partners or other family members (i.e., informal supporters) have in the health care context is long overdue, particularly given the evidence that social support, more generally, is associated with better physical and mental health outcomes, coping, and treatment adherence (Johnson et al., 2003; Knowlton et al., 2007; Machtinger & Bangsberg, 2005; Power et al., 2003; Remien et al., 2003; Serovich et al., 2001; Simoni et al., 2007). Once we are able to establish the nature of informal supporter involvement and gain insight into how such involvement affects the patient–provider relationship and treatment adherence, we will have a better sense of how to best utilize this potential resource both within and outside of the health care setting.

Within the context of discussing their personal experiences with patients' informal supporters, providers offered various examples of enacted informational, emotional, and instrumental support, and discussed how the presence of informal supporters could be beneficial or detrimental to the patients or to their own ability to provide optimal care to patients. We have framed these data in terms of the roles that informal supporters and providers take in the health care context. Informal supporter roles included the information communicator (i.e., interpreter and reporter), the emotional conductor (i.e., emotional supporter and emotional abuser), the medical executor (i.e., treatment manager, health buddy, and treatment obstructionist), and the personal agenda driver. Provider roles included the social support facilitator and the gatekeeper.

Each of the key roles reflects a set of behaviors that are enacted to achieve specific objectives (Heiss, 1990). For example, a person enacting the role of information communicator is focused on the transfer of knowledge from provider to patient or vice versa. An actor taking the emotional conductor role has a part in moderating the HIV-positive person's emotional experience. The objective among those taking the role of medical executor is to influence the course of treatment, and those occupying the role of personal agenda driver are focused on getting their individual needs met above the proximal needs of the patient. Likewise, providers playing the social support facilitator role use the relationship as a resource to improve patient mental health, social support, and treatment adherence. Those playing the gatekeeper role do so to make the appointment run more efficiently and to protect patient privacy.

Our findings reflect the perspective of HIV health care providers, a perspective which is critical to understand given that providers play a key role in either encouraging or dissuading their patients to rely on others for health-related support. Furthermore, the roles that informal supporters ostensibly take inform us about the ways in which informal health care-related support is provided and how it can benefit both the patient and the provider. In fact, support that is perceived to be most satisfying by the intended target is that which matches the demands of a particular stressor (Cutrona & Russell, 1990; Cutrona, Shaffer, Wesner, & Gardner, 2007). It stands to reason, then, that how well an informal supporter's resources appear to match a provider's health care objectives would influence how helpful the supporter is perceived to be, and in turn, how likely the provider is to encourage the informal supporter's health care participation.

HIV-related social support is generally considered to have a positive effect on patient mental health, adherence-related self-efficacy, and treatment adherence (Mosack & Petroll, 2009; Simoni, Frick, & Huang, 2006). Our data, however, shed light on the ways in which informal supporters can be harmful to HIV-positive persons or otherwise unhelpful to health care providers. From a provider's perspective, involving even supportive members of one's social network in medical decision making can come at a price. For example, informal supporters' presence requires more time when a provider has to explain something twice, attempt to convince them of the importance of a particular recommendation, or act as a mediator between the patient and others who attend an appointment. Other costs are more relevant only after an appointment, such as when a supporter provides poor advice or misinterprets the provider's treatment recommendations.

Given that informal supporter roles are not regarded in a universally positive way, provider ambivalence toward others' involvement is understandable, and might be related to the seemingly inconsistent roles that providers often take (i.e., the social support facilitator in some contexts and the gatekeeper in others). According to Merton and Barber (1976), "sociological ambivalence" is a characteristic of social relationships, and refers to "incompatible normative expectations incorporated in a single role of a single social status" (p. 123). Such ambivalence can result in role conflict, such that "performing the behavior considered appropriate for one role or sub-role might make it difficult or impossible to play another role or sub-role" (Heiss, 1990, p. 97). For example, playing the role of gatekeeper in relation to one patient might make switching to a social support facilitator role in relation to

another patient more difficult. More research is needed to more fully understand how providers negotiate multiple roles and the consequences role conflict might have for patient-centered care.

Study Limitations

Interviewing providers for a qualitative study about their experiences in medical treatment planning is unusual (Gerbert et al., 2004; Karasz, Dyche, & Selwyn, 2003; Roberts & Volberding, 1999; Winzelberg, Patrick, Rhodes, & Deyo, 2005). We certainly faced challenges in undertaking this study. Recruitment and enrollment of participants were difficult, although we found that after having been interviewed, providers were generally enthusiastic about the study and referred colleagues into it. We must assume that a self-selection bias existed, and that those who chose not to participate were different from those who did. Whether they differed with regard to patient-focused or family-centered orientations, philosophy of care, or other characteristics that are germane to patient–provider communication or the involvement of informal supporters in the health care context is not clear.

It is important to underscore that the informal supporter and provider roles that we have identified are derived exclusively from interviews with providers. This approach is inevitably accompanied with a certain degree of provider myopia. Had we asked patients and informal supporters about the roles informal supporters and providers take in the health care context, we might have elicited very different perspectives. Indeed, informal supporters might take issue with the roles that we have identified here. For example, although not suggested by these data, an informal supporter whom a provider perceives as unhelpful might perceive him- or herself as playing the role of the patient's advocate. Our intention was to understand provider perspectives specifically because providers can set the stage for others' involvement. In future research studies it will be important to investigate informal supporters' perspectives, and perhaps even more notable, the perspectives of those close social network members who do not participate in health care.

Although we targeted providers who were considered to be specialists in the treatment of HIV, we did not collect data on their academic specializations or whether they treated patients for conditions other than HIV/AIDS. We interviewed a relatively small sample of providers and, as a result, would not have been able to compare participant responses with regard to variables such as provider type (e.g., physician vs. nurse practitioner), caseload, health care context (e.g., university medical center, free-standing clinic, and so forth), years of clinical experience, or demographics (e.g., gender, age, ethnic identity). We did not intend to analyze data at the provider level, however. Indeed, our findings suggest that even individual providers take multiple roles depending on the contextual demands of specific situations.

Future Research and Clinical Recommendations

This study complements our previous work on soliciting patient perspectives on involving informal supporters in the medical treatment context (Mosack & Petroll, 2009). The current study represents an initial examination of providers' perspectives on the situations in which

informal supporter involvement is helpful or harmful in terms of meeting treatment objectives, and adds to the literature by illuminating one specific aspect of social support, i.e., the support that is provided in the health care setting and in relation to treatment planning. More investigation needs to be conducted to better understand how decisions are made about whether to involve informal supporters in HIV-related health care, and in the event that such decisions result from patient–provider communication, the nature of those discussions. The use of methods other than qualitative interviewing, and specifically the use of provider diary and observational methods to better understand the nature of informal supporter participation in the health care context, is warranted, especially given that inquiry into the roles that informal supporters take in the health care context is in its infancy. Of course, consideration of how to best provide support for patients who have limited or conflicted social networks will also need to be addressed (Berk, 1995).

Considering these findings in conjunction with the evidence that social support can have a dramatic and often positive impact on patient mental health, adherence, and health outcomes, we offer specific advice for health care providers. First, providers should consider the breadth of informal supporter role types and use these findings as a point of discussion with patients to troubleshoot potential pitfalls in advance of inviting others to participate in medical decision making. Second, providers might benefit from asking patients to think of specific individuals who might be inclined to enact these more positive roles (e.g., interpreter or health buddy), especially for those patients who seem to struggle in certain areas or who have obvious deficits (e.g., patients with HIV-related cognitive impairments). It could very well be that the person who might be the most helpful to either the patient or the provider is not the same person who would have been a natural choice (e.g., someone's partner). Finally, we recommend that providers assess the sort of support that the patient most needs from an informal supporter (e.g., emotional vs. instrumental support) and spend time talking with the patient about those in his or her support system who might best fill a particular role. Ultimately, our aim with this research was to better understand the nature of informal support in the HIV health care context so that such resources can be better utilized.

We have identified two key provider roles (i.e., gatekeeper and social support facilitators) that are seemingly at odds with one another, and which could lead to provider ambivalence and role conflict. We recommend that those who contribute to the medical education of new physicians discuss these roles, normalize the experience of gravitating toward one role in certain contexts and another role in others, and encourage them to be cognizant about these roles and how they might influence their interest in including other members of the social system in patient care. Ultimately, becoming aware of these roles might enable providers to be more deliberate in the decision about whether to encourage their patients to include others in their care.

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Table 1

Informal Supporter Roles

Role	Subrole	Definition
Information communicator		A role enacted by an informal supporter who mediates the communication of information between provider and patient
	Interpreter (+/−)[a]	A role enacted by an informal supporter who explains to the patient what was discussed in the appointment, how HIV works, and what the treatment protocol is
	Reporter (+/−)	A role enacted by an informal supporter who supplies information to the health care provider about patient medical history, symptom experiences, treatment adherence, and so forth
Emotional conductor		A role enacted by an informal supporter who engages with the patient on an emotional level
	Emotional supporter (+)	A role enacted by an informal supporter who encourages the patient, validates and responds to his or her emotional needs, and maintains a positive outlook
	Emotional abuser (−)	A role enacted by an informal supporter who is emotionally manipulative toward the patient and who has a destructive influence
Medical executor		A role enacted by an informal supporter who is as involved in the medical care context or medical decision making as the patient him- or herself
	Treatment manager (+)	A role enacted by an informal supporter whose focus is on providing support to the patient for the express purpose of improving treatment outcomes
	Health buddy (+)	A role enacted by an informal supporter who participates in lifestyle changes designed to improve patient health outcomes
	Treatment obstructionist (−)	A role enacted by an informal supporter who communicates skepticism or opposition to the health care provider or treatment protocol
Personal agenda driver	(+/−)	A role enacted by an informal supporter who uses the appointment to address his or her own needs

[a]The +/− indicates whether the role was conceptualized as being helpful or unhelpful (positive or negative) in terms of meeting patient or provider needs.

Table 2

Provider Roles

Role	Definition
Social support facilitator	A role that is enacted when a provider supports the decision to involve informal supporters in patients' health care, either by passively allowing informal supporters to attend appointments or actively encouraging their involvement
Gatekeeper	A role that is enacted when a provider carefully considers the affects informal supporter involvement has on the patient's well-being and the provider's own treatment objectives and, when warranted, takes steps to reduce others' involvement or minimize the degree of communication the provider has with these individuals

Note. Both role types were conceptualized as being helpful in terms of meeting patient or provider needs.