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"The More Support You Have the Better": Partner Support and Dyadic HIV Care Across the Continuum for Gay and Bisexual Men

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Abstract

Background—Gay, bisexual, and other men who have sex with men account for a disproportionate burden of HIV incidence in the United States, with one-third to two-thirds of these new HIV infections occurring within main partnerships. Early initiation and adherence to highly active antiretroviral treatment is a key factor in treating and preventing the transmission of HIV; however, the average rate of adherence in the United States is low. Social support has been examined as a source of improving health for people experiencing a variety of chronic health conditions. This study aims to understand perceptions of how dyadic HIV care could influence partner-specific support for same-sex male couples with a goal of improving adherence.

Methods—Data were collected from 5 focus group (n = 35) discussions with gay and bisexual men in same-sex male relationships in Atlanta, GA. Participants discussed perceptions of how dyadic HIV care would impact partner support among serodiscordant and seroconcordant HIV-positive same-sex male couples. Verbatim transcripts were segmented thematically and systematically analyzed to examine patterns.

Results—Participants described how dyadic HIV care can facilitate emotional, informational, and instrumental support at various stages across the continuum of care, depending on partner dynamics. Participants stated that dyadic HIV care can provide an additional "sense of togetherness" and "solidarity" that helps to "alleviate stress."

Conclusions—Results suggest that dyadic approaches for HIV care across the continuum may be useful in promoting partner support and improving adherence. Future research should further examine dyadic interventions for HIV treatment among same-sex male couples.

Keywords

MSM; HIV	treatment; HA	AART adherenc	e; partner sup	port; continuum	of care
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INTRODUCTION

In 2010, men who have sex with men (MSM) accounted for 63% of new HIV infections in the United States. Recent evidence identifies that approximately one-third to two-thirds of new HIV infections among MSM are attributed to main sexual partners. Early initiation and adherence to highly active antiretroviral treatment (HAART) is a key factor in treating and preventing the transmission of HIV^{4–9}; however, the average rate of adherence in the United States is too low to achieve viral suppression. HIV care is experienced across a continuum, including the identification of a new HIV infection, linkage to care, engagement in ongoing care, and a reduced viral load. Recent analyses have found that only 80% of all people living with HIV/AIDS (PLWHA) in the United States are linked to care and 40% remain in care, with only 30% of all PLWHA achieving viral suppression. 11

PLWHA experience multiple HIV-specific stressful events; among this population, social support and the perception of social support have been found to improve quality of life and mental health. ^{13–15} This support can be categorized as *emotional support* (comfort and empathy), *informational support* (advice, suggestions, and information), and *instrumental support* (tangible services). ¹⁶ The effects of social support on physical health may be explained by psychological mediators (eg, stress reduction, improved mood). ^{17–19} Evidence also suggests that general HIV-related social support (eg, support from family members, friends) and partner-specific support may improve HAART adherence among MSM living with HIV/AIDS ^{20–25}; this link occurs both directly (eg, transportation to a health care facility, acquiring medications, providing reminders, organizing and monitoring medications) ^{20,22,24,25} and indirectly through psychological mediating factors (eg, reduced negative affect, improved mental health). ²³ Although some research shows that HIV-specific partner support may play a role in improving the prevention and treatment of HIV among MSM, we do not understand MSM's perceptions of HIV-specific partner support and preferences for how to receive support throughout the continuum of care.

In this study, we examine MSM's perceptions of how a dyadic approach toward the HIV continuum of care could impact HIV-specific partner support and HAART adherence. We conceptualize dyadic care as a system that allows 2 partners in a same-sex male relationship to receive HIV care across the continuum together as a couple, beginning at the identification of a new HIV infection and continuing through linkage and retention in care. We examine dyadic care within seroconcordant HIV-positive and serodiscordant relationships to understand the potential unique experiences of social support and the potential strengths and weaknesses of dyadic approaches for each type of relationship. Although other studies have looked at partner support for living with HIV or partner support for adherence and have taken a more static approach, we use a continuum approach that examines how support changes throughout different stages in HIV care and treatment—a more dynamic approach.

METHODS

This study was approved by the Emory University Institutional Review Board. Methods, including recruitment strategy and domains of interest, for this study have been previously described in Goldenberg et al.²⁶

Recruitment and Study Population

We recruited gay and bisexual men (GBM) who had previously participated in other studies at Emory University and agreed to be contacted for future research. Men were eligible to participate if they were aged 18 years or older, self-identified as gay or bisexual, were currently in a main partnership with a man lasting 3 months, and lived in the metropolitan area of Atlanta, GA. HIV serostatus was not included in the eligibility criteria, and data on individual or couple serostatus were not collected. Data collection was conducted through focus group discussions (FGD) with participants providing feedback on hypothetical scenarios of couples seeking HIV care; the use of hypothetical scenarios meant that participants did not need to have experienced care or to be living with HIV (or have a partner with HIV) to be able to respond. Given the group setting, we opted not to ask individual serostatus; even if participants had reported serostatus on the confidential eligibility screener, we believed that having reported their serostatus may have made them uncomfortable having open discussion in a group forum. Thus, our data represent perceptions of HIV dyadic care from GBM of unknown serostatus. Although this is a limitation of the data, we believed it allowed us to have open discussions of perceptions of dyadic care. We used hypothetical scenarios and provided an educational background on the continuum of HIV care to ensure that all participants had the necessary information to provide feedback.

Data Collection

A trained moderator conducted 5 FGDs with 35 GBM using a semistructured FGD guide. Both members of the couple were able to participate in this study, but only if they participated in FGDs separately to ensure safety and openness within FGDs. Participants received US \$30 for participation. In the FGDs, participants discussed reactions to scenarios of a hypothetical same-sex male couple who recently received serodiscordant HIV results (FGD1–FGD2) or seroconcordant HIV-positive results (FGD3–FGD5). Participants were randomly stratified to participate in an FGD with a scenario for a serodiscordant couple or seroconcordant HIV-positive couple.

In this hypothetical scenario, a same-sex male couple receives HIV counseling and testing together as a couple. Depending on the FGD, 1 or both individuals in the couple learn about a seropositive HIV status during this counseling session. In the scenarios, the hypothetical couple then goes through all of the next stages of care together as a couple, including linkage to care, retention to care, initiating HAART, and HAART adherence. Previous studies have examined dyadic HIV testing for same-sex male couples, 27,28 but these scenarios enabled participants to provide feedback about the experiences that occur immediately after identification of a new HIV-positive serostatus. At each stage of the continuum, participants shared opinions on the benefits and challenges of receiving care

together as a couple versus receiving individual care. For the seroconcordant HIV-positive couple scenario, dyadic care was defined as both individuals receiving care together. For the serodiscordant couple scenario, dyadic care was defined as the HIV seronegative individual attending appointments and going through the HIV care continuum together with his partner. When discussing these scenarios, participants also identified types of partner support that facilitate adherence to HIV care and discussed the relationship between dyadic care and types of support.

Data Analysis

All FGDs were audio-recorded, transcribed verbatim, and thematically analyzed using MAXQDA, version 10. Analysis was completed using principles of grounded theory.²⁹ Multiple close readings of the transcripts were completed to identify major themes discussed across all FGDs. A trained data analyst applied codes to all textual data based on reoccurring themes in the transcripts.²⁶ Segments of data were retrieved using individual codes and intersections of codes to compare and contrast reoccurring themes within and between FGDs and FGD participants. Through close readings of segmented data, we compared themes across different FGD scenarios (dyadic care for a seroconcordant HIV-positive couple versus a serodiscordant couple) and across different stages of the continuum of HIV care. Patterns were identified, and agreement and disagreement among participants were examined. Descriptions of challenges and benefits of dyadic HIV care are described in Goldenberg et al.²⁶ For this analysis, we focused on the types of partner support that were described across the continuum of HIV care.

RESULTS

Participant demographics are described in Table 1. Participants described examples of support that can be experienced with a partner within the context of receiving dyadic HIV care; based on how partner support was described by participants and based on how social support has often been examined in the literature, we categorized these descriptions of social support into 3 types of support (emotional, informational, and instrumental). Results for each type of social support are summarized in Table 2. Participants described each of these types of support similarly across all stages of the continuum, identifying how emotional, informational, and instrumental support are valuable at each stage. The types of support were also described similarly for serodiscordant scenarios and seroconcordant HIV-positive scenarios. However, participants in the FGDs with a hypothetical serodiscordant couple identified an increased need for establishing empathy and emotional support when compared with the seroconcordant HIV-positive couple.

Emotional Support

Overall, GBM perceived emotional support to be a key factor in the experience of receiving HIV treatment. Although some participants stated that it would provide enough emotional support to have a partner participate in HIV care in ways other than attending doctor appointments (eg, waiting together in the waiting room), participants in multiple FGDs expressed how dyadic care can provide an additional "sense of togetherness" and "solidarity" that helps to "alleviate stress":

From the experiences that I've had in the past, most individuals that I've gone with have taken a certain measure of comfort having support there with them instead of conquering it on their own because in that scenario it tends to build a lot of anxiety leading up to and then the waiting process and at least having someone there for moral support, emotional support. It tends to take away some of that anxiety... especially if it's your partner, the level of comfort should even be greater (P29, FGD4).

In multiple FGDs, participants recognized that emotional support from anyone can be valuable, but that partner support provides an additional level of comfort:

Just to give another word to it, comfort. It's kind of like what P31 was saying that, just the comfort of another person being there, in this case, this is your partner, this is someone you love, this is someone that loves you and for that to be, to provide a lot of comfort for you during, going through this (P35, FGD5).

Participants stated that empathy between partners increases "togetherness" resulting from emotional support; participants in multiple FGD described how dyadic care may establish empathy. This was especially emphasized in FGDs using a hypothetical scenario with a serodiscordant couple:

If one partner goes, you establish only sympathy because the other partner doesn't understand what the doctor said. But if both partners go you established empathy where would the one who is effected be like, oh my gosh, I understand that you can go through this and I understand the trauma you're going to go through so I actually understand rather than like, oh yeah, sorry you feel bad today just because. No. Having that doctor there and speaking to both parties will establish the connection between those two and so that it will help strengthen the bonds of the relationship (P6, FGD1).

Participants expressed that in cases where partners are able to support each other, the relationship can be made stronger through dyadic care. However, some participants also identified that relationship dynamics can play a role in the ability to facilitate emotional support in dyadic care. In some cases, dyadic care was not perceived as a preferred method for receiving treatment because the partner would require more emotional support than the patient:

I think I would want to go by myself at first. You have to know what the emotional makeup of the partner is because... I would be the stronger one out of the two, I think. You never know until you're sitting there but I think I would probably need to get my ducks in a row so that I could reassure my partner what's going to happen going forward (P5, FGD1).

Informational Support

Informational support was a saturated theme in the data. Having candid and educational conversations with doctors was perceived to be important in increasing one's awareness about HIV and improving HIV treatment.

Receiving Information From the Doctor—Dyadic care allows for both partners to receive information from the doctor together. Participants perceived this as beneficial because it may allow partners to support each other in understanding the information provided by the doctor. This was described similarly across the different hypothetical scenarios and across the continuum of HIV care:

If you go individually, the information you're given will be overwhelming, but if you have your partner there, you've got someone to support you, somebody else who is listening, they catch something you may not catch (P18, FGD3).

In addition to increasing the level of understanding of information that is received, a couple may also be able to get more information from the doctor because one partner may think to ask questions that the other missed:

With two different people in the appointment together, there might be something that [one partner] thinks about that [the other partner] doesn't think about to ask the doctor. Or, it's something that they can all discuss together and that they, you know, two heads are better than one kind of scenario (P11, FGD2).

According to participants, dyadic care also increases informational support because it can provide the space for both partners to work through all of the questions that they have and communicate about them:

It's also an opportunity for both of them to express how they feel about those questions and certain things because they are together. Whatever questions they're asking then, they get a chance to see and hear how each other feel when they're communicating because they're looking at each other and then looking at the person that they're giving the answers to (P32, FGD 5).

In a seroconcordant HIV-positive relationship, going to the doctor together can also prevent partners from receiving contradictory information about HIV care. Dyadic care can also allow for both partners to make sure that they interpret the information in the same way:

I think even if they get separate information, they may interpret it differently if they go at different times. And so if they're together in the same room and they hear the same thing, then they can discuss it later and say well this is what I heard and this is what I heard and you kind of compare notes and make sure that you're interpreting it the same way (P20, FGD3).

In addition to improving the quality and comprehension of the information received from the doctor, being together during a doctor's visit allows for each partner to understand what is happening with the other. This is relevant in both serodiscordant and seroconcordant HIV-positive relationships. Being together also provides additional information to both partners on medication, including instructions on how to take medication and what side effects to expect:

For example, the partner I was describing, they take their medicines. The regimen of medicine, we both take Seroquel. OK? And the Seroquel, their amount of Seroquel, makes them go to sleep for like 10 hours. And that's something that you have to convey to a person if you stay out late. And then you get up in the morning

and you're ready to go do something and then you have to remember that this person is on medicine and they have to actually sleep 10 hours (P28, FGD4).

This example shows how different types of support influence each other; an increase in information contributes to empathy and the ability to provide emotional support.

Sharing Information With the Doctor—Participants expressed a variety of opinions on how dyadic care impacts the sharing of information with the doctor. All participants were in agreement about the value of being candid with one's doctor and openly sharing information, but some participants expressed the value of increased openness resulting from a partner's presence in an appointment while others expressed concerns regarding confidentiality and privacy.

Some participants stated that having a partner present could lead to increased "honesty" and "transparency" with both one's doctor and one's partner:

I actually went through the process going with a partner to the doctor and I think I was more candid with the doctor because all parties were there. I was able to put things on the table and I think the doctor was challenged at being able to see the sincerity of what was coming out of the conversation of three of us being there together because a lot of times we sugarcoat things... when I had the partner there it was nothing to hide...There is nothing to hide to them and there's nothing to hide to the doctor. So we going to let it all out (P28, FGD4).

According to participants, this level of honesty can be used to share information with one's partner (eg, in the case of acquiring a new sexually transmitted disease), while also increasing honesty with the doctor and holding one accountable to following the doctor's instructions and staying healthy (eg, medication adherence, exercise).

Many participants also expressed concerns about how a partner's presence might jeopardize the ability to be completely open and honest with one's doctor. These concerns were increased for a hypothetical serodiscordant couple:

[In a serodiscordant relationship], they're going to both have two different issues to deal with and especially the one that's negative... He's going to want to have some questions and things that he might not be comfortable asking if his partner is sitting there. His question might be real heavy and he might be scared to come forward with questions if [his partner is] sitting right there beside him (P24, FGD4).

Instrumental Support

Instrumental support consists of tangible actions in which partners support each other in HIV treatment. Examples of instrumental support across the HIV continuum of care that were discussed in the FGDS include providing additional resources, managing time, providing reminders for taking medication and attending appointments, accompaniment to doctor's appointments, carpooling to doctor's appointments, paying for medication, establishing routines, monitoring a partner's adherence, and monitoring a partner's reaction to treatment. Three aspects of dyadic care were discussed in more depth: accompaniment to appointments, financial assistance, and reminders about appointments and medication.

Accompaniment—Dyadic care in and of itself was discussed as a form of instrumental support; according to participants, accompaniment to appointments may make it easier to attend the appointments consistently. A partner's accompaniment to an appointment can hold each person more accountable and ensure that they do not skip appointments:

Normally a single person, they can miss doctor's appointments. So if you're going as partners, one can motivate the other. If you don't feel like going, drag them along and vice versa (P26, FGD4).

Financial Assistance—Participants stated that dyadic care would be beneficial so that partners could work together to create a financial plan:

Going to doctors and talking about the medication... Medication can be very expensive and some can be [less] expensive. If your partner is there, if you go together, it's easy to make some decision... At least I'll cover this much, so it also helps to speak the particular... regimen (P10, FGD2).

When creating a financial plan, participants described how this is an important thing to do together as a couple, especially because both partners may differ on socioeconomic or employment status. However, some participants also recognized that these dyadic differences can create a strain in the relationship when figuring out how to cover the cost.

Reminders—Participants also identified reminders for doctor's appointments and taking medication as a valuable form of instrumental support that increases accountability, thus increasing the possibility for adherence:

One of the benefits of [the partners] going through this together is they have a... better chance of taking their medications on time because they can remind each other and constantly ask, "did you remember to take your medicine?" (P14, FGD3).

Reminders about medication consumption were seen as very helpful because they provide a "double check." One participant described a personal story of helping a roommate who was taking HIV medications. They watched television at the same time every night, while his roommate took his medication. This was described as "a really good opportunity to socialize and not make it so focused on the medicine" (P7, FGD2). These rituals illustrate how instrumental support can simultaneously function as emotional support:

P18: I think about them going together, it would encourage them to start a treatment program and stick to it...

P19: They're accountable to each other...

P20: And emotionally somebody to hold your hand literally and figuratively (FGD3).

Alternatively, participants also discussed how providing reminders and monitoring adherence could create tension in the relationship because these behaviors could be perceived as "nagging" or "controlling" over time.

DISCUSSION

Emotional, informational, and instrumental support were all described by participants as separate aspects of support; however, links between them were identified. All types of support were described as equally important and each type of support was described similarly across all stages of the HIV continuum of care. In most cases, participants identified dyadic care as a potential facilitator of these types of support; however, they also identified concerns (eg, confidentiality). In general, participants described the potential support resulting from dyadic care as being similar for serodiscordant and seroconcordant HIV-positive couples. However, emotional support and empathy were perceived as possibly more necessary to build among serodiscordant couples. In addition, informational support resulting from dyadic care was perceived as especially important for seroconcordant HIV-positive couples, especially to ensure that both individuals in the couple did not receive contradictory information.

According to participants, when positive relationship dynamics exist and partners have the capacity to provide emotional, informational, and instrumental support to each other, dyadic care may improve the experience of receiving HIV care. These data expand on previous studies ^{13–15,20,22–25} by examining how dyadic HIV care across the continuum may be a useful mechanism for establishing emotional, informational, and instrumental support between partners. These types of support may lead to adherence through improved mental health, increased knowledge about HIV, and increased accountability. These findings also support current research, which suggest that mutual partner support or other social support networks may improve HAART adherence. ^{21,30}

These findings suggest that at each stage of the continuum of care, a provider's focus beyond a biomedical approach that encourages partner-specific psychosocial support may assist with improving adherence to treatment. Engaging both partners in dyadic care across the continuum should incorporate appointment accompaniment, improved communication, mutual interest in establishing health plans and financial plans, and increased monitoring of appointment attendance and medication adherence. For partners who are able to provide increased social support, dyadic care may be a good option for increasing adherence to HIV treatment.

Our data also suggest that dyadic care throughout the continuum may not be an ideal method for HIV treatment for all same-sex male couples. In order for dyadic HIV care across the continuum to function for a same-sex male couple, both partners need to be capable of providing emotional support to one another; even when a relationship is strong, both individuals in the relationship need to have an "emotional makeup" that enables them to support their partner through the treatment of a chronic disease, such as HIV. If partners communicate openly and honestly, dyadic care can encourage increased informational support; however, if partners are not entirely open and honest with each other, having a partner present during conversations with a medical provider can limit the communication and information shared during treatment. Ultimately, increased access to and knowledge about dyadic HIV care across the continuum would enable partners to make informed

decisions about how they want to experience HIV treatment, even if dyadic care is not the best option for all partners.

There were some limitations in this study. These data are not generalizable beyond this specific cohort; however, these data are able to explain the perceptions and preferences for how MSM would like to receive HIV care across the continuum. Because FGDs were meant to capture general perceptions of partner support and dyadic care, FGDs used scenarios rather than personal experiences to discuss dyadic care. FGDs are more appropriate for capturing general perceptions about a sensitive topic than discussing personal experiences with HIV care. Although participants were all members of a vulnerable population, data on HIV status (for participants and their partners) were not collected and FGDs were not stratified by HIV status. This resulted in a varied range of knowledge on how HIV care works and a varied range of personal experiences with HIV and HIV care. This variety in experience and knowledge may influence the perceptions of HIV care that were expressed in the groups. Although the FGD guide did not include questions about participants' personal experiences, some participants still chose to share personal stories and many participants discussed experiences of other people who are in their community. To address any gaps in knowledge, the moderator clearly explained the continuum of care, including descriptions and questions at each step, to ensure that all participants understood how care is generally provided. We had 1 data analyst conduct the coding for this study, which limited the ability to assess disagreement and agreement between coders. The data analyst had extensive training and experience conducting qualitative data analysis but having 1 analyst could increase bias during the analysis process.

Despite these limitations, these data provide important insight into HIV treatment, specifically highlighting the potential value of dyadic care. Research about prevention and treatment of HIV among MSM is advancing, with programmatic efforts for interventions that address HIV among MSM; however, HIV incidence among MSM is still increasing and adherence across the continuum of care in the United States is low. 1,10,11,31 This evidence presents the need for examining novel interventions for HIV prevention and treatment, including HIV care that focuses on same-sex male dyads and strengthens HIV-specific partner support to improve HAART adherence and prevent the transmission of HIV.

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TABLE 1

Participant Demographics for Age, Race, Sexual Orientation, and Relationship Length

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	n (%)
Age, mean (range), yrs	42.1 (26–67)
Race	
White	11 (31.4)
African American/Black	20 (57.1)
Other	5 (14.3)
Sexual Orientation	
Gay/Homosexual	33 (94.3)
Bisexual	2 (5.7)
Relationship Length	
3–6 mo	2 (5.7)
6–12 mo	8 (22.9)
1–4 yrs	15 (42.9)
5 yrs	10 (28.6)

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TABLE 2

Overview of Results

Type of Support	Impact of Dyadic Care	Quotes	
Emotional	Reduces stress	"If you go separately it puts more stress on each individual"	
	Provides comfort	"Just the comfort of another person being there, in this case, this is your partner, this is someone you love, this is someone that loves you and for that to be, to provide a lot of comfort for you during, going through this"	
	Establishes empathy	"It creates a level of empathy. You're both able to emotionally support each other through the particular hardship of the side effects and things like that. A layer of understanding"	
Informational	Increases understanding in information received from doctor	"One of them might understand something more than the other might understand. So they work it out together and get the right information"	
	Allows space for additional questions in order to receive more information from the doctor	"It kind of helps fill in the blanks. I know frequently when I go to the doctor and then I come home and my partner is asking me XYZ and I'm like 'OK, you should have been there I guess because I didn't think to ask that question.' You get a little overwhelmed sometimes. So hopefully with each other being there, it would be beneficial to get more information from the doctors"	
	Increases transparency in the information shared with the doctor	"It would also though really lead to honesty something that's going to bring things to light. So hey, OK, you know, you're not being honest with the doctor here or it's obvious that you're not doing what you're supposed to do and if you're partners you would know that anyway"	
	Creates concerns regarding confidentiality and privacy	"The candidness between me and the doctor and what I might want to express to my doctor I don't have to filter myself because depending on where we are in our relationship, I may not want to share some things that my doctor might need to know"	
Instrumental	Increases accountability through accompaniment	"Normally a single person, they can miss doctor's appointments. So if you're going as partners, one can motivate the other. If you don't feel like going, drag them along and vice versa"	
	Enables partners to establish a financial plan	"They can find out together about will they be able to afford the medicine or how to get the medicine through insurance; they can take care of that together"	
	Increases accountability through facilitation of reminders	"One of the benefits of [the partners] going through this together is they have a better chance of taking their medications on time because they can remind each other and constantly ask, 'did you remember to take your medicine?'"	