

Perceived Barriers to Social Support from Family and Friends among Older Adults with HIV/AIDS

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Abstract

Research has found that HIV-infected adults age 50 and older are more socially isolated than younger HIV-infected individuals. This study examines the perceived barriers to obtaining emotional and practical social support from friends and family among 63 older adults (age 50+) living with HIV/AIDS. Many reported they did not receive enough emotional support (42%) or practical assistance (27%). Barriers to obtaining support included: (1) non-disclosure of HIV status; (2) others' fear of HIV/AIDS; (3) desire to be self-reliant and independent; (4) not wanting to be a burden; (5) unavailability of family; (6) death of friends to AIDS; and (7) ageism. These barriers may explain the greater social isolation of HIV-infected older adults and inform interventions targeted at reducing these barriers.

Keywords

ageing, attitudes, disclosure, HIV/AIDS, social isolation, social support, stigma

AS THE AIDS epidemic enters its third decade in the United States, its face has changed. In addition to including a growing percentage of women and ethnic/racial minorities, the HIV/AIDS population is also growing older. By year end 2001, a cumulative total of 90,500 AIDS cases had been reported in the USA among adults 50 years of age or older at the time they were diagnosed (CDC, 2001). These cases represent approximately 11 percent of all male AIDS diagnoses and 10 percent of all female AIDS diagnoses. However, the CDC statistics underestimate the true prevalence of HIV/AIDS among adults over 50 because they include neither individuals who are HIV-infected, but have not yet been diagnosed with AIDS, nor do they include individuals diagnosed at an earlier age (e.g. their 40s) and who have survived into their 50s. A re-analysis of the 1996 CDC data, which accounted for individuals' ageing and mortality suggests that as many as 15 percent of individuals currently living with AIDS are over age 50 (Ory & Mack, 1998). Further, a larger number of older adults may remain undiagnosed as they are less likely to be tested for HIV (Mack & Bland, 1999) and are diagnosed at a later disease stage than younger adults (Ferro & Salit, 1992) due in part to misattribution of early HIV symptoms to other conditions (Siegel, Schrimshaw, & Dean, 1999). As HIV-infected individuals live longer due to more effective antiviral medications and as the population in general ages, the prevalence of HIV/AIDS among late middle-age and older adults is likely to continue to increase.

Despite the significant number of older adults living with HIV/AIDS, there remains little research examining their psychosocial adjustment to the illness. Although older infected adults (50+) have not been found to be more depressed than younger adults with HIV/AIDS (Meadows, le Marechal, & Catalan, 1998; Nokes, Holzemer, Corless, Bakken, Brown, Powell-Cope, Inouye, & Turner, 2000), they (like younger individuals with HIV/AIDS) are at significant risk for depression. For example, among a sample of 113 middle-age and older infected adults (45+), 29 percent were estimated to have moderate or severe depression and 31 percent mild depression (Heckman, Kochman, Sikkema, & Kalichman, 1999); and 26 percent had thought about taking their own lives in the

previous week (Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2000). Further, among their sample of 73 infected older adults (50+) Nokes et al. (2000) reported an average CES-D score of 21.4 which is notably above the often used 16-point cut-off for probable cases of clinically significant depression.

The importance of social support in the psychological adjustment to living with HIV/AIDS is well documented (Hays, Turner, & Coates, 1992; Ingram, Jones, Fass, Neidig, & Song, 1999; Kelly, Murphy, Bahr, Koob, Morgan, Kalichman, Stevenson, Brasfield, Berstein, & St Lawrence, 1993; Nott, Vedhara, & Power, 1995; Schrimshaw, 2002; Siegel, Karus, & Raveis, 1997) with greater perceived support consistently associated with better psychological adjustment. However, virtually all research on this issue has been conducted with younger infected adults (i.e. less than 50 years of age). In the only sample of older HIV-infected adults (45+) in which the relationship between social support and psychological adjustment has been examined, a lack of support and information, financial constraints and stigmatization were found to distinguish depressed and non-depressed individuals (Heckman et al., 1999). Further, among the same sample, lower levels of perceived social support from both family and friends were found to distinguish those older adults who had thought about suicide from those who had not (Kalichman et al., 2000). In an effort to improve the mental and social health of HIV-infected older adults, interventions have already been proposed that aim to enhance their available social support (Heckman, Kochman, Sikkema, Kalichman, Masten, Bergholte, & Catz, 2001).

The small amount of existing empirical data on the availability of support for older infected adults suggests that they may be at risk for poor social supports. For example, among 156 middle-age and older adults (44+) living with HIV/AIDS, 44 percent were unsatisfied with the emotional support they received from their family, and 46 percent were unsatisfied with the practical help their family provided (Speer, Kennedy, Watson, Meah, Nichols, & Watson, 1999). Further, at least some research suggests that older infected adults may have lower levels of support than younger infected adults. Although Nokes et al. (2000) found that older

adults (50–64) perceived no less support available to them than younger HIV-infected adults, other research has found older adults with HIV (54+) to be significantly more socially isolated than younger infected adults (Meadows et al., 1998). Consistent with this, HIV-infected women over 50 have been found to be more likely to live alone and to be separated/divorced than their younger counterparts (Schable, Chu, & Diaz, 1996). Even after controlling for disease characteristics and demographic variables, older age has been associated with poorer social functioning (i.e. more restricted social involvements) among HIV-infected adults (Piette, Wachtel, Mor, & Mayer, 1995). In other analyses of the study sample reported on below, older HIV-infected adults (50+) reported that among the disadvantages they perceived to be associated with their older age was that they were more socially isolated and that they received less compassion and sympathy from others regarding their disease than younger adults (Siegel, Raveis, & Karus, 1998).

Although existing evidence suggests that older adults with HIV/AIDS may be at risk for poor social support, we could find no reports in the extant literature of research focused on understanding the factors that may account for this circumstance. Research on younger HIV-infected adults (primarily gay men), however, has identified several barriers to social support that may also exist among older infected adults. One of the most frequently noted is non-disclosure of their HIV infection to their social network (Serovich, Brucker, & Kimberly, 2000; Smith & Rapkin, 1996; Turner, Hays, & Coates, 1993). Clearly, friends and family cannot provide support if they are unaware of the individual's need. Moreover, Nokes et al. (2000) found that HIV-infected adults over 50 were significantly less likely than younger HIV-infected individuals to have disclosed their HIV infection to others. Similarly, Simoni, Mason, Marks, Ruiz, Reed and Richardson (1995) found that among HIV-infected women (ages 18–69), older age was associated with less disclosure of their illness to others.

Support may also be impeded if friends and family members are fearful of AIDS, hold negative attitudes toward people with AIDS, lack knowledge about or have misinformation regarding HIV/AIDS (Collins, 1994; Kadushin,

1999). Such fears and attitudes may lead potential support providers to avoid or distance themselves from the infected individual. Similarly, infected gay men may experience less support because of negative attitudes toward homosexuality held by family members (Collins, 1994; Kadushin, 1999; Smith & Rapkin, 1996). Older infected adults may be at even greater risk for encountering negative attitudes toward HIV/AIDS and/or homosexuality because their families and friends are typically also older, and older age has been found to be associated with poorer knowledge about HIV/AIDS (Peruga & Celentano, 1993), which in turn is likely to be associated with holding irrational fears and negative stereotypes about HIV-infected individuals.

There may also be structural or access barriers to receiving social support from friends and family. Both Serovich et al. (2000) and Smith and Rapkin (1996) found that due to distance from family, death or lack of a romantic relationship some HIV-infected individuals simply had smaller social networks, and as a result may have fewer people they can rely on to provide support or assistance. HIV-infected older adults may also be more likely to have experienced the loss of members of their social network (i.e. family, partners, friends) due to death from AIDS or other illness. Finally, infected individuals may be unwilling to seek support both because it may require acknowledging their dependency or because of the fear of burdening others (Kadushin, 1999; Smith & Rapkin, 1996).

In summary, older adults with HIV/AIDS may be at risk for poor levels of social support. Yet what research exists on the barriers to obtaining social support among infected adults is largely limited to samples of younger adults (i.e. less than age 50), especially gay men. To date, we could not identify any studies that have focused on identifying the barriers that may compromise the adequacy of social support among older adults with HIV/AIDS. Indeed, Heckman et al. (2001) have called for qualitative research on this issue to inform the content and delivery of supportive interventions to older adults. The present report represents an effort to fill this gap.

Method

Participants

Interviews were conducted with a diverse sample of 63 HIV-infected late-middle aged and older adults (over age 50) living in New York City. Sample characteristics are presented in Table 1. Potential participants were screened over the telephone to determine their eligibility. Individuals were eligible for participation if they: (1) had tested positive for HIV antibodies;

(2) were 50 years of age or older; (3) attributed their infection to either sexual behavior or intravenous drug use; (4) were either African American or White (non-Hispanic) and born in the USA, or if Puerto Rican had resided in the USA for four years or more; and (5) were cognitively competent as assessed with a brief screening measure (Katzman, Brown, Fuld, Peck, Schecter, & Schimmel, 1983). Further sample selection was guided by the principles of representative case sampling (Shontz, 1965).

Table 1. Demographic characteristics of older adults living with HIV/AIDS (*N* = 63)

<i>Variable</i>	<i>N</i>	<i>%</i>	<i>M</i>	<i>(SD)</i>	<i>Range</i>
Age (in years)			56.3	(5.5)	50-68
50-59	44	70			
60-68	19	30			
Gender					
Men	45	71			
Women	18	29			
Race/ethnicity					
African American	25	40			
Puerto Rican	15	24			
White	23	36			
Marital status					
Single	32	51			
Divorce/Separate/Widow	25	40			
Married	6	10			
Household Income			Median = \$5,000-9,000		
< \$10,000	33	52			
\$10,000-19,999	20	32			
\$20,000 or more	10	16			
Education					
Less than high school	11	17			
High school graduate	11	17			
Post-secondary education	25	40			
College graduate or more	16	25			
Currently employed ^a	12	19			
Sexual orientation (self-identified)					
Heterosexual	31	50			
Bisexual	8	13			
Homosexual/Gay	23	37			
History of injecting					
Drug use	14	22			
HIV disease stage					
Asymptomatic	19	30			
Symptomatic	8	13			
AIDS	36	57			
Number of HIV-related symptoms			9.9	(6.5)	0-24
Most recent CD4 cell count			400	(311)	40-1500
Length of time since testing HIV + (in years)			5.9	(3.3)	1 month-11.75 years

Note: Percentages do not sum to 100 due to rounding error.

^a Of those not currently employed (*n* = 51), 63 percent were not working due to their illness.

That is, while the eligibility criteria set the broad parameters for inclusion, within these parameters participants were selected to ensure the sample had considerable variability on time since diagnosis, disease stage, age, race/ethnicity and gender.

Procedure

Individuals were recruited from a number of community-based health and social organizations, support groups, advocacy organizations and drug treatment centers in New York City. Recruitment took place in both organizations that served HIV-infected individuals and in non-HIV specific organizations (e.g. drug treatment centers, gay and lesbian organizations). In order to preserve participant confidentiality, the study relied on self-referrals. Flyers about the study and how to contact the researchers were distributed within the organizations and staff were requested to directly offer potentially eligible clients/members a flyer. Interested individuals were requested to contact the researchers by telephone using a study phone number provided in the flyer.

When individuals called the study telephone line, they were screened for eligibility. Eligible individuals wishing to participate were scheduled for an interview at the investigators' research offices. Interviews were conducted from the fall of 1996 through the fall of 1997 by Master's level clinical interviewers. Puerto Rican participants were given the option of completing the interview in either Spanish or English. After obtaining written informed consent, each participant completed a semi-structured interview (typically completed over the course of two meetings, each lasting approximately two hours). At each meeting, participants were given \$25 and reimbursed for transportation costs.

Interviewers employed an interview guide that covered a variety of topics related to living with HIV/AIDS. The guide was not used as a structured interview schedule, but rather as an outline of topics of potential theoretical importance to be covered in the interview. Interviewers were encouraged to pursue issues raised by the participants that were not included in the guide, but might have relevance for understanding their psychosocial adaptation to the illness. They were also trained to use the participant's

comments, when possible, as a natural bridge from one topic area to another. Interviewers were trained to phrase questions neutrally and broadly in order to allow the participant to address the question from their own frame of reference. Further elaboration of the recruitment, sample selection and interview methods are available in previous reports from this study (e.g. Siegel, Dean, & Schrimshaw, 1999).

One topic area covered by the interview guide was the participant's receipt of emotional and practical support. Each participant was asked, 'Do you receive as much emotional support as you need?', as well as a corresponding question about practical support. In addition, participants were asked whether their family and friends provided support, and the types of support they provide. They were also asked whether they had any difficulty asking people for either emotional or practical support. For those who reported they did not have enough emotional support, practical support or who viewed it difficult to ask for support, follow-up questions were used to identify the reasons for this.

Data analysis

Interviews were audio taped and transcribed for thematic analysis. The investigators began by identifying all material in the interviews that related to the participants' experiences of social support. In addition to participants' responses to the direct questions (identified above) about emotional and practical support, a computer-based text analysis program was used to search the entire interview for references to support, aid, help, assistance, talking, sharing and disclosure. These key words were identified from reading the full transcribed interviews as part of earlier analyses of the data. The extracted material was then equally divided between the authors (with a separate set of cases to each author, equally divided by race/ethnicity). Each author independently identified a preliminary set of themes related to barriers to receiving or asking for social support based on the set of cases they analyzed. These initial themes were then discussed to develop a mutually agreed upon set of codes to reflect the dominant themes related to their barriers to obtaining needed social support from friends and family. Finally, direct quotations were selected which most clearly represented the

participants' perceived barriers to obtaining social support. The age, gender, race/ethnicity and sexual orientation are provided with each quotation. History of injecting drug use was noted when this was present (i.e. participants whose drug use is not specified did not report a history of injecting drug use). In addition, each participant was assigned a unique identification number (modified to protect their confidentiality), so that individuals with similar demographic characteristics may be distinguished.

Results

Many of the late middle-aged and older adults living with HIV/AIDS interviewed expressed dissatisfaction with their social support networks and the amount of emotional and practical support they received from their friends and family. When asked directly whether they received as much emotional support as they need, 42 percent reported they did not receive adequate emotional support. Similarly, 27 percent reported they did not receive enough practical assistance. There were no statistically significant differences in reported satisfaction with emotional or practical support by age (60+ or younger), gender, race/ethnicity, income (> \$20,000 or not), or education (college graduate or not). Surprisingly, neither living alone, nor parental status was associated with satisfaction with emotional or practical support. However, a marginally significant difference in satisfaction with emotional support (but not practical support) was found to be associated with disease stage, $\chi^2(1, N = 59) = 2.89, p < .09$. Individuals with an AIDS diagnosis reported not receiving enough emotional support (51%) more frequently than those with less advanced disease (29%). Further those who had been diagnosed as HIV-positive more than five years ago were more likely to report not receiving enough practical support (38%) than those diagnosed less than five years ago (14%), $\chi^2(1, N = 54) = 3.70, p < .05$.

Several participants commented that if there was no one to assist them with a need, the need simply went unmet (e.g. 'Whatever I can't do, it just stays undone', reported a 51-year-old Puerto Rican heterosexual man with a history of injecting drug use #522). Others suggested they were profoundly lonely as they grew older (e.g.

'I think mainly my issues have been a kind of loneliness . . . I find myself as somebody getting on, and not having people in my life. Needing people, wanting people', reported a 64-year-old gay White man #629). Although many were satisfied with the levels of support available to them, this was often not because supportive friends and family had come to their assistance, but rather because they felt that they were currently doing well enough physically and emotionally, to not need a great deal of support. For example, a 64-year-old heterosexual White man told us:

I'm not asking for support. I'm not really asking for, you know, 'Oh please, come hold my hand' type of stuff at all. Or 'I can't do this, I can't do that.' I don't need help right now because I'm not sick. Not at all. (#625)

When asked why they thought they were not receiving adequate support, these older HIV-infected adults offered a number of explanations. Even many of those who reported being satisfied with the support they were receiving nevertheless suggested that there were barriers or problems they had encountered which had made obtaining support difficult. The identified barriers to their receipt of adequate emotional and practical support from friends and family are discussed below, in order of decreasing prevalence. Although some of the barriers appear to be associated with older age, others do not appear to be specific to older adults and may be found among younger HIV-infected adults as well (see Discussion).

Not disclosing status to others

Although many participants had known for years ($M = 5.9$ years, $SD = 3.3$ years) that they were infected, some had not disclosed their illness to family or friends or only to a few select individuals. The principal reasons for nondisclosure were fear of the reactions notification would elicit (i.e. anticipated stigma), feeling that they did not know how to make the disclosure, or a wish to safeguard their privacy. Many participants, however, recognized that not disclosing their status to family and friends precluded opportunities to obtain needed support. Rather than risk potential negative reactions to disclosure that they knew would be very distressing to them, many participants

chose to do without the support of friends and family. For example, when asked if she found it difficult to ask people for support, a 50-year-old heterosexual African American woman told us:

Yeah. Yeah . . . Like I said, I don't want everybody to know, so I just don't bother asking nobody for help. If I need to ask somebody I know, [then I would ask] someone that's in [support group name]—same status with me . . . If I can't do it myself, I just don't bother with it. (#426)

Similarly, although eager to obtain more emotional support, fear of others' reactions to disclosure, as well as fear that they might tell others of his illness prevented a 52-year-old gay Puerto Rican man from communicating his need for additional support. When asked why he believed he did not receive as much emotional support as he needed, he replied:

Well, in part, because I can't find a way to tell anyone [about the illness] and to tell them that this is happening. That is the only problem. [Has there been a time when you would want to ask someone for emotional support?] Yes, but I don't know how. I don't know how to do it in the first place. What would they think? I have thought about it many times, but I don't know how or who. Because there is a friend of mine, and I could call her and tell her, but they are the kind of people that can't keep secrets. So they would talk about me. That is why I don't dare ask anyone for emotional help. (#516)

Several others similarly suggested that they were very private people and feared that disclosure of their illness would result in a loss of privacy. For example, a 68-year-old gay White man, had not told anyone in his Buddhist community, even though he reported this community was very central to his life and his well-being, because he felt this would compromise his privacy. He said:

I told my sister and her husband. And my niece. And they're totally supportive. That's the only three. I told them not to tell anybody, because I'm a private person. And not everybody is going to react the same way. Even in the organization of Buddhists, I don't tell them. I don't know, I just don't feel like

publicizing it. . . . As I said, I'm a private person, so that's the only three people that I've told. (#630)

Fear/ignorance about HIV/AIDS

Even after disclosing their infection to others, some participants reported that family members or friends were unwilling or unable to provide them with needed support because of their fear or ignorance about the disease. Participants reported experiencing a number of different stigmatizing interactions that made obtaining support difficult or impossible. For example, they spoke of others avoiding them due to a fear of contracting the disease through casual contact. They reported too that some family and friends held prejudices and negative attitudes about the disease that they found difficult to confront. Other participants were unwilling to ask for support from family and friends who held such negative attitudes toward HIV infection. For example, a 52-year-old heterosexual African American woman with a history of injecting drug use reported that she did not receive much support from her family due to their lack of information regarding HIV/AIDS. She reports:

It's like my baby sister. She don't know the facts about it. But she's scared to death of certain things around us. [She knows that you have HIV?] Yeah. [And she's acted that way toward you?] She hasn't acted that way, but—it's the things, some thing she says. She doesn't know about it. She doesn't have much knowledge about anything. She dropped out of school in the eighth grade, and she's been drugging ever since . . . And it's like I cannot have an intelligent conversation with her. She doesn't understand. She just—I can't deal with her. I'm not going to even stress myself out for it. This is the way I feel about certain people. Some things—some people are not worth the bother. (#418)

This absence of support from family members who feared AIDS or held negative attitudes toward those with the disease was clearly distressing to many participants. For example, a 55-year-old White gay man, when asked if he receives as much emotional support as he needs, told us:

No. The emptiness of my family not supporting me is my problem. That's the main problem. I have all this support that's in the community, it's fine. But my own family I grew up with that I was so close with my whole life is what upsets me the most. That I can't get the support I want from them. I mean they won't even hug me. I walk in the house. They won't even hug me. They figure they'll catch the illness. This—that hurts very bad, you know. It's very rough. I have other people hugging me all day. [So what would you say is preventing them from giving you the emotional support you need?] Their lack of education. Uneducated about the illness, and they're afraid. . . . So you know, if they feel that way, they'll never be able to support me emotionally, as long as they think they're going to catch something from me. (#614)

For other gay men in the sample, it was hard to separate the uneasiness family and friends felt in dealing with their HIV infection from their discomfort with homosexuality. One 64-year-old White gay man, when asked if there were friends and family who provided emotional or practical assistance, responded:

A bit, but not a lot. Not a lot. [Who are these people?] Well, there's family, and they can be somewhat supportive. They are supportive but they don't want to, ah, it's hard for me to ah, share the pain of my daily life with them, you know? They're uncomfortable with it, and I don't think it's because I'm HIV. I think it's because I'm homosexual. [Oh really?] Yeah. They don't know how to deal with it. And they're nice people. They're really wonderful people. I like them. It's just either so alien to them, so foreign and uncomfortable for them. Or maybe they're just not caring as people. (#629)

Self-reliance and independence

Many participants emphasized that self-reliance and taking responsibility for solving one's own difficulties in life were important personal values for them. They felt it was wrong to rely on others to find solutions for one's problems. Some implied that these were values that had been imparted to them and adopted early in life and practiced even before their diagnosis. As a result of these values, many were unwilling to

seek support, even though they felt they needed more support. For example, when asked if he found it difficult to ask for emotional or practical support, one 64-year-old White gay man told us:

I would say yes. An unqualified yes, without even adding on HIV. It's difficult for me to ask. I was trained to be independent. I remember my father when I received my BA degree when I graduated from college. He said it cost me ten thousand dollars to put you through school. Back then that was a lot of money. . . . But he said that's it. The well runs dry or something to that effect. You can't come to me anymore. You're on your own. He taught me to be independent, to take care of oneself. [Does having HIV make it harder or easier?] Makes it harder, because it's just so much more vulnerability to be of need. (#624)

When asked whether he found it difficult to ask for support, another 53-year-old gay White man responded:

Well, yes and no . . . I don't feel—I mean I have [support], I guess, through the Alanon or something, but I don't feel—I mean, I believe in these things called boundaries. You know, I don't feel it's appropriate to seek out a lot of emotional support from other individuals. I don't feel it's appropriate behavior for me to do that because I think it's unfair to the people that you're asking . . . it's part of my value system. I don't think it's appropriate behavior for people to look to other people to solve their emotional issues, unless it's in a professional context, where you're seeking professional advice. (#617)

Several participants prided themselves on the fact that they had rarely accepted assistance or help from others, and had been almost completely self-reliant throughout their lives. They suggested this posture was associated with a need to maintain a strong masculine self-image. For example, when questioned about whether he found it difficult to ask people for support, a 59-year-old heterosexual Black man reported:

I ain't never asked nobody for nothing. I was always—it was a phoney pride, but it was there. I wouldn't ask nobody for nothing. If I didn't have it, I would do without, until I get

it. [Has that changed or is that the same for you?] That's even more so now. No, I wouldn't—I'd have to be real sick to ask somebody to come by the house, something like that, to help me out. [What is difficult for you about asking for help?] I never did it before. Maybe it's a macho image or something I always had. I don't know, but see when I grew up, any time I did it myself, it boosts my ego. Makes me feel better, that I could say and say it honestly, 'I don't ask nobody for nothing. I work every day.' Makes you feel good. So I haven't ever asked nobody for nothing. (#424)

Don't want to be a burden to others

Some participants reported that their resistance to asking for help from others stemmed from a fear of becoming a burden to others. In contrast to those noted above (see Self-reliance and independence) who were unwilling to seek support, these participants suggested that they would like to ask for support but could not do so because they worried they would become a burden to others. Their own parents, when still alive, were frequently elderly and infirm, while siblings were typically busy raising children, pursuing career goals or dealing with significant life stressors of their own. They felt to impose on or tax the energies of already stressed family members or friends would be wrong or unfair. For example, a 50-year-old heterosexual Puerto Rican woman told us that although she wanted more emotional and practical support, she had trouble asking others. When asked why she said:

Not from my family, because my daughter has two children. She lives far away. She's pregnant. She's living in a shelter. So I don't want to put any more pressure on her than what she has. I tend not to . . . [Do your friends come help you?] Yes, they do, if I ask. [What makes it difficult for you to ask them?] Taking away from another person, their precious time. (#525)

Another 53-year-old gay White man reported that he received no support from his family, not only because they live far away, but also because he did not want to 'unload' his problems on them when they do visit. He said:

Once in a while I will hear from or get a visit

from one of them [a member of his family]. But ah, I figure they've got enough—they've got enough problems to deal with. Why should I unload them with something else? Unload something else on them, unless it's something absolutely necessary. If it really becomes necessary—if they ask me—I'll tell them. But they don't ask. (#618)

Other participants suggested that they were intentionally not asking for assistance currently because they did not want to seek help from their support network while they could still manage on their own, even if with some difficulty. They feared that if they did so, others might feel they were trying to exploit their illness in order to reap secondary gains. They also worried that if their network members experienced burnout, or if they used up the goodwill they had with these people, they might be unable or unwilling to offer assistance later when they became more seriously ill and dependent. For example, when asked if he found it difficult to ask for support, one 53-year-old White gay man told us:

Yes, I do find it difficult. Because I don't want them to think I'm manipulating them. And I just don't want to be like that, so I don't ask. I think if I was really in serious trouble, I would ask. But I really have to be hard pressed to do that . . . [Do you feel you're getting the emotional support you need?] That's tough. Maybe not. [Why not?] Because I'm not asking for it. Yeah. Or I save it for when I really need it. I mean, you know, I keep doing all this, like thinking, you save everything towards the end, like if you get real sick, that's when you want—you need your friends. That's because I know with [deceased partner's name], when he was so sick, people get tired, you know. They burn out. And at the end, when he was very sick, I needed people. (#612)

Unavailability of family supports

The older age of family members and their age-associated illnesses made many participants feel that they were not realistic sources of meaningful support. For example, a 53-year-old gay White man remarked:

Well, I don't have a very large family. I have

an older sister who has pretty advanced Alzheimer's, so there's no point [in telling her about his HIV infection]—most of the time she wouldn't even know who I was. I have a younger sister that I rarely see or talk to, who's kind of a religious fundamentalist who's still reeling from the impact that I'm gay, let alone HIV positive. And then my parents, both of whom are like in their 80s, and my father probably won't live more than another couple of years. He has prostate cancer. They live in California . . . And that's the extent of my immediate family. (#617)

Others had lost parents or siblings that they would have otherwise turned to in time of crisis. For example, a 53-year-old heterosexual Black woman with a history of injecting drug use reported that she has received little emotional support since the death of her sister:

I do have a problem asking for help. Emotional help . . . The one person that I've shared everything with, my sister, has passed away. And um, I don't know. Now I guess I'll have to start sharing more with my children, because everything before was with my sister. Like today I went to call my sister, and she is not there. So I feel the loss of her not being there . . . [It sounds as though right now there isn't anyone like that for you?] No, nobody like my sister. (#413)

Others lived too far away from relatives to rely on their assistance or had only weak ties to them to make a request for help seem inappropriate. For example, a 52-year-old heterosexual Black woman told us:

My mother and father are dead. I have no close relatives. The relatives I do have, they live in Long Island, the outskirts of Long Island and upper New York State. They have their own homes and cars and whatnot, and they feel they're a little bit better than everybody else. I would not take such a thing to them. We're not close. We're not close. I don't hear from them. So I have just made up in my mind that I'm alone, that I'm by myself and it's not the worse thing. I have children. I brought five children into the world and though I would love to have some contact with them, love to hear from them occasionally, I don't for the most part. (#411)

Another 53-year-old gay White man told us he really does not get any support from his family because they have died or live far away:

First of all, my family, is all—they're in [town name] Michigan. My youngest sister has moved to Florida. So I'm not dealing with them on a daily basis. [Is there anyone else in your family?] Well, my parents are deceased. One brother and three sisters. I don't have anything to do with them, but once in a while. (#618)

Death of partners and friends to AIDS

Several participants, particularly among the older gay men, had lost partners to AIDS or had their friendship network decimated by the disease. These individuals felt emotionally depleted from their losses and some had withdrawn socially. This barrier was reported almost exclusively by gay men in their 60s compared to those in their 50s. For example, a 63-year-old White gay man explained that he had stopped socializing and volunteering because he had already lost much of his social group and that the loss of still others would be extremely distressing for him. He seemed to need to defend against the possibility of further loss by withdrawing from relationships with HIV-infected individuals. He explained:

After years in which, you know, a few people would die, in '94, 19 people I knew died, including five from each of the two support groups I was in. So that wiped out one group completely. I was the only person left alive. And it was truly horrendous. So I stopped doing volunteer work with AIDS organizations and dropped out of the support groups. (#620)

Similarly, a 63-year-old Black gay man told us:

I founded two support groups because there weren't any in Harlem. So I co-founded two and talked. They're all dead. All the members except myself are dead. So you know what I miss today? My peers. They're dead. (#434)

A 60-year-old White gay man reported that he really had only two surviving friends, and that they were not able to provide much support. When asked how much he socialized, he replied:

Very rarely if at all. I said that most of my friends have passed away. A lot of my—people that I associate with—are friends of my roommate, and now he's gone. So there's not that relationship anymore. (#628)

Still another 64-year-old White gay man reported that he spent more time alone due to multiple losses he had sustained of friends. He reported:

I would say yes [he does spend more time alone], but not because I'm HIV infected but because I've lost so many close and dear friends to the epidemic. But then also because I'm beginning to accept the fact that I'm ageing and that's a process of ageing too—of losing people and being a survivor. So those two factors contribute too. (#624)

Ageism

As identified in a previous report on this sample (Siegel et al., 1998), several participants suggested that they believed that older infected adults received less sympathy and compassion than younger individuals with HIV/AIDS because their plight was viewed as less tragic. They believed that much of the public felt that because young people were stricken with the disease before they had had an opportunity to accomplish important life goals, they suffered more than older people who had had such an opportunity. They also felt that while younger adults' indiscretions and excesses that might have led to their becoming infected were viewed with some tolerance, older adults who became infected were judged harshly and seen as foolish. Because of these ageist circumstances, several participants reported that they received less support or were less willing to ask for support from others. A 53-year-old heterosexual African American woman with a history of injecting drug use explained that one of the reasons that she did not seek support from others was her age:

I feel at my age, 53, that to ask people for help, they would feel that well, she should know how to do this or she should know where that's at. I just feel people expect me—expect me to know. So I do have a problem with asking for help. (#413)

Further, some of the gay men believed that their

community placed a high emphasis on youth and vitality. As a result, they believed that older gay men, especially those who were not physically healthy, were devalued and marginalized. For example, a 53-year-old gay White man explained that he lacked support because of ageism within the gay community. He explained:

I feel I'm not getting support from the gay community. I think when you're older, the gay community—they don't—you become invisible. And a lot of friends say 'Oh nonsense. Nonsense.' But they can say that because they're younger . . . I do feel that something about the gay community is very—it's different. It's not like others—it's all about youth and beauty—and muscles and ah, and I don't know where people are that are my age. I don't see them. I mean I know a lot of them are dead, and a lot of them must be hiding out in their houses. I don't know. I don't—but it's lonely in that way . . . And I think what makes it complicated is, it's bad enough to be gay and getting older, but then to have the HIV on top of it, I mean, forget it. You're a pariah. And so, that's basically the problem. (#612)

Discussion

Previous research has suggested that older adults living with HIV/AIDS experience greater social isolation and receive or at least perceive less social support than younger adults (Meadows et al., 1998; Piette et al., 1995; Schable et al., 1996; Siegel et al., 1998). The present study sought to identify the barriers to social support reported by HIV-infected older adults. We found that 42 percent of the participants reported they needed more emotional support and 27 percent reported they needed more practical support from family and friends. Speer et al. (1999) similarly found that 44 percent of older HIV-infected adults (44+) were unsatisfied with the emotional support they received from their family. However, they found that 46 percent were unsatisfied with the practical support provided by family members. In the present study, those who felt they lack adequate support suggested a number of barriers that prevented them from obtaining support.

A number of barriers to social support were

identified by the study participants. Surprisingly, only one of these was clearly unique to older adults living with HIV/AIDS. Specifically, several participants believed that societal ageism was responsible for their obtaining less support than they needed. Because they felt stigmatized, different and excluded because of their age, many suggested they were either unwilling to ask for support, or found it more difficult to develop supportive relationships. This finding is consistent with an earlier report based on the current study sample (Siegel et al., 1998), which suggested that older adults felt they were judged more harshly and were more stigmatized than younger infected adults. However, the present report provides further evidence that older infected adults' experiences of stigmatization may lead to problems obtaining social support.

Although most of the barriers to support that were identified here parallel those that have been noted among younger infected adults, there is reason to believe that some may be more prevalent or severe among older HIV-infected adults. For example, these older adults reported that they were unable to utilize their families for support because their parents and, in some cases, siblings were deceased, or were too old or too ill to provide either emotional or practical support. Similarly, older adults may be more likely to have lost numerous friends and partners to AIDS than younger infected adults since their friends (like themselves) were more likely to have been infected and diagnosed at an earlier time (i.e. the 1980s or early 1990s) when treatments were considerably less effective in extending survival. Indeed, within this sample, those who were in their 60s were more likely to report the death of friends and partners than those in their 50s.

Older adults with HIV/AIDS may also be more likely to have less access to social support due to nondisclosure; as they have been found to be less likely to disclose their illness to others than younger infected adults (Nokes et al., 2000). Their resistance to revealing their diagnosis was motivated primarily by a desire to avoid negative reactions or rejection as well as a wish to protect their privacy. Although many recognized that nondisclosure restricted their ability to obtain needed support, their concerns about the ramifications of disclosure deterred

them from sharing their diagnosis with their family and friends. Further, in contrast to Smith and Rapkin's (1996) sample of younger HIV-infected adults among whom fear of disclosure was one of the least frequently reported barriers to seeking family assistance, in the present sample nondisclosure was one of the most frequently noted barriers reported by older HIV-infected adults. Thus, non-disclosure appears to be a greater barrier to support for older HIV-infected adults than for younger infected adults.

Even those older adults who had disclosed their HIV infection to friends and family did not always receive the support they desired. As with younger adults (e.g. Collins, 1994), a number of participants reported stigmatizing reactions from friends and family who were ignorant or prejudiced concerning HIV/AIDS. Their fears of HIV transmission through casual contact and their negative attitudes toward homosexuality posed barriers to accessing support from these individuals. Although younger HIV-infected adults also experience this barrier, older adults may be at greater risk for encountering prejudice and fear from their family members and friends because older cohorts of the public have been found to be less knowledgeable regarding HIV/AIDS (Peruga & Celentano, 1993). Whether or not they are more prevalent, fears of encountering negative attitudes toward HIV/AIDS (i.e. fear of negative reactions that prevent disclosure, and actual expressions of rejection upon disclosure) were a major barrier to soliciting social support from friends and family among older HIV-infected adults.

Finally, two personal values prevented a number of infected older adults from seeking or accepting support from their family and friends—the importance they placed on being self-reliant and not wanting to burden others with their problems. As noted above, many reported that they had been raised to take responsibility for solving their own problems and therefore were unwilling to ask for support from their friends and family. Others reported although they would like to ask for more support, they did not want to burden family and friends with their problems and therefore were unwilling to reach out for support. Both of these barriers may stem from living in a society that emphasizes individualistic approaches to

dealing with problems. Although these barriers to support have also been identified among younger HIV-infected adults (e.g. Smith & Rapkin, 1996), it is possible that this barrier may be more common for older adults. The values of independence, self-reliance and doing for oneself rather than burdening others may be more common in older adults (i.e. a cohort effect).

The barriers to obtaining emotional and practical support from friends and family identified here offer several potential explanations for previous findings that HIV-infected older adults feel more isolated and less supported by others than younger infected adults. As such, these findings provide useful data for informing the development of interventions aimed at improving the support available to older adults living with HIV/AIDS (e.g. Heckman et al., 2001). Some of the barriers identified might be addressed in psychosocial interventions, support groups or individual therapy. For example, working through fears and realistically appraising the risks and benefits of disclosure to different individuals can open new avenues of support. Similarly, interventions could address older adults' need to remain self-reliant and avoid imposing on others by helping older adults realize that others may be happy to have the opportunity to offer assistance and may not feel burdened by the chance to do so. Identifying opportunities for some form of reciprocity may also ease the psychological conflict many older adults feel in asking for help.

Other barriers are not as easily addressed. The negative societal attitudes and those of friends and family toward HIV/AIDS and society's ageism may require more community-based intervention to reduce these two prevalent stigmas. Even more difficult are the structural barriers identified. Clearly interventions cannot replace family, friends and partners who have died or are too ill or aged to provide adequate support. However, interventions designed to create new and larger social networks—e.g. through involvement with volunteer 'buddies' or in support groups—might be very helpful in eliminating the social isolation experienced by many older adults living with HIV/AIDS. In the absence of reducing these barriers, professional supportive services are needed for HIV-infected older adults. Noting

the unwillingness of many to seek support, these professional services may need to actively reach out to older adults, offering them support and assistance, and encouraging them to take advantage of it.

Potential limitations of the study must be acknowledged. First, although past research has found that older HIV-infected adults are more socially isolated than younger HIV-infected adults, the present study did not include a younger comparison group. Therefore, we cannot examine this hypothesis directly. Future research is needed to determine this more definitively. Relatedly, we have argued that a number of the barriers to support identified here, while also present for younger HIV-infected adults, may be more prevalent or more severe for older adults with HIV/AIDS. Again, we cannot determine if this is the case in the absence of a comparison group. Rather, we have provided evidence that these barriers are viewed by older adults to reduce their ability to obtain adequate social support, and have provided arguments for why these may be related to their older age. Clearly identification of these potential barriers is a first step to identifying their true prevalence, whether they differ by age, and whether they are in fact associated with lower levels of social support.

The research is further limited because the semi-structured interviews and sampling strategy are not designed to achieve reliable estimates of prevalence. We cannot provide estimates of the prevalence of each barrier to social support identified because the interview questions changed over time, the amount of time addressing social support varied from individual to individual and because it would only represent those who mentioned that barrier, not the actual prevalence. Furthermore, the data extraction procedure may have missed brief or subtle discussions of social support. Therefore, any estimates probably reflect an underestimate of the true prevalence. In contrast, we have provided prevalence estimates for satisfaction with emotional and practical support with this convenience sample because these questions were asked in the same form to nearly every participant and required only a brief (yes/no) response. However, this should not be considered a true prevalence estimate of the support satisfaction of older HIV-infected

adults because the study sample is not representative of the population due to the sampling methods employed here. However, prevalence estimates were not the purpose of the current study, nor are they the strength of qualitative methods that are better suited for generating insights into the phenomenon of interest.

Despite these limitations, the present study provides insight into the difficulties late middle-age and older adults living with HIV/AIDS face in obtaining emotional and practical support from their family and friends. The identification of barriers to support and the development of interventions to address these barriers offers one method by which the low levels of social support, a risk factor for compromised psychological well-being, of HIV-infected older adults can be addressed.

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