Caregiving and Caregivers

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Remarkable strides have been made in the treatment of HIV/AIDS, yet a considerable proportion of those infected with the virus may continue to require care. Those with cognitive deficits, those aging into a second decade of HIV infection, and those struggling with debilitating physical and mental symptoms may need at home caregiving. Since its inception, AIDS caregivers have provided physical, mental, and spiritual support to the infected. As AIDS was first identified the majority of caregivers were young, white, gay males who were largely unprepared to provide care for a young, terminally ill partner or friend. Today, HIV is increasingly a chronic disease of the disenfranchised: the poor, especially women and men of color, injection drug users, sex workers, the homeless, the young, and those approaching their senior years. Paralleling changes in the HIV infected are changes in the face of AIDS caregivers. Caregivers are a diverse group of people with varied perceptions and experiences of caregiving. Yet even under the best of all possible circumstances, there is one factor which binds them together: the stress of caregiving for a person with AIDS is often experienced as being burdensome at some level. Whether caregiving burden is perceived to be largely a physical burden, a psychological burden, or both and what mediates the burdensome experience depends on a number of factors. Even when the amount of burden reported differs across caregiver group, the common sequelae of caregiving for a person with AIDS are often physical health problems and depression.

Caregivers continue to provide a valuable service. As AIDS care has moved to home-based care and health care costs persistently rise, the significance of informal systems of care becomes commensurately greater. This entry examines the needs of a diversity of HIV caregivers and targets recommendations for each caregivers group on methods of increasing caregiver well-being.

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S. Loue (ed.), *Mental Health Practitioner's Guide to HIV/AIDS*,
DOI 10.1007/978-1-4614-5283-6_15,

Differences in the Stress Process and Experience of Burden

Generally, stress is experienced both on physical and psychological levels. Objective burden is conceptualized as the strain resulting from direct negotiation of situational stressors, including the demands of the physical activities required in the caretaking process (e.g., bathing and feeding the care recipient). Subjective burden is conceptualized as the emotional/experiential appraisal of caregiving such as feeling entrapped by the tasks required, feeling anxious or depressed about what the future holds for the ill family member, and the additional conflicts between family members secondary to the strain of caretaking. Moreover, findings indicate that the cultural background of the caregiver greatly influences the appraisal of burden, in addition to stressful events, use of support, and coping behaviors. Investigations suggest that differences in the quantity of burden a caregiver reports is associated with ethnicity or racial culture. Importantly, the experience of burden varies with caregiver characteristics including relationship to the person with AIDS, residence of the care giver, the ethnic or racial and cultural background of the caregiver, religious and spiritual involvement, the number of years in providing care, age of both the caregiver and the recipient, and the physical health status of both. Recent studies suggest that caregiving is indeed experienced in diverse ways; thus we must first understand the experience if we are to provide support for diverse groups of caregivers.

A Closer Perspective of AIDS Caregivers: A Varied Group with Varied Needs

Gay Men

Most scientific information on AIDS caregiving is available on gay male caregivers as men who have sex with men were the first to receive highly active antiretroviral therapy (HAART) and move from hospital care to home. Along with this shift in care came the needs for caregiving. With HIV viral loads reduced for countless numbers, many gained a renewed life; others with HIV continued to experienced decline or debilitating side effects from medication including insulin resistance, elevated triglycerides with increased risk of heart attack, and heightened risk of bone fractures and avascular necrosis due to corticosteroid therapy. The need for hip and knee replacements became more likely. For this group, because illness associated with aging is showing up earlier than expected in peer cohorts, assistance with activities of daily living (ADLs) is often required. Other symptoms of aging with HIV include memory and cognitive deficits, and liver and kidney disease. These are conditions that may be experienced as especially burdensome for caregivers.

Caregivers for this group largely consist of aging gay men experiencing episodes of severe depression that are associated with objective burden: the direct tasks of caregiving such as bathing, toileting, managing problematic behavior, and cognitive impairments. In fact, male caregivers seem to be more vulnerable to feeling overloaded in their caregiving roles than do other groups, perhaps because they are less socialized to perform such tasks. In fact, among these caregivers vulnerability to depression rises as ecological factors such as younger caregiver age, lower income, lower educational level, and unemployment increase. Other factors impacting depression may include internalized homophobia and HIV-related stigma. Moreover, it likely that this group of caregivers has experienced sustained multiple HIV-related losses which can result in a potent prescription for depression. Yet for others with dispositional optimism who cope by viewing everyday as a gift of life to savor, resiliency to stress is more readily at hand. Other conditions which appear to buffer stress in this group of caregivers include higher feelings of self worth, stronger sense of mastery over life, and an active coping styles. Among those caregivers who are themselves HIV-positive, family support can play a cardinal role in lowering stress and depression.

Today, middle-aged and older partners and male friends of men who have sex with men continue to provide care to the HIV infected who have aged into their middle and senior years. Service providers will need to assess the specific type of burden experienced by this group of caregivers. Objective burdens often respond to increased caregiving resources such as housekeeping services and respite care. Depression treatment including medication evaluation may be necessary. Support groups in the gay community are readily available and can be quite effective in increasing sense of control and empowerment.

Women as Caregivers

Women have provided caregiving for people with AIDS since the beginning of the pandemic. Commonly, working class and poor women of color now assume the bulwark of caregiving. Such women may be wives, mothers, sisters, and in-laws of those requiring care. Even female adolescents and pre-teens provide a portion of AIDS caregiving to disabled mothers and fathers.

Female AIDS caregivers dedicate an extensive portion of their lives to all manner of caregiving: to their families including children, partners, parents, and in-laws in addition to caregiving for a person affected by HIV/AIDS. Research findings reveal that about half of these women are themselves infected and are caring for others with HIV, thus resulting in multiple caregiving responsibilities for people of all ages. Female caregivers of color are a very diverse group. The majority is Latina from diverse cultures including the Caribbean, Central and South America, or they are of African-American heritage. While HIV in Asian populations is growing, Asian female informal caregivers continue to be fewer in number in the USA and Canada. It is paramount for service providers to assess cultural values with Latin cultural groups as those whose ethnic origin is the Caribbean may hold distinct values from those of Central or South America. Migration history is important to assess and particularly recency of arrival to the USA as acculturative stress may profoundly impact the burden experienced in caregiving.

Latina Caregivers. Particularly in Latino communities where cultural gender role expectations are strong women comprise the great majority of AIDS caregiving. Especially for the newly immigrated, the caregiving experience may be more burdensome than for other groups. Latina AIDS caregivers may be coping with the stress of acculturation and they may be monolingual Spanish-speaking. Therefore, they may lack knowledge of medical and social service resources, and importantly, few may exist in their neighborhoods and even fewer with cultural values parallel to their own. Moreover, this group of caregivers likely ended their compulsory education at grade eight, and they may have arrived in the USA from rural areas where a complex bureaucratic system of medical care and associated medical regimens simply do not exist. In spite of this situation, research findings indicate that family members and caregivers themselves view outside social service support as unnecessary, intrusive, and insensitive to family needs. Hence, these caregivers may be reluctant to seek outside help or early care for their own illnesses. In addition, those who are undocumented may fear being deported. Those who are seropositive likely were infected through heterosexual contact with an injecting drug user, through use of unsterile injecting equipment used for culturally prescribed medical treatment, or more commonly, through sexual contact with a man who had unprotected sex with another man. Often their serostatus goes undetected until a prenatal appointment reveals a high viral load. For these women, being seropositive is simply one condition among other chronic illnesses including diabetes, asthma, heart disease, and hypertension, all of which may culminate in physical depletion and impair caregiving responsibilities. Often, it is common in Latina cultures to put the needs of others ahead of one's own (*simpatía*) and to be long suffering in the face of stress in imitation of the Virgin Mary (*Marianismo*). In addition, religious coping such as *mandas* (rituals of sacrifice such as hair cutting) are customary.

Literature reveals that the stress process differs for this group of caregivers. Major life events such as being forced to move from one's home also have been implicated in the stress process. Moreover, due to HIV stigma it is quite likely that many women involved in AIDS caregiving lack a confidant(e), even within the family, who is aware of the particulars of their situation including the HIV status of themselves and the care recipient. To be an effective caregiver, they must care for a sick relative, facilitate required services often within a complex urban environment, understand the care plan, and maintain adequate health to care for others in the family.

In light of these circumstances, it is not surprising that these women face a powerful stress process. Despite heavy caregiving responsibilities, few report objective burden due to direct caregiving. Instead, in combination with poor health and major life events, it is the management of cognitive difficulties with the care recipient, feeling trapped and isolated in the caregiving role, and poor self esteem which predict poorer mental health for Latina AIDS caregivers. In addition, anxiety due to low adherence behaviors in others has been frequently cited.

Implications for service call for a multipronged approach to meet both physical and mental health needs. Advances in service call for culturally appropriate service plans. Health promoters (*promotoras*) who are indigenous to the community may succeed in providing support, education, and limiting psychological burdens for this caregiver group. Moreover, they may succeed in influencing belief systems that affect stigma and guilt surrounding HIV. Because religious and spiritual coping is likely to be strong, service providers may include spiritually based interventions such as prayer and meditation, which may be efficacious as affect regulators. In addition a Spanish speaking telephone buddy who may be called on for advice and support may be useful. It is unlikely that services such as support groups which require additional time commitment and are externally based would provide needed assistance. However, a cooperative caregiving service including a church-based or community-based approach to support is likely to be effective in reducing caregiving burden.

African-American Women. African-American female AIDS caregivers are a very diverse group. They are older women caring for adult daughters with HIV, young women caring for children whose health is compromised by HIV, and women caring for partners. Others may include adolescents caring for infected parents. Both professionally and informally, African-American women have long provided care for others in this country. Literature suggests that informal caregiving is largely culturally normative among African-Americans compared to other US-born populations. These women are a strong resource in their community and often lead lives of self-sacrifice and dedication caregiving for multiple family members in more than one generation. They are often of lower socioeconomic status, have greater disease burden, and have lower life expectancies than other cohorts of HIV caregivers.

There are many interacting circumstances which make caregiving especially challenging for this group. First, drug use and increased incarceration of drug offenders in African-American communities have fueled infection rates due to HIV. Prevalence rates of HIV among African-American men who have sex with men is very high. Moreover, in many communities those who are HIV-negative may harbor homophobic reactions resulting in substantial stigmatization of HIV-positive men and their caregivers. Further, the African-American church is not seen as a resource for the HIV-infected; hence, it plays less of a central role in addressing social welfare needs of the community of infected and their caregivers. Such is the case in large part due to stigma surrounding HIV transmission methods. Thus, HIV lives underground in many African-American communities, present yet absent in acknowledgment of its damage.

Impacting caregiving is the status for whom caregivers provide care. African-American women are at high risk for disease transmission primarily due to drug use and secondarily due to unprotected sexual activity with an HIV infected partner. Importantly, disproportionate drug use and competing subsistence needs among African-Americans contribute to lower access to HIV treatment. Moreover, economic costs for HIV medical care for injection drug users are greater due to their commensurately greater use of hospital services. Drug and alcohol use may follow with the increased need to regulate emotional responses due to these realities. Not surprisingly, use of substances may result in injurious outcomes for those who are seropositive. These factors set a background against which HIV care giving plays out. In the context of little access to formal medical care, informal care needs may be especially great. The culmination of these influences compound the complexity of caregiving for African-American female caregivers.

In the majority, HIV-positive African-American women are likely to be low income single parents who are unemployed and/or receive public assistance. The need to provide care to others presents an overwhelming demand on scarce resources. Unfortunately, these are women who are at very high risk for a number of reasons. They are more likely than other HIV-positive women to be at risk for substance abuse and subsistence sex work. Other sources suggest that alcohol is used as a method for self medication among African-American women and especially in those caregivers who have access to fewer resources and great childcare and family responsibilities. Moreover, such women are more likely than men with alcohol problems to experience depression and anxiety. Considerable evidence also documents that rates of heavy drinking and drug use are higher among people living with HIV/AIDS and their caregivers and specifically higher among African-American HIV-positive women with lower incomes and lower levels of education who are caregiving than among other seropositive caregivers. In fact, study findings report that of African-American female caregivers who provide primary support of the people with AIDS, 26% were current drug users, 6% reported drinking daily, a majority were living below the poverty line (54%), and nearly a quarter of these women were HIV positive. Because alcohol use among people with HIV/AIDS is associated with behavioral issues related to the treatment and management of HIV disease, these caregivers have diminished chances of being prescribed antiretroviral treatment (HAART). For those who do receive HAART, heavy alcohol use is associated with higher HIV (RNA) levels and lower CD4 counts, indicating reduced efficacy of treatments. In addition to impacting the effectiveness of these medications, heavy drinking has been shown to amplify the toxicity of HIV medications. These findings have substantial implications both for many African-American HIV-infected female caregivers and the person for whom they provide care. Of great concern, these women often experience late diagnosis and treatment of their HIV illness. They are disproportionately impacted by histories of physical and sexual abuse, and both emotional and physical abuse in their adult intimate relationships. Depression and other mental health problems are implicated as outcomes.

There are multiple implications for caregiver services targeted for this group. Economic and structural supports such as financial help, housing, and child care are crucial. In addition, there is the clear need for advocacy in the area of medical treatment for HIV and, if needed, substance abuse treatment. Depression screening and treatment may also be required. These services should be gender-sensitive and focus on the needs of the African-American female experience. The history of caregiving among women of African-American heritage is long and strong. Programs must be designed to be relevant to these women who have cared for others across the generations.

Non-Hispanic White Women. Investigations indicate that Non-Hispanic White female AIDS caregivers differ substantially from their sisters of color. Most have attained high levels of education, have medical insurance, are HIV seronegative, and are caring for an adult partner or child with HIV. Moreover, this group of caregivers experiences fewer physical illnesses and has more years AIDS caregiving than other female caregiving groups. Major stressors associated with elevated depression center on subjective burden, such as a feeling of being captive to the caregiving role and a loss of identity to caregiving. Stronger levels of self-esteem appear to mediate this relationship. In addition, White women seek more services for depression than any other group of caregivers which may point to their knowledge of resources and willingness to reach out for help.

For this group of caregivers, efforts such as respite care and support groups may be helpful in decreasing loss of identity and role captivity and increasing social network, self esteem, and supportive psychoeducation. Depression treatment may be assessed and referrals made to appropriate facilities.

Male Primary Caregivers of Children

It is little known that the number of male primary caregivers of children with HIV is substantial in the USA. Fathers, uncles, and grandfathers have taken up where mothers and other female relatives have left off in the primary care of these children. Only about half have some support of a female caregiver.

The majority (75%) are biological fathers and adoptive fathers of the child with AIDS. It is estimated that about 10% of these men are caring for more than one HIV-infected child and about half have other children in the home for whom they provide care. A large percentage of these invisible caregivers are African-American (58%) and Latinos (23%) caring for children with AIDS between the ages of 5 and 12 years. These men of color suffer from particular issues related to gender and racial discrimination with service agencies. For example, African-American men are the bearers of many negative stereotypes, most commonly the absentee father. As a result, medical and service providers may hold prejudices concerning the father's skill level for setting limits with children, or believe that they are limited in caring for or communicating with a sick child. Fathers may face challenges in terms of custodial rights to their children, thus complicating their fathering and caregiving responsibilities. Social service agencies may investigate and evaluate these fathers in a way that mothers do not have to endure. Plans for foster care placement for these children may surface without adequate assessment of the family status. Interrogations by medical and service providers and school personnel involved in the child's life may be experienced by male primary caregivers as shaming, intrusive, hostile, and emotionally exhausting. About a quarter of all male primary caregivers are estimated to be HIV-infected themselves and thus may have diminished energy for these external demands.

Such children, many of whom are HIV-infected, grow up with significant physical, developmental, and emotional problems. Hence, parenting these children poses a compelling challenge. Most male primary caregivers live alone with one or more children and have only sporadic instrumental or emotional support from friends and relatives on which to rely. Moreover, both child and father are likely to be actively grieving from the loss of the female relationship presence in the home. Because the bereavement process itself is experienced as depressing and enervating, caregiving resilience is likely to be inhibited. In addition, because children of different ages grieve differently, the father must have a repertoire of varying responses to the emotional needs of his children during this most complicated time. Anxiety surrounding how they will raise their children in the absence of their spousal support may be present. Those men with jobs face particular challenges with caregiver-job role strain as they must negotiate whether to go to work or stay at home with a sick child, or whether to reduce their work load hours or quit their jobs. Reduced hours and unemployment inevitably have an impact as financial obligations escalate, especially during economically challenging times. Given both internal and external stress, it is easy to understand why fathers are reluctant to access services and may be hesitant to provide information about their needs to service providers. Such circumstances may culminate in a sequence of mounting needs with few supports to meet them.

It is paramount for service providers to make time to build strong rapport and a working alliance with these caregivers. One is to inquire about the father's perception of need in the assessment. Service providers succeed when a strengths model is used. An alliance between client and provider is sustained when the client's own words can be accessed and repeated back to empower, sustain, and to continue on as head of their household. Concomitantly, service providers may assist in coaching and supporting fathers with this multilayered complex situation.

Grandparents and Other Older Relatives

Grandparents have been caregivers of their grandchildren for generations prior to the AIDS pandemic. Particularly in African-American and Latino communities, grandmothers have played a vital role in the family system, supporting parents who worked several jobs, or assuming the entire responsibility for child rearing where parents were unable to do so.

In the presence of AIDS, grandparents are a foundation for many children orphaned by the disease. Here, the conjugal picture involves a family system that may be extended to the utmost as aging grandparents care for young children when they themselves may require care.

Stress for these caregivers begins to proliferate as abridged energies in this group of senior caregivers inexorably confronts the needs of children who may be sick due to HIV infection, or who have been bereaved. The manifold needs of children coupled with the needs of the caregiver must be recognized. If the child is HIV-positive, the grandparent may grow to be anxious about medication regimen and overall health maintenance issues. Such ongoing stress can be extremely compromising.

A major stressor for this group of caregivers revolves around emotional and behavioral issues of grandchildren. At times, grandparents are caring for both their own offspring and grandchild. Bereaved children present a challenging set of circumstances even under ideal conditions. It is likely that these children have had to undergo several residential relocations, they have changed schools, they have lost a major attachment with their primary caregiver, and sometimes, they are sick themselves. Disruption in stability may result in behavioral problems. Grandparents have described externalizing behaviors as major caregiving concerns. Health concerns for this group are also significant should the grandparent need to go to the hospital or become ill themselves.

Such an intricate care situation presents challenges in service provision. Caregiver needs may include both physical and psychological care associated with their stressors. As with other caregivers, depression is a frequent occurrence and should be addressed. Moreover, given the tendency of these caregivers, mostly women, to put the needs of their grandchildren ahead of their own, service providers must take special consideration to inquire about caregiver well-being and needed services. A psychoeducational approach which encompasses sensitivity and knowledge of their unique situation coupled with education about available community services is a starting place. More definitively, caregiver grandparents may benefit from telephone support groups, stress management training, and case management for the multiple needs of all family members.

Conclusion

In their daily lives, many caregivers endure continuous fatigue, chronic substantial stress and illness, lasting depression and rely on few resources. Many face poverty; nearly all face stigma. Despite these conditions, countless AIDS caregivers report a sense of gain from HIV caregiving, more so than do caregivers coping with other illnesses. Those who fare better seem to adopt an attitude of having control over the role that HIV has in life, thus putting the virus in perspective. Getting involved in HIV/AIDS work outside the immediate caregiving relationship seems to increase feelings of empowerment and altruism for some groups. Others describe heightened intimacy within the caregiving relationship. A sense of personal gain and purpose may take different expressions for varying caregiver groups. Other beneficial themes evident in the caregiving literature involve personal growth and positive personality changes, increased understanding of others and their illnesses, a sense of satisfaction and achievement, and gained perspective in life.

Each group of caregivers presents a distinctive set of conditions that necessitate service providers to, in a sense, be cognizant of all major groups affected by HIV disease. Such is the case as caregivers are representatives from these groups. They are gay men, women, single fathers, the aging, and grandparents. They are Latino/a, African-American, and Caucasian. Some are better off economically but most face poverty and the enormous odds of living in neighborhoods ravaged by drugs, violence, and stigma. Some have better capacities to access resources, others have very few resources available to meet their own needs, let alone the needs of the HIV-infected. Some caregivers are addicted, some fear leaving children or partners behind. Many are bereaved. A multitude of uncertainties lives in the lives of AIDS caregivers; one issue is definite: caregivers are prodigious in their commitment to those for whom they provide care.

Related Topics: Coping, social support.

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