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Preferences for Professional vs. Informal Care at End of Life Amongst African American Drug Users with HIV/AIDS

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Abstract

Introduction—With the advent of antiretroviral therapies (ART), persons living with HIV/AIDS (PLHIVs) are living longer, but with increased impairment and care needs. The purpose of this study was to assess whether a vulnerable population of PLHIVs preferred informal versus professional care when unable to care for themselves, and individual and support network factors associated with preference for informal care. The findings have potential implications for facilitating the population's informal care at end of life.

Method—Data were from the BEACON study, which examined social factors associated with health outcomes among former or current drug using PLHIVs in Baltimore, Maryland. Structural equation modeling was used to identify individual and support network characteristics associated with PLHIVs' preference for informal (family or friends) compared to professional care.

Results—The structural equation model indicated preference for informal care was associated with female sex, greater informal care receipt, reporting one's main partner (i.e., boy/girlfriend, spouse) as the primary source of informal care, and a support network comprised of greater numbers of female kin and persons supportive of the participant's HIV treatment adherence. Not asking for needed help to avoid owing favors was associated with preferring professional care.

Discussion—Findings suggest that interventions to promote informal end of life care should bolster supportive others' resources and skills for care provision and treatment adherence support, and should address perceived norms of reciprocity. Such intervention will help ensure community caregiving in a population with high needs for long term care.

Keywords

End of life care; HIV/AIDS; informal caregivers; illicit drug users; social support networks

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Declaration of Conflicting Interests

None

INTRODUCTION

With the advent of antiretroviral therapies (ART), persons living with HIV/AIDS (PLHIVs) are living longer, but with growing levels of impairment, and need for informal (unpaid) care from family or friends. African Americans, compared to other racial/ethnic groups have disproportionately high rates of HIV/AIDS and, among PLHIV, have higher levels of injection drug use, HIV morbidity and mortality, and informal care needs (Santibanez et al., 2006; Knowlton, Hua, & Latkin, 2005). While African Americans generally provide higher levels and more intensive forms of informal care, including for HIV/AIDS, drug-using communities most severely impacted by HIV/AIDS may have more challenges accessing and maintaining caregiving relationships (Johnston, Stall, & Smith, 1995; Purcell et al., 2004).

Drug using PLHIVs' possible dearth of support network members or social ties available to provide care may affect their expectations of informal care (Santibanez et al., 2006). However, PLHIVs currently receiving informal care may be more likely to perceive availability of informal care at end of life. Nonetheless, PLHIVs' active drug use may strain their main supportive ties (Morris, Golub, Mehta, Jacobson, & Gange, 2007; Kong, Nahata, Lacombe, Seiber, & Balrishnan, 2012). Consequently, their willingness to mobilize informal care may be impeded, and they may have low perceptions of care availability at end of life. Moreover, many PLHIVs, males in particular, may espouse self-sufficiency and reluctance to accept care from friends or family, which may be perceived as incurring indebtedness (Stumbo, Wrubel, & Johnson, 2011).

In the present study, we examined characteristics of individual PLHIVs, their support networks, and their main supportive ties that were associated with their preference for end of life care from partners, family or friends as compared to professionals. Specifically, we assessed preferences for receiving end of life care from family or friends versus professionals, and sought to identify factors of their informal caregiver, support network, and demographics associated with such preference.

METHODS

Procedure

Data were from baseline of the BEACON (Being Active and Connected) study, which examined social environmental factors associated with physical and mental health outcomes, and ART adherence among disadvantaged persons living with HIV in Baltimore, Maryland (Mitchell, Robinson, Wolff, & Knowlton, 2014). Participants comprised a convenience sample recruited from clinic and community venues (N = 383). Data were collected using a combination of interviewer-administered and Audio Computer-Assisted Self-Interviews conducted at the study offices in Baltimore, MD from 2008–2012. Selection criteria included being an HIV seropositive adult, former or current injection drug use, taking ART, Baltimore City residence, and being willing to invite one's main supportive tie(s) to participate in the study. Caregivers were selected based on criteria of PLHIV care recipient report of s/he having provided the recipient general emotional or instrumental assistance and health-related assistance in the prior six months, and the recipient having authorized the

caregivers' recruitment to the study. Caregiver exclusion criteria included providing care to the recipient in a professional (paid) capacity. The study on which this manuscript is based is fully approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (#248). All caregivers and care recipients, including those with and without participating caregivers, completed informed consent.

Measures

The survey utilized a combination of items including outcome and predictor measures. Participants were also asked to complete demographic data such as sex, age, main supporter relationship (e.g., one's partner, kin, or friend), current substance use (drug use in prior 6 months or hazardous alcohol use in previous 30 days), and depressive symptoms CES-D (Radloff, 1977). The outcome measure was agreement with an item created for the BEACON study, "If you were sick and couldn't care for yourself, you would want to have a professional like a doctor, nurse, or home health aide to assist you rather than family or friends." Predictors included items from a support network inventory (Barrera, 1981), and assessed the number of support network members who believed it was important for the PLHIV to take HIV medications, could provide the PLHIV emotional support, and the proportion of network members who were the participant's female kin. Health assistance was measured by eight items such as, "Has anyone brought or prepared food or cleaned for you?" (Pearlin, et al., 1994). Physical limitation was measured by limitations in activities of daily living (Lawton & Brody, 1969). Not wanting to owe favors was measured by a yes/no item created for the BEACON study, "Often I don't ask for help when I need it because I don't want to owe favors to people."

Analyses—Uni- and bi-variate statistics were generated. Next, exploratory factor analysis for latent constructs (e.g. physical functioning limitations, health assistance) was completed. The outcome, preference for family care, and other independent variables of interest (e.g. sex, not wanting to owe favors, proportion of female kin in their network) were entered into a structural equation model (SEM) using Mplus Version 7.0 (Muthén & Muthén, 2009).

RESULTS

The majority of the 383 PLHIVs were low income African Americans, earned less than \$1,000 per month, and believed in not asking for help so as not to owe favors (Table 1). Slightly less than half (47.0%) indicated that if they could no longer care for themselves, they would rather receive care from family or friends than a professional.

Unadjusted odds ratios indicated care recipients who were female, had more education, received more health assistance, had a partner as their main supporter, had larger support networks, a greater proportion of female kin in their networks and more network members who believed it was important to take HIV medications, had increased odds of preferring family care over professional care. Older care recipients and those who indicated they did not want to ask for help, had reduced odds of wanting family care compared to professional care.

Females were more likely to prefer family care, as were those with a main partner as their caregiver, and those who received health-related assistance from network members (Figure 1). The strongest positive predictors, as evidenced by the largest standardized coefficients, included having more network members who felt it was important to take HIV medications and having a greater percentage of female kin in their network. Care recipients who did not want to ask for help because they did not want to owe favors were less likely to prefer family care.

DISCUSSION

More than half (53%) of the respondents indicated they preferred professional rather than family care at end of life. This finding supports previous research which found that African Americans, compared to Whites, wanted life-sustaining treatments and preferred to die in a hospital rather than receiving palliative care at home (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009). The reduced use of hospice by minority patients is complex and includes different end of life care preferences, lack of information, mistrust of the health care system, emphasis on personal resilience and spirituality, and lack of access in the minority community (Wicher & Meeker, 2012; Reese, Smith, Butler, Shrestha, & Erwin, 2013). Possibly, these PLHIVs felt they would be a burden to their family members, which could produce feelings of indebtedness. Also, these individuals may have had weaker ties to their network members. Receiving care from family and friends is likely more feasible in this population of disadvantaged PLHIVs and often critical for ensuring life quality at end stage illness.

Female PLHIVs were more likely to prefer family care compared to males. This may be due to females being more successful in actively mobilizing caregiving relationships and providing caregiving is a traditionally female sex role. Therefore, they may perceive greater ability to draw on informal care for themselves when needed, while males tend to prefer independence. Cultural norms of self-sufficiency, especially among males, may compel some persons to avoid relying on others for help (Stumbo, Wrubel, & Johnson, 2011). Therefore, intervening with males in this context may be especially important to ensure their access to community care when needed.

As found in prior studies, having greater levels of health-related assistance from social network members, such as assisting with their medication regimen, may increase the likelihood of PLHIVs' preference for family care rather than professional care (Mosack & Petroll, 2009). These PLHIVs may have stronger support network ties. In turn, having stronger relationships may enable PLHIVs to feel more comfortable and less burdensome by relying on their network members for needed help. Also, we found that the proportion of female kin in the support network was positively associated with preference for family care (World Health Organization, 2009). Prior research indicates that informal caregiving is a normative role of female kin, especially older female kin (Wolff & Kasper, 2006). Therefore, PLHIVs who have greater support from female kin may feel their care would be less of a burden to these caregivers compared to other family or friends. In our study, PLHIVs with main partners as informal caregivers were more likely to prefer family care than professional care. This suggests that, similarly for female kin, informal caregiving is

normative for main partners and thus perceived as less burdensome. However, findings from our previous research indicated that women had unmet expectations of informal HIV care from main partners with 53% indicating they most preferred their main partner provide them with HIV care, but only 35% reported their partner was actually the main person providing care (Knowlton et al., 2011).

Due to reciprocity norms, PLHIVs may not want to ask for help to avoid owing favors. Intervention is needed to address potential ways to feasibly reciprocate support (e.g., acknowledgment and displays of affection or gratitude) as a way of maintaining a sense of autonomy and independence. Also, support network members need to be involved in PLHIVs treatment in order to promote the caregiving role and continuity of care.

Limitations

Because the data were cross-sectional, definitive conclusions cannot be made regarding cause and effect. Also, findings may be an underestimation of informal care availability and preference in the study population as the sample was recruited primarily from a medical clinic and selection criteria included being on HIV medication and willing to invite a main supporter to the study.

Conclusions

The results suggest that interventions to promote informal caregiving for this population should bolster supportive others' resources and skills for care provision, especially among males, and persons with less care from a main partner or female kin. Building relationships between PLHIVs and their family and other caregivers could benefit PLHIVs by expanding the number of people who could reasonably provide care for them. Overall, our results suggest that interventions that focus on strengthening the relationships between PLHIVs and their caregivers have the potential to increase the preference for end of life family caregiving, which would help ensure care at the end of life in a population with high needs for long term care and possible challenges obtaining or accepting needed informal care.

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Figure 1.

Predictors of preference for informal (family or friend) care vs. professional care. (N = 383).

Solid lines indicate significant paths at $p < .05$. Dotted lines indicate non-significant paths.

All factor indicators were significant at $p < .05$.

Confirmatory factor analysis (CFA) on the physical functioning limitation items had adequate fit (Comparative Fit Index (CFI) of 1.00, a Root Mean Square Error of Approximation (RMSEA) of .10, and a Standardized Root Mean Square Residual (SRMR) of .06. CFA for the health assistance model indicated adequate model fit (CFI = .98, RMSEA = .08, and SRMR = .07). The complete model fit statistics (CFI = .95, RMSEA = .06) indicated good fit (Hu & Bentler, 1999).

Regression estimates are standardized coefficients produced by the weighted least squares mean and variance adjusted estimator produced by Mplus 7.0.

Table 1

Individual level and support network characteristics associated with preference for informal vs. professional care at end of life among former or current injection drug using persons with HIV/AIDS (Beacon study; Baltimore, MD; N=383).

	N (%)	Mean (SD) ^a	Unadjusted Odds Ratio	95% CI ^b
Individual Level Characteristics				
Sex (Female)	148 (38.6)		2.08***	1.37, 3.16
Ethnicity (African American/Black)	329 (85.9)		1.34	.75, 2.41
Age (years)		48.2 (6.3)	.96*	.93, .99
Education (high school diploma/GED or more)	207 (54.0)		1.58*	1.05, 2.36
Income (<1,000 per month)	306 (79.9)		1.09	.86, 1.38
Current substance use	148 (38.8)		1.78	.78, 1.78
Depressive symptoms (16+ on CESD scale) ^c	155 (40.5)		.71	.47, 1.07
Physical functioning limitations	NA		1.00	.92, 1.09
Does not want to owe favors	247 (64.5)		.38***	.24, .58
Support Network Level Characteristics				
Main supporter relationship (Partner)	121 (31.6)		1.72*	1.11, 2.65
Health Assistance	NA		1.24***	1.11, 1.38
No. of total network members		6.7 (3.2)	1.14***	1.06, 1.22
No. of network members who could give material support		2.2 (1.2)	1.02	.87, 1.18
Network members supportive of PLHIV's HIV treatment, no. of		5.2 (3.2)	1.15***	1.08, 1.23
Female kin in network, proportion of		30.6 (20.2)	1.02***	1.01, 1.03

* $p < .05$,

** $p < .01$,

*** $p < .001$

^aSD = Standard Deviation

^bCI = Confidence Interval

^cCESD = Center for Epidemiologic Studies Depression Scale