Brief Report

Support Network Factors Associated With Naming a Health Care Decision-Maker and Talking About Advance Care Planning Among People Living With HIV

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Abstract

Context. Little attention has been given to social environmental factors associated with advance care planning (ACP) among African Americans or people living with advanced HIV (PLHIV).

Objectives. The present study aimed to identify support network factors that affect the likelihood of naming a decision-maker and of talking to family/friends and doctors about ACP among vulnerable PLHIV.

Methods. PLHIV were recruited from a large urban HIV clinic. A social support network inventory was used to calculate number of persons available for various types of support. Characteristics of network members were also collected. Multivariable logistic regression models were fit to examine associations between social network factors and ACP discussion, adjusting for age, sex, education, and total number of network members.

Results. The sample ($N = 370$) was mostly African American (95%), male (56%), and 48% had less than a high school education. Almost half the sample (48%) had talked to their family/friends or doctor about ACP, and 34% had named a medical decision-maker. Adjusted analysis revealed that talking about ACP with family/friends was associated with female sex and a larger closer support network who provided health information and physical assistance. Talking to doctors about ACP was associated with larger support networks who provided physical assistance but lower numbers from whom emotional support was received. Naming a decision-maker was associated with greater numbers of network members who provided emotional support, health information, and medication adherence reminders.

Conclusion. The findings revealed aspects of family/support network structures and caregiving function associated with ACP in a population with often vital yet vulnerable networks. J Pain Symptom Manage 2019;58:1040–1047. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Support network, HIV/AIDS, advance care planning, naming decision-maker, family or informal caregiver, African American or black, palliative care

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Introduction

Palliative care is relevant to people living with HIV/AIDS (PLHIV), especially if the person lacks access to organized health care and has multimorbidities that contribute to greater utilization of acute care services and intensive treatments. The role of social support network in dealing with a crisis has been described.[1] However, little attention has been given to the role of the social support networks among African American PLHIV. Social support networks can be defined as people who provide specified types of support to an individual; network members are thus defined by supportive functions of ties more than role relation.[2] Social support refers to the psychological and material resources provided by a social network to help individuals cope with stress. Poor social support has been linked to depression[3,4] and adherence to HIV treatment.[5] Research suggests that people available for caregiving within a community and the care they provide are linked to the community context. For instance, informal care was sought by PLHIV from an array of available sources, both kin and nonkin, within and outside their household. It is possible that this finding may be explained by difficulties this population faces in accessing formal care services.[2,6]

Social support association with HIV medical outcomes is mixed.[7–9] Among those with informal care, greater reciprocity of support with caregivers was associated with greater medication adherence.[10] Furthermore, advance care planning (ACP) discussion was correlated with including supporters in health decisions, religious attendance, and knowledge of health care mandates preferences (ever hearing of Medical Orders for Life-Sustaining Treatment form or advanced directives).[11] ACP is the process of communication and planning for when individuals cannot make their own health care decisions; this includes documentation of advance directives, living wills, and/or palliative care to improve quality of life at the end of life.[12] ACP discussion is crucial in this population because most African American PLHIV have high rates of comorbidity and a strong desire for life-sustaining treatments and living as long as possible.[11] Moreover, there is literature suggesting that ACP discussion is more important than completion of ACP documents[13,14] and, despite completion, the care delivered is sometimes not concordant with patient preferences.[15]

The present study aims to identify support network factors that may affect the likelihood of naming a decision-maker and of talking to family or friends and doctors about ACP among PLHIV recruited from a large urban HIV clinic. The hypothesis is that several variables measuring types of social support and characteristics of network members would be associated with rates of ACP discussion.

Methods

Study Design and Participants

The research was conducted as a mixed-methods longitudinal study (Affirm Care study) of African American PLHIV and their caregivers who participated in three semiannual surveys of 60–90 minutes administered by computer-assisted personal interview. Data analyzed in this research were part of the Affirm Care baseline surveys collected from 2014 to 2016 that examined social and environmental factors associated with ACP, health outcomes, and well-being among PLHIV and their informal caregiver. Care recipients were recruited from a Baltimore HIV clinic and several other Baltimore-area community venues. Inclusion criteria included age 18 years or older, documented HIV seropositive, being either a current drug user or a former drug user (e.g., cocaine, heroin, or stimulants), and being willing to invite one's main supportive tie(s) to participate in the study. The study was approved by the Johns Hopkins University Bloomberg School of Public Health Institutional Review Board, and PLHIV completed consent forms before study participation.

Measures

Outcomes. The outcome variable of naming decision-maker was a single yes/no item that asked, "Have you ever been asked to name a medical decision-maker or signed a document naming such a person?" The outcome variables of ACP discussion were two yes/no items that asked, "Have you ever talked with your family or friends about what medical treatments you would want if you were not able to make decisions for yourself?" and "Have you ever talked with your doctor about medical treatments you would want if you were not able to make decisions for yourself?"

Independent Variables. A social support network inventory was used to calculate numbers of persons perceived available for various types of support and persons from whom support was received.[16,17] The support network inventory was a modified version of the Arizona Social Support Inventory.[16] We have found the inventory (alpha 0.85) to have adequate predictive and concurrent validity.[17,18] Participants were asked name-generating questions for eliciting a list of individuals whom they could go to for each type of support (*perceived support network*) and whom they actually did receive support from (*enacted support network*) in the past six months. Types of *social support* included emotional, financial (material aid), informational (health information or advice), and instrumental (physical assistance, e.g., assistance with mobility or transportation). *Network characteristics* included structural (e.g., number of ties or closeness to participant in a scale 1–10), functional (e.g., a person who remind you about medication adherence), and relational (attributes of network members, e.g., sex, HIV status knowledge) aspects.[19]

Sociodemographic characteristics, including age, sex (female/male), education, ethnicity, income, function limitation (two items from health-related quality of life questionnaire[20] pertaining to difficulty in doing moderate activity and climbing stairs where 0 = no limitation; 1 = yes, limited a little; and 2 = yes, limited a lot), general health status (dichotomize item that asked participants to rate general health into excellent/very good/good and fair/poor), marital and relationship statuses, the presence of main partner, current illicit drug use, depression (scored 10+ on Center for Epidemiological Studies–Depression scale[21]), and relationship to caregiver, were collected to examine their association with the dependent variables.

Statistical Analysis

Frequencies and percentages for categorical variables as well as means and SDs for continuous variables were computed using SPSS, version 24 (IBM Corp., Armonk, NY).[22] For each outcome variable, stepwise bivariate logistic regression models were fit for variables of interest to investigate unadjusted odds ratios (ORs). Using backward stepwise technique, independent variables significant at $P = 0.10$ or lower in bivariate analyses and those of theoretical interest were included in adjusted multivariable logistic regression models. The Hosmer-Lemeshow test,[23] likelihood ratio Chi-squared test, and pseudo R^2 statistic were used to assess fit of the adjusted logistic regression models.

Results

Respondents in this sample ($N = 370$) were nearly all African American or black (95%), and less than half were female (44%; Table 1). Approximately half (52%) had at least a high school education, one-third of respondents scored in the probable depression range of the Center for Epidemiological Studies–Depression scale (37%), have poor or fair health status (36%), and more than one-third currently used drugs (40%). Table 1 shows participant characteristics.

Slightly less than half of respondents in the sample (48%) had talked to their family/friends or doctor about ACP and named a medical decision-maker (34%). Respondents had an average of three people in their network of perceived or enacted any type of social support. Subjects had a mean of five (range 1–14) members in their networks, of which in average two were next of kin and three were females who mostly were in the perceived support network (data available on request).

The adjusted multivariable logistic regression analyses showed that participant's female sex was strongly associated with the likelihood of discussing ACP with family and friends in all three models (Table 2). There was higher odds of discussing ACP with family and friends with perceived physical assistance (adjusted odds ratio [aOR] 1.25; 95% CI 1.01, 1.56), enacted health information (aOR 1.38; 95% CI 1.07, 1.80), and increase in average closeness to network (aOR 1.32; 95% CI 1.07, 1.62) after controlling for the covariates. Knowledge of HIV+ status and medication adherence reminders was close to significant in increasing the likelihood of discussing ACP with family/friends. Whereas, the total number of network members was associated with the likelihood of discussing ACP with doctor in all three models. We found higher odds of discussing ACP with doctors with increased physical assistance (aOR 1.40; 95% CI 1.10, 1.78) after controlling for the covariates. The odds of naming a medical decision-maker were found to increase with increased perceived health information (aOR 1.22; 95% CI 1.04, 1.43) and enacted emotional support (aOR 1.48; 95% CI 1.16, 1.88) after controlling for the covariates. We found higher odds of naming a medical decision-maker with increase in medication adherence reminder (aOR 1.30; 95% CI 1.06, 1.60) after controlling for the covariates in

Table 1
Participant Characteristics ($n = 370$)

Background Characteristic	N (%) or Mean ± SD
Male	208 (56)
Age (yrs); mean ± SD (24–67)	52 ± 6.7
African American race/ethnicity	353 (95)
Education: high school or higher	193 (52)
Income: $1000 or more	96 (26)
Current use of heroin or cocaine	145 (39)
Current alcohol use	228 (62)
Married	48 (13)
In a committed relationship	89 (24)
Have a main partner	205 (55)
Poor or fair general health	132 (36)
Depression (10+ on CES-D)	136 (37)
Physical functioning limitation; mean ± SD	1.7 ± 1.3
Relationship with caregiver	
Partner	69 (19)
Kin	217 (61)
Friend	26 (7)
None	44 (12)
Named a medical decision-maker (missing = 1)	126 (34)
Talked to doctors about ACP	145 (39)
Talked to family/friends about ACP	212 (57)

CES-D = Center for Epidemiological Studies–Depression scale; ACP = advance care planning.

Table 2

Unadjusted ORs and AORs (and 95% CI) of Independent Variables Associated With Talking to Family/Friends or Doctors About ACP and Naming Medical Decision-Maker

Variables	Unadjusted ORs (95% CI)	Model 1: Types of Perceived Support	Model 2: Types of Enacted Support	Model 3: Network Characteristic
		AORs[a] (95% CI)		
Outcome: Talking to family/friends about ACP				
Control variables				
Age		0.98 (0.95, 1.01)	0.99 (0.96, 1.02)	0.98 (0.95, 1.02)
Education		1.25 (0.80, 1.94)	1.20 (0.77, 1.87)	1.19 (1.00, 1.32)[b]
Female sex		**2.20 (1.40, 3.45)**[c]	**2.20 (1.40, 3.45)**[c]	**2.17 (1.37, 3.44)**[c]
Total network size (*n*)		1.08 (0.97, 1.20)	**1.11 (1.01, 1.22)**[b]	0.98 (0.82, 1.17)
Could provide emotional support (*n*)	1.29 (1.07, 1.56)[d]			
Could provide material aid (*n*)	1.24 (1.06, 1.46)[d]			
Could provide social participation (*n*)	1.15 (1.01, 1.32)[b]			
Could provide health information (*n*)	1.26 (1.08, 1.48)[d]			
Could provide physical assistance (*n*)	1.39 (1.15, 1.68)[c]	**1.25 (1.01, 1.56)**[b]		
Could provide any type of social support (*n*)	1.20 (1.07, 1.35)[d]			
Did provide emotional support (*n*)	1.44 (1.13, 1.82)[d]			
Did provide material aid (*n*)	1.32 (1.07, 1.63)[d]			
Did provide social participation (*n*)	1.17 (1.00, 1.37)[b]			
Did provide health information (*n*)	1.52 (1.19, 1.96)[d]		**1.38 (1.07, 1.80)**[b]	
Did provide physical assistance (*n*)	1.37 (1.11, 1.69)[d]			
Did provide any type of social support (*n*)	1.25 (1.09, 1.44)[d]			
Kin in could support network (*n*)	1.24 (1.07, 1.43)[d]			
Kin in did support network (*n*)	1.28 (1.08, 1.53)[d]			
Total kin in network (*n*)	1.21 (1.07, 1.36)[d]			
Average closeness to network	1.33 (1.10, 1.61)[d]			**1.32 (1.07, 1.62)**[d]
Remind you of medical care (*n*)	1.40 (1.13, 1.73)[d]			1.24 (0.98, 1.56)[e]
No. of females in network	1.22 (1.08, 1.38)[d]			
No. of females in could support network	1.26 (1.09, 1.46)[d]			
No. of networks know PLHIV is HIV+	1.21 (1.10, 1.3)[c]			1.19 (1.00, 1.42)[b]
Outcome: Talking to doctors about ACP				
Control variables				
Age		0.99 (0.96, 1.02)	1.00 (0.96, 1.03)	0.99 (0.96, 1.02)
Education		0.80 (0.52, 1.25)	0.81 (0.52, 1.26)	0.84 (0.54, 1.30)
Female gender		0.94 (0.60, 1.46)	1.03 (0.65, 1.62)	0.97 (0.62, 1.50)
Total network (*n*)		**1.13 (1.02, 1.25)**[b]	**1.17 (1.06, 1.29)**[d]	**1.19 (1.09, 1.30)**[c]
Could provide emotional support (*n*)	1.16 (0.98, 1.37)[e]			
Could provide material aid (*n*)	1.18 (1.01, 1.36)[b]			
Could provide social participation (*n*)	1.08 (0.95, 1.22)			
Could provide health information (*n*)	1.16 (1.02, 1.32)[b]			
Could provide physical assistance (*n*)	1.33 (1.12, 1.57)[b]	1.20 (0.98, 1.46)[e]		
Could provide any type of social support (*n*)	1.17 (1.05, 1.31)[d]			
Did provide emotional support (*n*)	1.04 (0.86, 1.26)		**0.74 (0.56, 0.97)**[b]	
Did provide material aid (*n*)	1.12 (0.93, 1.34)			
Did provide social participation (*n*)	1.08 (0.94, 1.23)			
Did provide health information (*n*)	1.15 (0.97, 1.37)			
Did provide physical assistance (*n*)	1.32 (1.09, 1.59)[d]		**1.40 (1.10, 1.78)**[d]	
Did provide any type of social support (*n*)	1.15 (1.01, 1.30)[b]			
Kin in could support network (*n*)	1.14 (0.99, 1.30)[e]			

(*Continued*)

Table 2

Continued

Variables	Unadjusted ORs (95% CI)	Model 1: Types of Perceived Support	Model 2: Types of Enacted Support	Model 3: Network Characteristic
		AORs[a] (95% CI)		
Kin in did support network (*n*)	1.09 (0.94, 1.28)			
Total kin in network (*n*)	1.19 (1.06, 1.34)[d]			
Average closeness to network	1.12 (0.92, 1.35)			
Remind you of medical care (*n*)	1.24 (1.03, 1.50)[b]			
No. of females in network	1.22 (1.08, 1.37)[c]			
No. of females in could support network	1.17 (1.02, 1.34)[b]			
No. of networks know PLHIV is HIV+	1.19 (1.09, 1.29)[c]			
Outcome: Naming a medical decision-maker				
Control variables				
Age		0.99 (0.96, 1.03)	0.99 (0.96, 1.02)	0.99 (0.96, 1.03)
Education		1.41 (0.89, 2.18)	1.41 (0.89, 2.22)	1.55 (0.98, 2.45)[e]
Female gender		1.61 (1.02, 2.53)[b]	1.01 (0.92, 1.11)	1.52 (0.96, 2.40)[e]
Total network (*n*)		1.00 (0.91, 1.11)	1.01 (0.92, 1.11)	1.05 (0.95, 1.15)
Could provide emotional support (*n*)	1.31 (1.10, 1.57)[d]			
Could provide material aid (*n*)	1.21 (1.04, 1.40)[b]			
Could provide social participation (*n*)	1.16 (1.02, 1.32)[b]			
Could provide health information (*n*)	1.24 (1.09, 1.43)[d]	**1.22 (1.04, 1.43)**[b]		
Could provide physical assistance (*n*)	1.31 (1.11, 1.55)[d]			
Could provide any type of social support (*n*)	1.13 (1.02, 1.27)[b]			
Did provide emotional support (*n*)	1.54 (1.23, 1.94)[c]		**1.48 (1.16, 1.88)**[d]	
Did provide material aid (*n*)	1.19 (0.99, 1.43)[e]			
Did provide social participation (*n*)	1.17 (1.01, 1.35)[b]			
Did provide health information (*n*)	1.19 (1.00, 1.42)[e]			
Did provide physical assistance (*n*)	1.22 (1.02, 1.45)[b]			
Did provide any type of social support (*n*)	1.19 (1.05, 1.36)			
Kin in could support network (*n*)	1.13 (0.98, 1.30)[e]			
Kin in did support network (*n*)	1.19 (1.02, 1.40)[b]			
Total kin in network (*n*)	1.10 (0.98, 1.24)[e]			
Average closeness to network	1.24 (1.01, 1.52)[b]			1.23 (0.99, 1.53)[e]
Remind you of medical care (*n*)	1.35 (1.12, 1.64)[d]			**1.30 (1.06, 1.60)**[b]
No. of females in network	1.13 (1.00, 1.27)[b]			
No. of females in could support network	1.19 (1.03, 1.38)[b]			
No. of networks know PLHIV is HIV+	1.11 (1.02, 1.21)[b]			

ORs = odds ratios; AORs = adjusted odds ratios; ACP = advance care planning; PLHIV = people living with HIV.

Note. Controlling for age, sex, education, and total number of network members.

Variables that were significant in adjusted model are bolded.

[a] Hosmer-Lemeshow test of model fit for adjusted logistic regression model was not significant.

[b] $P < 0.05$.

[c] $P < 0.001$.

[d] $P < 0.01$.

[e] $P < 0.10$.

a model that included the network characteristic variables. In summary, five social support network factors were associated with discussing ACP and naming a decision-maker: closeness to network, medication adherence reminders, emotional support, health information, and physical assistance. Three other factors were close to significant in increasing the likelihood of these conversations, including education, knowledge of HIV+ status, and medication adherence reminders for ACP discussion with family/friends; education and average closeness to network for naming decision-maker.

Discussion

The purpose of this research was to contribute to the sparse literature examining social contextual factors associated with ACP. Consistent with prior findings on African Americans, in this vulnerable population with disparities in health care outcomes and support resources, PLHIV reported higher levels of talking to family or friends (57%) as compared with their doctor (39%) about end-of-life care preferences. Our study identified characteristics of their social support networks associated with an increased likelihood of discussing ACP and naming a health care decision-maker. Overall, female PLHIV, greater total number of network members, types of social support specific to caregiving (i.e., physical assistance, emotional support, health information, medication adherence reminders), and having disclosure of one's HIV to a greater number of support network members were associated with ACP discussion with family/friends or doctors and naming a decision-maker.

The findings suggested differences in network correlates of ACP discussion with family/friends (support network members) as compared with discussion with doctors. ACP discussion with family/friends was associated with being female and greater mobilization and HIV disclosure to support network members and greater quality of informal care. However, the findings on qualities of support network relationships associated with the ACP process were mixed. Greater average closeness was associated with talking to family or friends about end-of-life care preferences and greater number of persons who had provided emotional support were positively associated with likelihood of naming a decision-maker, whereas we found that a lower number of persons who provided emotional support was associated with the likelihood of talking to one's doctor about ACP. The results highlight the important role of enacted support, and caregiving in particular, in the ACP process. Further research is needed to examine temporal patterns of the ACP process and the role of participants' health status or health care utilization in explaining the study findings.

Perceived and enacted physical assistance were associated with ACP discussion with doctors, whereas enacted emotional support and perceived health information was associated with naming a decision-maker. Such assistance may consist of instrumental (physical) assistance like transportation to doctors' visits and emotional support like coping with stressful events.[11] Perceived health information support was associated with naming decision-maker, and enacted health information was associated with ACP discussion with family/friends. This suggests that informational social support is as necessary as instrumental support or emotional support in promoting ACP discussions. Studies on the differences between perceived and enacted social support have found that individuals receiving enacted support had decreased levels of depression compared with individuals with perceived support.[24] Social support researchers should consider how the quality of communication and relationships within social networks impact the provision and subsequent outcomes of social support in varying contexts. The "more is better" social support hypothesis embedded in clinical practice approaches (i.e., clinician offering a multitude of resources to all patients/families) is challenged by research suggesting that even well-intended acts of support may not be received as helpful by recipients.[25] The findings suggest that clinicians ought to identify PLHIV' support networks and quality of functioning and engage with patients and their caregivers in the ACP process. Furthermore, caregivers should be assessed to determine their own social support network needs to ensure their sustained quality care and decision-making roles through patients' illness progression.[26]

Our findings concur with the findings of Maragh-Bass et al.[11] on the contextualization of ACP within African American PLHIV. One of the factors impacting discussion of ACP was sources of HIV supportive care, including within social networks and health care providers. These sources of supportive care represent channels through which ACP discussion can occur, and our study describes further the characteristics of social network that influence discussion of ACP. Our study suggests that having a greater number of network members providing instrumental social support is associated with increased likelihood of ACP discussion with doctors. A large survey showed that 86% of those who had named decision-maker had discussed their wishes with that person, but barely more than half had told their doctors.[15] Among the reasons participants stated they had not had ACP conversations included that they were not sick and did not think it was necessary to talk with their doctors about end-of-life preferences or to designate a decision-maker; many expressed confidence that family members and health care providers would know best.[15] Similarly, in our study, enacted emotional support decreased the likelihood of ACP discussion with doctors, and this speaks to the confidence that patients have in their network members to observe their wishes. In fact, surrogates are often overconfident and ill informed about what the person would actually want,[27] even when communication has taken place.[28] Future interventions with this population are needed to improve end-of-life health care literacy and engaging with both providers and caregivers in ACP discussion and specific procedures involved with documenting preferences. Such interventions should also include caregivers in ACP skills building with education tailored to the person's preferences and support network and to the need for surrogates to understand their duty with exploration of the role of trust[29] in these relationships.

The study has several limitations. First, all study data were cross-sectional, which prevents the ascertainment of fluctuations over time or the establishment of temporal sequence between independent and outcome variables. Second, other unobserved covariates might explain additional variance in the outcome, such as caregiver characteristics. Third, participants in the present analyses were almost all African American (95%), middle aged, insured, and in HIV medical care; many also had low income and history of substance use. Thus, although the current research makes important contribution to the field by advancing our understanding of a uniquely vulnerable hard-to-reach population that is often excluded from studies,[30] our findings might not apply to other populations.

Conclusion

In our study, the social support network factors associated with ACP discussion and naming decision-maker were physical assistance, health information, emotional support, closeness to network, and providing medication adherence reminders, according to care recipients' perception. Our findings underscore the importance of social network and caregiving research to inform the development of ACP and end-of-life health care literacy interventions. The results suggest the importance of clinicians' early identification and engagement in ACP discussion with vulnerable PLHIV and their caregivers to ensure their mutual understanding of care preferences and preparation and resources for their caregiving roles through patients' end of life.

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