# Caregiving by Older People Living with HIV

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## Introduction

- People living with HIV (PLWH) are living longer. In the US, more than 50% of PWH are older than 50 years <sup>(1, 2)</sup>.
- PLWH are more likely to face psychosocial stressors related to stigma, social isolation, cognitive loss, and fragile social networks earlier than the general population (1, 2, 3).
- PLWH can also play the role of caregivers (CG) for their older partners, spouses, and other family members and friends <sup>(1, 2)</sup>.
- In the US, the number of PLWH who are CG is anticipated to increase with the advances of medical care (1, 4).
- Limited evidence about caregiving in PLWH exists that suggests the extent to which PWH are able to fulfill their roles, receive support while caregiving and managing their individual medical challenges.
- This study addressed this gap by determining the characteristics of PLWH who are caregivers, identify their care recipients, and examining the factors associated with caregiving in PLWH.

## Methods

- Cross sectional design
- Participants were from a New York City clinic and randomly selected to complete the Research on Older Adults with HIV survey (ROAH 2.0)
- N= 331 PWH, with **43.2% of PLWH**reported being **CG** in the previous 5
  years
- Age range = 50-84 years
- Mean = 59.30, SD = 6.36
- Descriptive statistics were conducted. Correlation and regression models were estimated, controlling for age, race/ethnicity, education level, living arrangements, Social Vulnerability Index, number of chronic conditions and HIV related variables (e.g., viral load, AIDS diagnosis, duration of HIV diagnosis).

# Acknowledgement

Grant support from the National Institute of Aging (K23 AG072960), National Center for Advancing Translational Sciences (UL1TR000457), and Arthur Ashe Endowment

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#### Results

- Our findings showed that **being older** ( $\beta$ =0.484, SE=0.244, p=0.037), **being a female** ( $\beta$ =0.038, SE=0.018, p=0.047), and having a **high generativity score** ( $\beta$ =0.074, SE=0.031, p=0.008), were positively associated with caregiving in PWH
- Caregiving in PWH was significantly associated with increased needs for **support in instrumental activities of daily living** ( $\beta$ =-0.246, SE=0.136, p=0.015) and for **emotional support** ( $\beta$ =-0.218, SE=0.127, p=0.045)
- No significant associations were found between caregiving in PWH and psychosocial determinants loneliness, depression and HIV-related stigma

- **79.6% of caregivers living with HIV (CWH)** cared for 1 care recipient, **13.9%** for 2 care recipients, and **6.6%** for more than 3 care recipients

- 47.6% of CWH cared for other family members and 28.7% for a friend
- 45.5% of CWH had more than 5 chronic conditions, compared to 38.5% of non-caregivers

Table 1.
Characteristics of People Living with HIV (Caregivers vs. Non-Caregivers)

Characteristics	Participants (N)	n (%) / Mean (SD	Caregivers (n=143)	Non- Caregivers (n=188)	P value
Age (years)	331				.078
Range		50-84			
Mean (SD)		59.3 (6.36)	60.0 (6.47)	58.8 (6.24)	
Median (IQR)		58 (54, 63)	59	58	
Age Groups	331				.285
50-59		184 (55.6%)	74 (51.7%)	110 (58.5%)	
60-69		122 (36.9%)	55 (38.5%)	67 (35.6%)	
70+		25 (7.6%)	14 (9.8%)	11 (5.9%)	
Sex (at birth)	324				.071
Male		221 (68.2%)	88 (62.9%)	133 (72.3%)	
Female		103 (31.8%)	52 (37.1%)	51 (27.7%)	
Sexual Orientation	331	•	•	, ,	.610
Heterosexual		143 (43.2%)	63 (44.1%)	80 (42.6%)	
Gay/Lesbian/Bisexual		139 (42.0%)	62 (43.4%)	77 (41.0%)	
SGL/Queer/Other		49 (14.8%)	18 (12.6%)	31 (16.5%)	
Ethnicity	302	(///		5. (.0.070)	.632
Hispanic/Latino	302	94 (31.1%)	43 (32.6%)	51 (30.0%)	.002
Non-Hispanic/Latino		208 (68.9%)	89 (67.4%)	119 (70.0%)	
<u> </u>	217	200 (00.070)	33 (07.470)	113 (70.070)	925
Race	317				.825
American Indian/Asian/Pacific		0 (0 40/)	E (0.70/)	2 (4 50/)	
Islander		8 (2.4%)	5 (3.7%)	3 (1.5%)	
Black/African		4E0 (40 00()	60 (47 00/)	OF (E4 OO()	
American/Caribbean		158 (49.8%)	63 (47.0%)	95 (51.9%)	
White/Caucasian		119 (37.5%)	53 (39.6%)	66 (36.1%)	
Multiracial	201	32 (10.1%)	13 (9.7%)	19 (10.4%)	0.10
Education	331	10 (10 00)	00 // / 55/	00 (10 55)	.218
Less than high school		46 (13.9%)	20 (14.0%)	26 (13.8%)	
High school					
graduate/GED/Vocational		90 (27.2%)	44 (30.8%)	46 (24.5%)	
training		4== 44= 5544	EA 100 000		
College graduate/Some		150 (45.3%)	56 (39.2%)	94 (50.0%)	
college/Associate degree		.=			
Master's degree or higher		45 (13.6%)	23 (16.1%)	22 (11.7%)	
Income	325				.635
No financial strain		99 (30.5%)	41 (29.1%)	58 (31.5%)	
Financial strain		226 (69.5%)	100 (70.9%)	126 (68.5%)	
Social Vulnerability Index	319				.683
(SVI)					
Range		0.028-0.998			
Mean (SD)		0.722 (0.270)	0.714 (0.275)	0.727 (0.267)	
Median (IQR)		0.827 (0.538,	0.811 `	0.829 `	
•		0.960)			
Viral Load	324	•			.849
Less than 20	<del></del> -	300 (92.6%)	131 (92.9%)	169 (92.3%)	
≥ 20		24 (7.4%)	10 (7.1%)	14 (7.7%)	
AIDS Diagnosis	316	(/v/	,	( , . ,	.092
Yes	310	151 (47.8%)	59 (42.4%)	92 (52.0%)	.032
No		, ,	· · · · · · · · · · · · · · · · · · ·	, ,	
	204	165 (52.2%)	80 (57.6%)	85 (48.0%)	101
Time since HIV	331				.424
Diagnosis(years)		4.40			
Range		1-42	00 00 (0 ==)	00 00 (0 00)	
Mean (SD)		22.48 (6.71)	22.83 (6.75)	22.23 (6.68)	
Median (IQR)		22.0 (18.0, 27.0)	22.0	22.0	

Table 2.
Correlations between Caregiving, HIV-related variables and Social and Emotional Support

	Caregiving	Viral Load	AIDS Diagnosis	Time since HIV Diagnosis	Social support- IADLs	Need social support- IADLs	Emotional support	Need Emotional Support
Caregiving								
Viral Load	0.011							
AIDS Diagnosis	-0.095	0.048						
Time since HIV Diagnosis	0.044	-0.022	0.141*					
Received social support-IADLs	0.085	-0.065	0.004	0.017				
Need social support-IADLs	-0.145*	0.060	-0.084	0.035	0.130*			
Received Emotional support	-0.045	0.045	-0.092	-0.030	0.470**	0.292**		
Need emotional support	-0.152**	0.061	-0.065	0.042	0.172**	0.472**	0.327**	

Notes: \*p < 0.05; \*\*p < 0.01. IADLs = Instrumental Activities of Daily Living

#### Discussion

## Strengths

- One of the few studies to examine caregiving in PWH and the associations between caregiving and psychosocial and HIV-related indicators
- Use of electronic health record to obtain chronic conditions and HIV-related data to supplement ROAH 2.0 survey

# Limitations

- Retrospective self-reports of caregiving
- Potential underreport of depression, loneliness or to not disclose stigma
- Sample might not reflect the national distribution of US PWH, since it is geographically limited

# Implications

- Our findings illuminate the importance of caregiving in the context of living with HIV and the significance of assessing caregivers' needs in order to develop sensible interventions to promote generativity and reduce caregiver strain
- Future research, policy, and practice may particularly focus on the role of generativity as a positive determinant of caregiving to help mitigate caregiver's burden, enhance meaning and purpose in life and promote well-being.

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