

EMORY



Emory Roybal Center Overview and LGBT Pilot

Whitney Wharton, PhD
Associate Professor, Nursing and Medicine
Emory University



Emory Roybal Center

- Kenneth Hepburn, PhD (PI) Emory SON
- Molly Perkins, PhD (MPI) Emory SOM
- “As the U.S. continues to experience major reconfigurations in its social and demographic composition, we expect caregiving to occur in an ever-increasing set of heterogeneous contexts.” KH

Emory Roybal Call for Pilots

- \$20,000 to \$100,000 total costs, 1 yr
- LOI due – Dec 31, 2019 Notification January 8, 2020
- Full Proposals Due – (by invitation only) February 15
- “Caregiving is not one homogenous entity but is *context-specific*. Contexts are framed by various illness conditions, family, cultural, or social caregiving situations, geographical location...”
- 2nd, 3rd marriage, step vs biological children etc

LGBT Caregiver Roybal Project

- 2.7 million U.S. older adults (50+) self-identify as LGBT¹ will increase to more than 4 million by 2030.²
- Compared with heterosexual older adults, LGBT older adults experience a higher prevalence of chronic disease and disability, as well as poorer physical and mental health¹

Higher rates of smoking, drinking, depression, exposure to violence. More likely to age alone, less likely to marry or have children, families of choice vs blood.

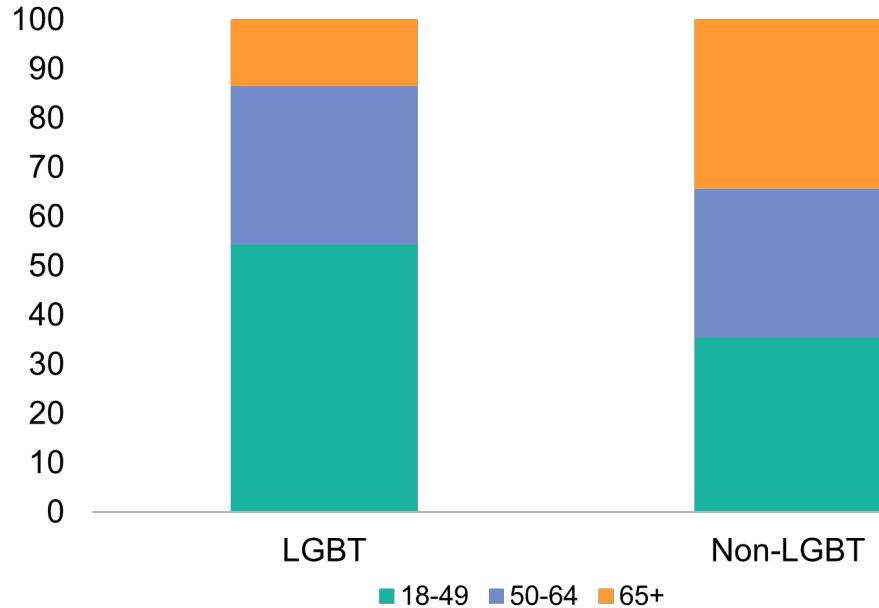
LGBT as a National Health Concern

- Aging disparity related to sexual and gender identity is acknowledged by the NIH,⁴ the National Academy of Medicine ⁵ and the Alz Association.
- Given the national health objectives to reduce health disparities and adverse health outcomes resulting from social, economic, and environmental conditions,⁶ the NIH & NAM has identified LGBT as a key gap in health disparities research.

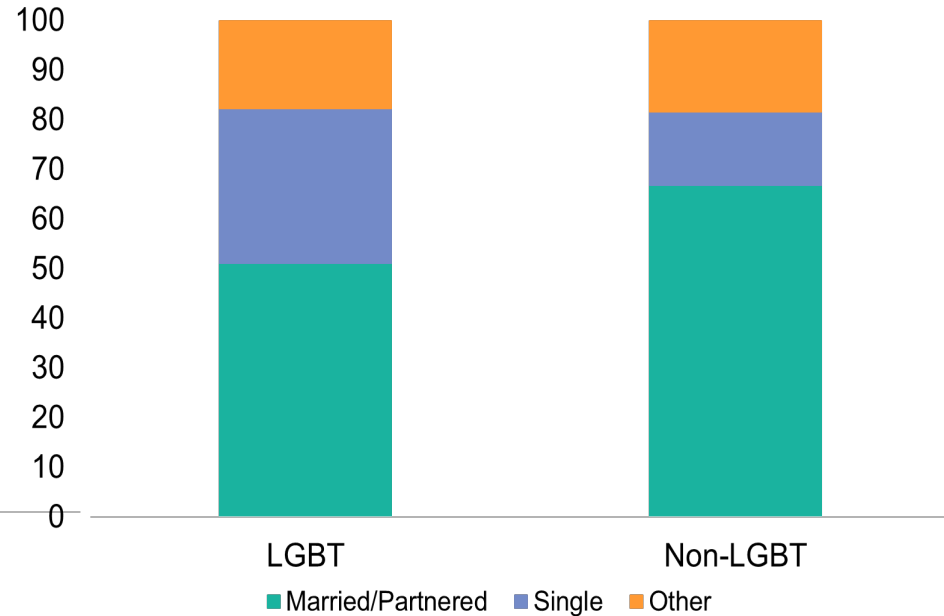
LGBT Caregivers

- 27% to 45%³ provide care for a loved one with chronic illness.
- Higher rates of physical, emotional, and financial strain, and are more likely to help with medical/nursing tasks ^{7,8}
- Less likely to seek out supportive services ⁹
- Fear of discrimination, denial of services, and receiving poor-quality services may contribute to reluctance to seek assistance ^{7,13}

Age

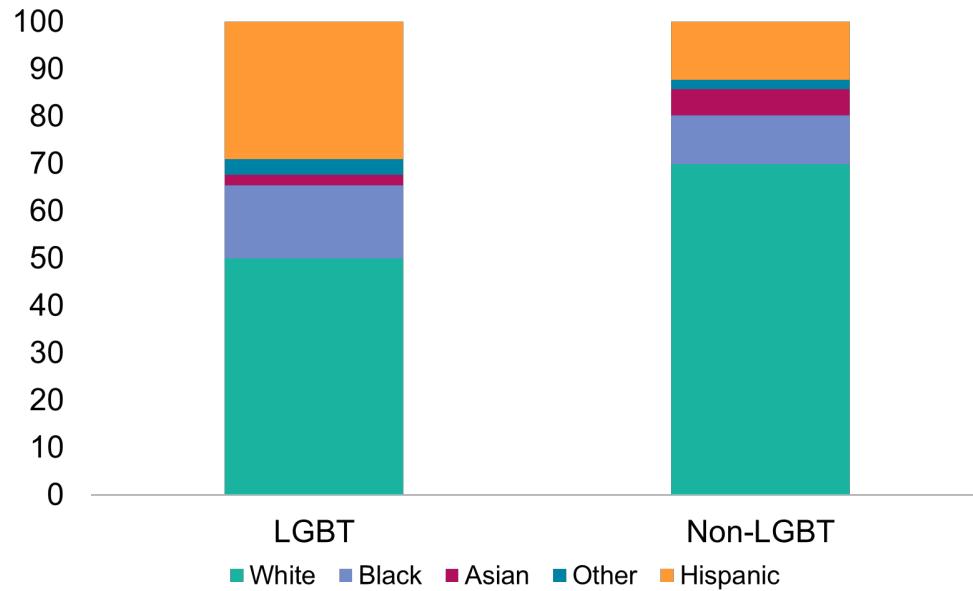


Marital/Partner Status

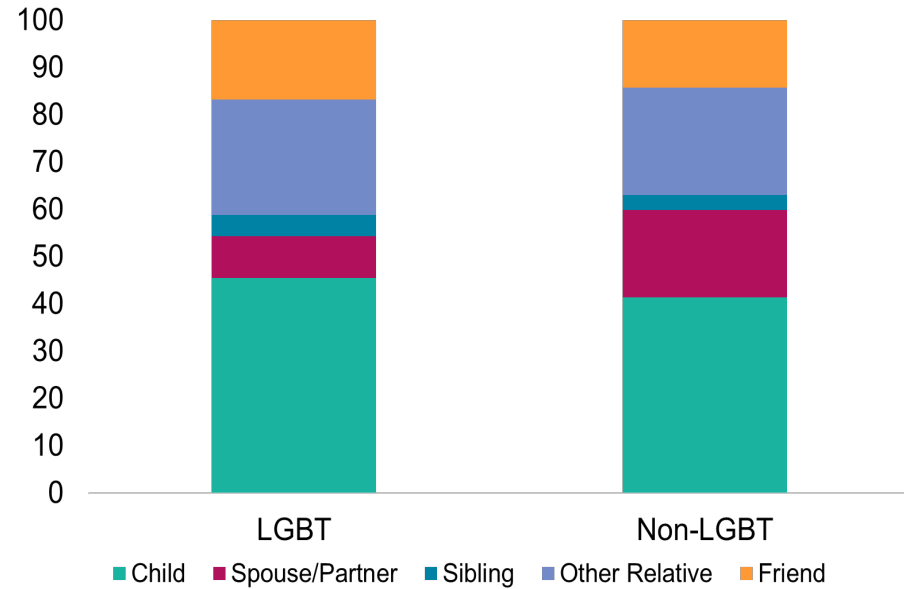


LGBT caregivers significantly younger ($p=0.001$) and more frequently reported being single ($p<0.001$).

Race & Ethnicity



Relationship to Care Recipient



LGBT caregivers more racially and ethnically diverse ($p=0.001$) and more often the adult child, another relative or friend of the older adult care recipient ($p=0.001$).

Physiological Ramifications of Stress

- LGBT caregivers who identified as child of care recipient 2.5 times more likely to report high emotional strain ($p = 0.008$)
- LGBT adult children more likely to provide care than heterosexual sibling.
- Depression and stress have been linked to caregiving, and are independent risk factors for dementia 1-3.
- In addition to subjective indices of stress and depression, stress biomarkers (inflammatory markers, CRP and cortisol) have been shown to be higher in dementia caregivers vs. non-caregivers 14.

Roybal Pilot

- Stage I pilot clinical trial in which we adapt an established, evidence-based caregiver intervention, the Savvy Caregiver Program (SCP), to address the context-specific challenges faced by LGB informal caregivers of PLWD, and test its acceptability and preliminary efficacy LGB caregivers, and modify the program based on participant and CAB feedback.

Figure 1. Design and Timeline for the Proposed Pilot Clinical Trial

Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 9	Month 10	Month 11	Month 12
Trial recruitment (N= 45total) / Begin SCP (N= 15) Advisory Board Focus Groups (3)			SCP participant Focus group	Modify Savvy based on participant focus group and Advisory Board feedback		Modified LGB Savvy Pilot Intervention N=30				Post LGB Savvy Pilot Focus Group Blood inflammatory assays	

Savvy Groups (N=15)		
Pre Visit	Savvy Caregiver Program	Post Visit
Individual Clinic visit	1 group of 15	Individual visits
-Consent -Clinical & Stress Questionnaires -Blood Collection	6 weeks 2hrs per week (12 hours total)	Repeat -Clinical & Stress Questionnaires -Blood Collection

Modified LGB Savvy Groups (N=30)		
Pre Visit	Modified LGB Savvy Caregiver Program	Post Visit
Individual Clinic visits	2 groups of 15 with staggered start	Individual visits
-Consent -Clinical & Stress Questionnaires -Blood Collection	6 weeks 2hrs per week (12 hours total)	Repeat -Clinical & Stress Questionnaires -Blood Collection

Table 1: LGB Advisory Board

Name	Affiliation	Expertise
Linda Ellis	CEO, Health Initiative and SAGE Atlanta	Organization for older LGB activities, education, training and support.
Mary Anne Adams, MSW	Director ZAMI Nobla, National Organization of Black Lesbians on Aging	Older African American LGB Caregiving
Hillary Thomas	AARP, Atlanta Gay and Lesbian Chamber of Commerce Board Member	Community Relations Board Chair AGLCC
Matthew J. Lee	Solomon Baggett, LLC	Stonewall Bar Association of Georgia, the organization for LGB and allied lawyers
Don Terry	Community Leader, Alzheimer's Association	LGB family support group leader and AD family caregiver
Jill Disney	Alzheimer's Association Program Director	LGB outreach and dementia care
Michael Goodman, MD, MPH	Associate Professor, Department of Epidemiology, Emory University	Sexual minority Preventative Health and sex hormones
Karen I. Fredriksen Goldsen, PhD	Professor, University of Washington; Director Hartford Center of Excellence	PI: Aging with Pride: NHAS (NIH/NIA, R01) PI: Aging with Pride: IDEA (Innovations in Dementia Empowerment and Action) (NIH/NIA, R01)
Jason Flatt, PhD, MPH	Asst. Professor, UCSF	AD and older LGB healthcare
Joel Anderson, PhD, CHTP, FGSA	Assoc Professor, University of Tennessee, Co-Chair, Chancellor's Commission for LGB People	Investigator LGB dementia Caregiving
Jaime Perales, PhD	Kansas University Alzheimer's Disease Center	Dementia among Latin American LGB individuals

Outcomes Pre/Post

- Medical / medication / demographic history
- 1 hr subjective stress inventory
- Caregiver mastery assessment
- 90 minute focus group
- Blood (inflammation) LGBT biobank
- BP

Thank You

- w.wharton@emory.edu
- <http://neurology.emory.edu/research/laboratories/whartonlab/index.html>
- Twitter @WhitneyWharton4