

User-Centered Input for Culturally Adapting Savvy Caregiver® for LGBTQIA+ Caregivers of People with Dementia

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INTRODUCTION

- Our previous work found that LGBTQIA+ caregivers of people living with dementia reported higher levels of caregiver stigma, depressive symptoms, and stress than LGBTQIA+ caregivers.
- The higher levels of stress may be related to less frequently seeking supportive services and disclosing their LGBTQIA+ identities.
- Low use of caregiver support services by LGBTQIA+ caregivers might be related to barriers unique to LGBTQIA+ caregivers. LGBTQIA+ care partnerships may suffer from overlapping years of stigma, including higher levels of caregiver stigma and self-stigma, with fear of discrimination, denial of services, and/or receipt of poor-quality services leading to a reluctance to seek support
- Most caregiver interventions are not designed with LGBTQIA+ caregivers in mind and do not take into account the unique needs and experiences of LGBTQIA+ caregivers.
- Savvy Caregiver® is a leading evidence-based dementia family caregiver training program that significantly decreases caregiver distress, burden, and depressive symptoms.
- The goal of this study was to develop a culturally adapted version of Savvy Caregiver® for LGBTQIA+ caregivers of people with dementia for subsequent feasibility testing.

METHODS

- We used key informant interviews with LGBTQIA+ caregivers and a Delphi study with professionals in caregiving and LGBTQIA+ health, including certified facilitators of Savvy Caregiver®.
- Data from the caregiver interviews and Delphi study were analyzed separately using content analysis until saturation was achieved. Data were then merged for interpretation based on overall convergence and divergence of the themes identified.

Interventions for LGBTQIA+ caregivers of people with dementia need to address minority stressors and cultural biases experienced by these caregivers and their care recipients, including the lack of LGBTQIA+-specific resources and stigma and bias in health care and support settings.



Table 1. Caregiver sample characteristics

ID	Age	Gender	Sexual orientation	Transgender	Latino	Race	Level of education	State of residence	Years caregiving
1	64	Male	Queer	No	No	White	Bachelor's	New York	2.5
2	66	Male	Gay	No	No	White	Master's	DC	10
3	42	Female	Lesbian	No	No	Indigenous Sioux, White	Master's	North Dakota	9
4	58	Female	Gay	No	No	White	Bachelor's	Georgia	4
5	57	Male	Gay	No	No	White	Bachelor's	Florida	15
6	32	Female	Lesbian	No	No	Black	Bachelor's	Minnesota	2
7	51	Female	Bisexual	No	No	Sami heritage, White	Postdoctoral	Utah	4
8	25	Female	Queer	No	No	Southeast Asian, White	Master's	New York	1
9	82	Female	Lesbian	No	No	White	Master's	DC	13
10	30	Non-binary	Asexual	Yes	Yes	Not disclosed	Associate's	Florida	5
11	71	Male	Gay	No	No	White	Master's	Texas	12
12	64	Male	Queer	No	Yes	White	Bachelor's	California	3.5
13	84	Female	Lesbian	No	No	White	Bachelor's	Minnesota	2
14	64	Female	Lesbian	No	No	White	Associate's	South Carolina	10
15	59	Male	Straight	Yes	Yes	White	Master's	Oregon	5

Note: All demographic characteristics are self-described.

Table 2. Delphi study sample characteristics

ID	Gender	Sexual orientation	Latino	Race	Professional expertise
1	Transgender man	Straight/heterosexual	Yes	White	Community organization/service provider
2	Cisgender man	Gay	No	African America/Black	Community organization/service provider
3	Female	Lesbian	No	White	Certified Savvy Caregiver trainer
4	No response	Straight/heterosexual	No	White	Certified Savvy Caregiver trainer
5	Female	Bisexual	No	White	Health sciences researcher
6	Female	Queer	No	White	Health sciences researcher
7	Female	Straight/heterosexual	No	White	Health care provider
8	Female	Lesbian	No	White	Community organization/service provider
9	Female	Straight/heterosexual	No	White	Certified Savvy Caregiver trainer
10	Agender	Queer	No	Prefer not to answer	Community organization/service provider
11	Female	Lesbian	No	White	Health care provider
12	Nonbinary	Asexual, Lesbian	No	American Indian/Alaska Native, White	Health sciences researcher
13	Cisgender female	Bisexual, Queer	No	White	Health sciences researcher

RESULTS

- The study sample consisted of LGBTQIA+ caregivers (n=15) and professionals in caregiving and LGBTQIA+ health (n=13).
- Participants endorsed Savvy Caregiver® as a potentially valuable intervention to support LGBTQIA+ caregivers, so long as it was adapted to address the unique needs and experiences of these caregivers.
- Given that Savvy Caregiver® was “designed for a heteronormative audience,” participants stressed the importance of addressing the challenges faced by LGBTQIA+ caregivers.
- Overarching themes included:
 - Addressing minority stressors and cultural biases experienced by LGBTQIA+ caregivers and their care recipients;
 - The lack of LGBTQIA+-specific resources, including representation of racially/ethnically minoritized LGBTQIA+ caregivers;
 - Stigma and bias in health care and support settings; and
 - Policy issues affecting caregivers at the local, state, and federal levels.

LIMITATIONS

- Small, predominantly White sample
- Digital research methods excluded those without Internet access

STRENGTHS

- Diverse caregiver sample in terms of sexual orientation, gender identity, age, location, and caregiving experience
- Strong convergence between caregiver interviews and Delphi study

DISCUSSION

- Given existing interventions do not account for the particular needs and experiences of LGBTQIA+ caregivers, there is a need for targeted interventions for these caregivers.
- Our findings inform the development a culturally adapted version of Savvy Caregiver for addressing stress and burden among LGBTQIA+ caregivers.

FUNDING

This research was supported by the RRF Foundation for Aging under award number RRF2024130. The content is solely the responsibility of the authors and does not necessarily represent the official views of the RRF Foundation for Aging.