A health needs assessment of the LGBT+ community, aged 50+, living with HIV in Puerto Rico.

Developed and Implemented by Waves Ahead Corp and SAGE Puerto Rico. In collaboration with SAGE’s HIV & Aging Policy Action Coalition. Lead by SAGE Puerto Rico and JSI Research & Training Institute, Inc., Boston, MA
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Importance

Policymakers, researchers, advocates and service providers in Puerto Rico (and the United States) lack information about the health needs of LGBT+ older adults living with HIV.

Methods

This Community Needs Assessment was implemented as an initial step to remedy the lack of information on the health needs of this population. It represents the views of 264 survey respondents and 13 interview participants aged 50 or more, living with HIV, and proud members of the LGBT+ community.

Results

The typical respondent was a person that knows how to navigate the healthcare system, has developed coping mechanisms to deal with stigma and homophobia and serves as a champion and fierce advocate of younger LGBT+ folks. Unlike their counterparts in the mainland (Latino elderly living with HIV), they are highly educated (graduates and postgraduates), do not experience service barriers due to lack of health insurance, or language impediments, or blatant discrimination, nor experience the feeling of otherness or encounters with providers lacking in cultural humility. Despite these strengths, the data paints a picture of people in distress, a condition that is manifested in terms of depression, anxiety, and social isolation. However, this needs to be understood within the frame of the respondents’ life context and experiences. A significant portion feel housing and food insecurity, is in need of medical, mental health, complementary and alternative services and not able to obtain them. Despite their education, they cannot escape poverty. They feel lonely, and isolated lacking a partner/spouse and with no children. The testimonies collected highlight the many instances in which they suffer financial hardships either for losing a home to the earthquakes or hurricanes or losing their employment or business to Covid-19. Some are still taking care of their aging parents and many have experienced numerous traumatic events (hurricanes, earthquakes, epidemics, economic collapse).

Recommendations

What can be done to promote their wellbeing? First, policymakers should recognize that for the most part, they obtain their services in a system of care that was designed for the cis gender heterosexual population. Through their advocacy, assertiveness, and persistence, the respondents have been able to nudge the system to align service delivery in a manner aligned with their needs as members of the LGBT+ community. However, these efforts have not been successful. Some respondents still report experiencing HIV, gender, and age discrimination.

Second, the strengths of this population should be recognized, celebrated, and activated. Previously we alluded to some of those strengths (resiliency, assertiveness, high levels of education). There is a rich intellectual capital within this community. About 27.5% have completed a Bachelor’s degree, 22% a Masters and 6% a Doctorate degree.

Third, there is a need to increase accessibility to all existing services. We encourage a creative and flexible conceptualization of “accessibility.” Thus we encourage policymakers and service providers to consider strengthening the use of social media, mobile services, modification of existing services, involvement of people with lived experience in service delivery, diversity, equity, and inclusion audits, and other creative solutions “outside of the box” while using science-based interventions to improve those services that are already in place. Their anxiety and distress caused by housing and food insecurity can be mitigated if they are aware of resources and opportunities to deal with such challenges.

Fourth, while most of the participants were digitally literate, they wanted more training and capacity development services in the use of technology.

Third, the participants reflect a diverse segment of the LGBT+ community, all aging, and all ever-changing, experienced individuals who are living with HIV, and trying to live to their full potential. Public servants, elected officials, public health advocates, providers, and community members-at-large should read these findings as a window to a community that is searching for equity and equality in health-care, in their community, and in Puerto Rico as whole. Listen, learn, and advocate!

Limitations

First, the data was collected during the COVID-19 epidemic, and it is difficult to ascertain whether or not the distress documented in the findings is due to COVID-19 or to already existing causes. Data was collected between late April and June 2021. Second, we referred to the LGBT+ community as a whole. However, between and within the Lesbian, Gay, Bisexual and Transgender community, and the myriad sexual orientations denoted by the “*” symbol there are unique needs, differences, strengths, and worldviews. Those, due to budgetary limitations these issues were not attended in this study. Third, the sample was recruited through social media platforms like Facebook, and Twitter meaning that the participants are those that already know how to access social media. Although some surveys were collected in person, COVID situation in Puerto Rico at the time, impeded us to continue in this format and hence we changed all activities to web-based. Fifth, the sample was a non-probability sample thus the findings are not generalizable to the general population. Finally, this cohort. Represents “very young older adults”[1] that is, participants as young as 50-year of age. As such, they did not express the need for assistance in performing activities of daily living typically reported by the old or very old counterparts.
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Between late April and June 2021, we conducted a health needs assessment of LGBT+ aged 50 and above living with HIV in Puerto Rico.

Participants

Number of eligible respondents: N=264
- Median Age: 57
- Age Range: 50-78
- Male= 244
- Female=20

What were the key findings of this research?

Family

- 80% have no children and 72% of respondents are NOT in a relationship.
- The respondents are mostly widowed. Many are living alone.

Social determinants of health

How we can help

"They call me, you lost your job, fired and we compensate you, I lost my status, lost the doctor, for now I say: wow, I already checked the inventory of the medicines, I have medicines, I can survive a month and a half more because I have medicines, I had left medicines still, between one thing and the other, they call me as a human and tell me: you have a refill available, and I say: how, but I don't have a medical plan, no, no."

Housing

- 8% (n=21) of respondents endorsed “do not have any where to sleep tonight”.
- About 1 in 5 either live with a friend or relative (11%), on temporary shelter (6.4%) or had other arrangements (4%).

Utilities

- 20% had their utilities shut off due to lack of payment

Food

- 21% (n=56) of respondents endorsed “do not have any food for tonight”.
- We need to worked hard to eradicate hunger among this population

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**Findings**
- Participants experienced loneliness and isolation.
- 68% reported needing smoking cessation counseling and 43% needed smoking cessation meds.
- 15% reported inability to obtain needed services such as medical, mental health, complementary and alternative services.
- Financial hardships either from losing their homes to earthquakes and hurricanes or losing their employment or business due to the Covid-19 pandemic.
- None of the respondents experienced language barriers. Only 1% experimented racial ethnic discrimination.

**Barriers to Access Services**
- 16% did not know where to go.
- 15% had a long waiting list and time.
- 19% could not afford medical care.

**Financial Hardship**
- 18% had no way to pay for the services either for losing a home to the earthquakes or hurricanes or losing their employment or business to Covid-19.

**Recommendations**

**Strengths**
- Celebrate, and activate the strengths of this population.
- Recognize systems of care that was designed for the cis gender heterosexual population.
- Use strategies such as of social media, mobile services, modification of existing services, involvement of people with lived experience in service delivery, diversity, equity, and inclusion audits to strengthening access to services.
- Provide training and capacity development services in the use of technology.
- Listen, learn, and advocate!

**Financially supported by:** AIDS United, SAGE Puerto Rico, SAGE’s HIV & Aging Policy Action Coalition and Gilead Sciences, Inc. Gilead Sciences, Inc has had no input into the development or content of these materials.