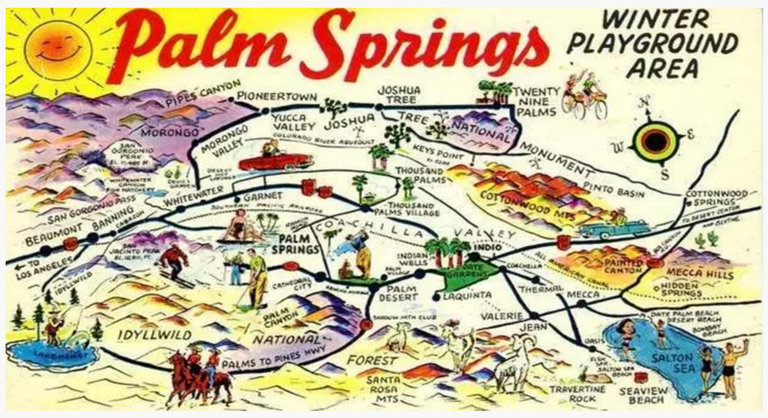
"We should choose or decide. You know, we're the ones that are here"

Selecting community-based research priorities in aging with HIV

Introduction

- Palm Springs, California, is a retirement and resort community with the highest prevalence of older people living with HIV (PLWH) in the US



- We engaged the local stakeholder community (PLWH, caregivers, community-based organizations, providers/academics) around HIV and aging for future research

Methods

- Following CBPR principles, study materials were created through a collaborative process involving the research team, older adults living with HIV, a 10-person steering committee of stakeholders, and a 10-person community advisory board of PLWH
- PLWH over 55 years of age, providers/academics, and CBO representatives were recruited to participate in focus groups
- Participants recruited using a study flyer distributed at community events, by word of mouth, and through our steering committee and community advisory board networks. Focus groups were 60-90 minutes and audio recorded for analysis. All participants received $50.
- Systematic analysis of qualitative data was conducted using the rigorous and accelerated data reduction (RADaR) technique

Results

People Living With HIV

Who should choose?

We should choose or decide. You know, we're the ones that are here. We're here to give our opinion. What we think is important to us as a group, should be studied. (69 year old Hispanic man)

Probably by groups like this, I mean this is a start...I mean you could sway some things. (77 year old white man)

Top Research Interests

I'd have to go with the long-term side effects of meds...We were basically guinea pigs for this lovely disease all of our lives, and I hope that something can be, found from what we went through. (76 year old Native America man)

My good friend died two years ago he didn't take [his meds] because he was depressed...There was no easy, available mental health...He couldn't comply with the medications, or even doctor follow-ups, he was so depressed. And I know I've had a few dips of depression, and I have been compliant with my meds, but it's difficult. (72 year old white man)

Community Based Organization Representative

Who should choose?

I personally would like the idea of surveying the population to find out what they find most challenging in their own lives. (58 year old white man)

Top Research Interests

Talking about the aging population, presuming that they're long-term survivors, they probably have trauma from losing friends or loved ones... just going through that period when, you know, the treatment was not allowing people to survive. (38 year old Hispanic woman)

I'm most concerned when people can't tap into their individual resiliencies... so perhaps therapy to help identify people's resiliencies and bring it to their awareness but when people are already isolated, alone, depressed, anxious, don't even know what these inner strengths are their experiences, and it has a very big impact on their wellbeing.(58 year old white man)

Providers /Academics

Who should choose?

Take it back to the community and say, what do you think? (72 year old white man, provider)

The community. Rather than coming in, poaching research subjects, and leaving. So that people get their journal articles published but without any sort of sustained work in the community. (48 year old white man, academic)

Top Research Interests

A lot of our clinical trials, one of the main exclusion criteria is if you're HIV-positive. So we definitely need to actually get a lot of clinical trials that are [about] comorbidities that we see a lot in older HIV patients. And a lot of our HIV studies don't allow HIV-positive patients. So definitely a lot more research, needs to be put into HIV-positive patients and the comorbidities that we have spoken about so far. (39 year old Hispanic man, provider)

Results and Next Steps

- Eighteen PLWHIV, eight health professionals and, eight CBO representatives participated in the focus groups. Most were non-Hispanic white (79.4%) and 85.3% of participants were male
- PLWH wanted research on the **long term effects of HIV treatment**, **mental health of people living with HIV**, especially **depression, social support, and isolation**.
- The health professionals and CBO group **echoed the priorities among PLWH** "take it back to the community and say, what do you think?", but also discussed HIV **drug interactions** and **comorbidities**
- **All groups agreed that research topics concerning those aging with HIV should be selected by community members aging with HIV**
- The patient perspective on priorities in future HIV and aging research is particularly important, and is line with the Denver Principles
- **Focus groups done with cis women, Trans people and the Deaf community, with analysis pending**

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