The Role of Technology in Supporting Older Adults with HIV AIDS and Their Informal Caregivers

Sara J. Czaja Ph.D.
Department of Psychiatry and Behavioral Sciences
Center on Aging
University of Miami Miller School of Medicine

The research presented is supported by the National Institute of Nursing Research, Community Alliance Against AIDS

Overview

• Discuss the role of technology in supporting older adults with HIV and family caregivers.
• Describe some ongoing research at the University of Miami Center on Aging.
• Discuss some challenges with technology access.

Background

• Currently estimates indicate that ~ 50-60 percent of those affected with HIV in the US are aged 55+.
• Older adults with HIV experience unique challenges:
  – More social isolation and loneliness
  – Higher rates of depression
  – Lack of emotional and social support
  – Challenges with informal care support
  – Medical co-morbidities
• Barriers to care and support
  – Unavailability of family
  – Fear of disclosure of HIV status and stigma
  – Discrimination
  – Ageism

Background

• Caregivers of older adults with HIV also face some unique challenges:
  – Future uncertainty
  – Depression and emotional burden related to the fears of disclosure
  – Conflicts with biological family members
  – Discrimination
  – Lack of access to support services
  – Decision-making limitations for non-related significant others
Understanding the Needs of LGBT Older Adults (Czaja et al., 2015, Mental Health and Aging)

Study Aims

- The aims of our study were to gather information on the concerns of LGBT older adults with respect to:
  - aging, health, and caregiving
- We focused on gay men and lesbian women as they currently represent the largest demographic groups within the LGBT community.

Method

- Total of 14 focus groups: 10 groups of gay men and 4 groups lesbian women. Each group consisted of 6 to 11 participants.

Themes from the Focus Groups: Gay Men

Discrimination in healthcare, in living settings, and by family:

"Before I was caregiving for my parents, I was a friendly visitor for an older gay man who was in a nursing home. I witnessed discrimination against him and that was hard. He was not out at the nursing home, but people were aware"  

"I’m a landlord myself and I’ve been a property owner in associations as a leader. You would be surprised how many landlords are out there who will not take gays into their units. I do because I’m gay, but there is a lot of discrimination."

Fears of coming out due to perceived prejudices:

"I think a lot of people my age are afraid when they go to the doctor. They conceal the fact that they are gay to their doctor. This is a particular thing. It’s our own fear to disclose to a doctor."

Lack of family/social support:

"I am a caregiver for two gay men. I am responsible for finding the resources to help them out because they don’t have partners any more. They’re both estranged from their families and so I have a burden here."

Sample Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Gay Men (n=92)</th>
<th>Lesbian Women (n=32)</th>
<th>Total (n=124)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean, st. dev.)</td>
<td>65.4, 8.3</td>
<td>66.3, 5.7</td>
<td>65.6, 7.7</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>59 (64%)</td>
<td>18 (66%)</td>
<td>77 (62%)</td>
</tr>
<tr>
<td>Married/Partner</td>
<td>33 (36%)</td>
<td>14 (44%)</td>
<td>47 (38%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>9 (10%)</td>
<td>4 (13%)</td>
<td>13 (10%)</td>
</tr>
<tr>
<td>Some college</td>
<td>24 (26%)</td>
<td>12 (38%)</td>
<td>36 (29%)</td>
</tr>
<tr>
<td>College or More</td>
<td>59 (64%)</td>
<td>16 (50%)</td>
<td>75 (60%)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>66 (71%)</td>
<td>22 (73%)</td>
<td>88 (71%)</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>1 (1%)</td>
<td>2 (7%)</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>21 (23%)</td>
<td>1 (3%)</td>
<td>24 (19%)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (4%)</td>
<td>5 (17%)</td>
<td>9 (7%)</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>39 (42%)</td>
<td>10 (31%)</td>
<td>49 (40%)</td>
</tr>
<tr>
<td>Not alone</td>
<td>53 (58%)</td>
<td>22 (69%)</td>
<td>75 (60%)</td>
</tr>
</tbody>
</table>

Other Concerns and Needs

- Financial and Legal Issues
- Lack of Knowledge about Resources
- Lack of Someone to Provide Needed Care
- Lack of Community Resources for LGBT Older Adults

Needed Programs:

- Programs that provide emotional support and counseling;
- Support services for caregivers;
- Programs for socialization;
- Programs to help prepare with aging transitions;
How can Technology Help?

Potential Role of Technology

• Facilitate access to health care professionals, family members, and other caregivers.
• Permits easier access to a wide array of information and services.
• Permits flexible communication.
• Offers opportunities to decrease problems with isolation and enhance connectivity.
• Enhances opportunities for monitoring and assessment.

Technology Applications

• Telemedicine applications
• Technology-based intervention programs.
• Interactive communication systems
• Informational websites
• Online Support Groups
• Wearables, assessment programs
• Sensing and monitoring systems
• Reminder systems.

Potential Benefits and Challenges of Using Technology

Benefits

• Helps eliminate logistic challenges for patients, caregivers and clinical teams.
• Provides a flexible format for presenting information – e.g., speech, videos, face-to-face.
• Facilitates access to a broad array of information and services and the ability to integrate that information in one convenient location – e.g., dedicated website.
• Can be easily updated for multitudes of users.
• Can be tailored to support user needs – e.g., artificial intelligence.

Challenges

• Lack of internet access.
• Lack of awareness of technology-based resources, technology skills.
• Lack of access to technology applications & training opportunities.
• Cost.
• Concerns about privacy/security.

Internet Use by Age Group and Year

Data from Pew Internet & American Life Project
A wide variety of technologies have been used to deliver interventions and support programs.

The available evidence indicates that technology-based intervention approaches are:
- acceptable and feasible with patient and caregiver populations
- efficacious
- Uptake of technology applications has been slower than anticipated.
- Problems with cost, usability and interoperability remain.
- Large scale support for this type of research has lagged.
- Patients and caregivers also increasingly need to interact with complex technology in the delivery of care.

Findings from the Center on Aging
Caring for the Caregiver Network: Evaluating the acceptability of a culturally tailored technology-based psychosocial intervention for family caregivers of AD patients.
- Enrolled and Randomized 244 Dyads:
  - 109 Hispanics
  - 79 White/Caucasians
  - 55 African Americans
- Low Attrition ~ 10%
- Caregivers easily adapt to the technology
- The interventionists find that technology is an effective delivery
- Caregivers enjoy the video support group sessions – able to participate from their home
- Caregivers like the flexibility of using the tablet – enhances the convenience of the intervention

What is the Evidence: Summative Findings for Caregivers
(NASEM 2017; Kaye, 2017; Czaja et al, 2013)

What is the Evidence: Summative Findings for HIV Patients
(Perazzo et al., 2017) Interview data from people living with HIV: 5 predominate themes:
1) The Internet Alerted me to the Possibility of HIV,
2) The Internet Showed me a Solution is Available,
3) The Internet Influenced my Decisions about Care,
4) The Internet Empowered me to Participate in my Treatment Decisions, and
5) The Internet Gave me Hope for my Future

(Reeves, 2001) Interview data from people living with HIV:
1) Use the Internet to find health information
2) Use the Internet to make social connections
3) Use the Internet to advocate for social and support programs
Recommendations

- There is a need to:
  - Examine cohort differences in the experience and consequences of living with HIV among older adults.
  - Understand the support needs of caregivers of HIV patients.
  - Develop a solid evidence base of what technology applications (existing and emerging) work, for whom and in what context.
- The research must:
  - Extend technology-based intervention programs and include other technology applications such as sensing/monitoring systems, assessment programs, EMRs, robotic applications, etc.
  - Include diverse populations
  - Include data on challenges and negative outcomes
  - Include multi-disciplinary research teams
  - Include measure of cost effectiveness and usability

Recommendations

- There is a need for new approaches for measurement and a careful consideration of metrics - how do we best define Impact.
- The development of interventions should incorporate findings and practices from implementation science to ensure that evidenced-based interventions are widely disseminated in community and clinical settings.
- There should be greater collaboration between federal agencies and industry (especially the tech industry) to support research within this domain.