Understudied Caregiver Populations

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National Rehabilitation Research and Training Center on Family Support





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Goals

- Describe understudied and underrepresented groups in caregiving research
  - Importance of inclusion
  - Unique strengths and contributions of understudied caregivers
- Describe how to increase inclusion and its impact on caregiver research
  - Issues to consider
  - Strategies to consider
- Describe two case studies
  - Strategies used
  - Challenges, Successes, and Lessons Learned

Understudied, Underrepresented

- **Minoritized groups** less likely to be involved in caregiving research
  - Racially and ethnically minoritized
    - >40% of the U.S. population identify as a racial/ethnic minoritized group
    - Increasing faster among age 65+ than other segments of the population
  - Lower socio-economic status
  - Languages other than English
  - People with disabilities
  - Sexual orientation, gender identity (SOGI) minorities
  - Education and literacy
  - Geographic location - rural vs. urban vs. suburban

Understudied, Underrepresented

Well documented lack of inclusion among studies of caregivers for people with…

- Alzheimer's and related dementias (Dilworth-Anderson, 2020)
- Strokes (Lopez, 2022)
- Traumatic brain injury (Sodders, 2020)
- Caregiving programs using Mobile Health (Garnett, 2022)

And many others…

Inequalities in caregiving strain during the COVID-19 pandemic: conceptual framework and review of the empirical evidence

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Importance of Inclusion

- Many caregivers are not reflected in, or served by, caregiving programs
- Greater incidence of chronic health conditions and health impacts among minoritized groups Caregiver support and healthcare for care recipients is harder to access
- Compared to white Americans, people in racially/ethnically minoritized groups
  - Provide more hours of family care
  - Provide more intense care
  - Experience worse physical outcomes



Importance of Inclusion

- Unique perspectives and strengths of specific groups can improve caregiving research and programs for everyone



Strengths and Unique Factors

Strong family ties, wider family networks, ‘chosen family’

- Family or extended family/friends’ connections can be strong and highly valued - which can translate into great partners for caregiving program design and research
- For example, compared to heterosexual individuals, those who identify as LGBTQ+ often obtain more peer vs. intergenerational care

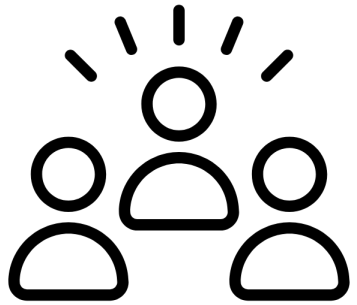
Resilience, strong sources of community support

- Black caregivers generally report less caregiving distress than white caregivers
- “African American stroke caregivers showed resilience in response to caregiving stressors, with better mental health than White caregivers” (Clay, 2013)

Motivation to participate in caregiving research

- “In general, we find that the queer population is actually pretty motivated to do [caregiving] research because we haven’t often been included in research” (Cultivating LGBTQ+ competent cancer Care Partner research, Waters, 2021)

Strategies for Inclusive Research



Community-Partnered Research

- Choose a topic that is community driven & desired
- Include community members as equal partners in each step of the research design and process
- Design research so that it is apparent how it can make an immediate and practical change
- Include plans for impacting the larger community and sustaining the progress made

"We define community-based participatory research as a partnership approach to research that involves community members, organizations, and academics as equal partners in all aspects of the research process. It enables all partners to contribute their expertise, with shared responsibility and ownership; it enhances the understanding of a given phenomenon; and, it integrates the knowledge gained with action."



- **The Detroit Urban Research Center**

https://detroiturc.org/about-cbpr/what-is-cbpr

FAM-ACT
FAMilies Taking ACTion for Health



Diabetes Comparative Effectiveness Trial

FAM-ACT

Why partner with this Latino/a community?

- Genesis of idea for FAM-ACT in Southwest Detroit Latino community
  - Familialism
  - Language, cultural, community ties between family members and people with diabetes are integral to diabetes management
- General considerations for Latinos & caregiving (Maldonado, 2016)
  - Familialism strengths and challenges
  - Gender roles
  - Healing traditions & Western medicine
  - Faith & spirituality
    - "Spirituality in the Latino family has been shown to increase positive aspects of caregiving and as a result decrease caregiver subjective burden" (Hodge & Sun, 2012)

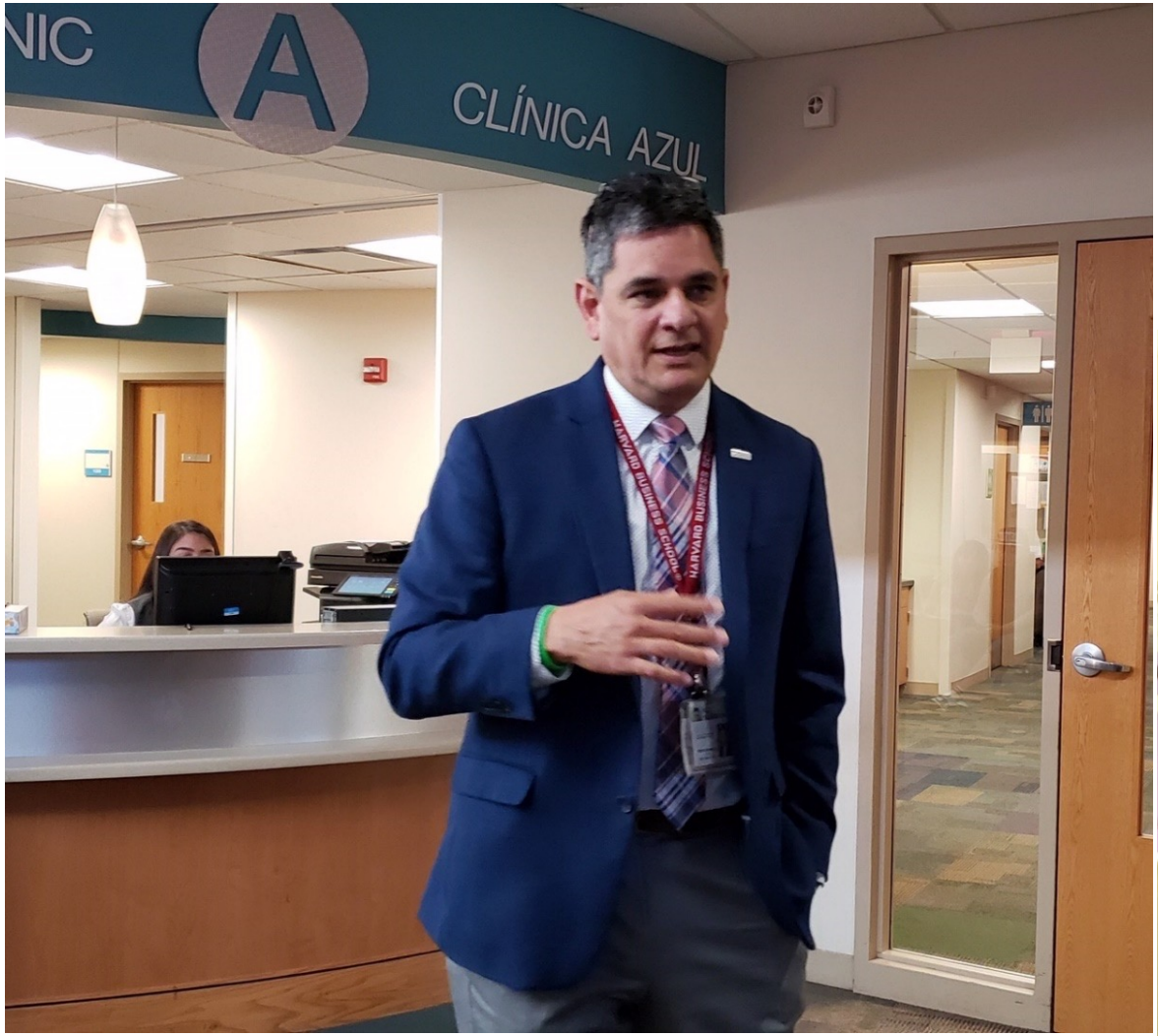

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Community Health And Social Services Center
A Community Partner
of Henry Ford Health System
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2019


www.chasscenter.org


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EXIT

Partnered-process of developing FAM-ACT

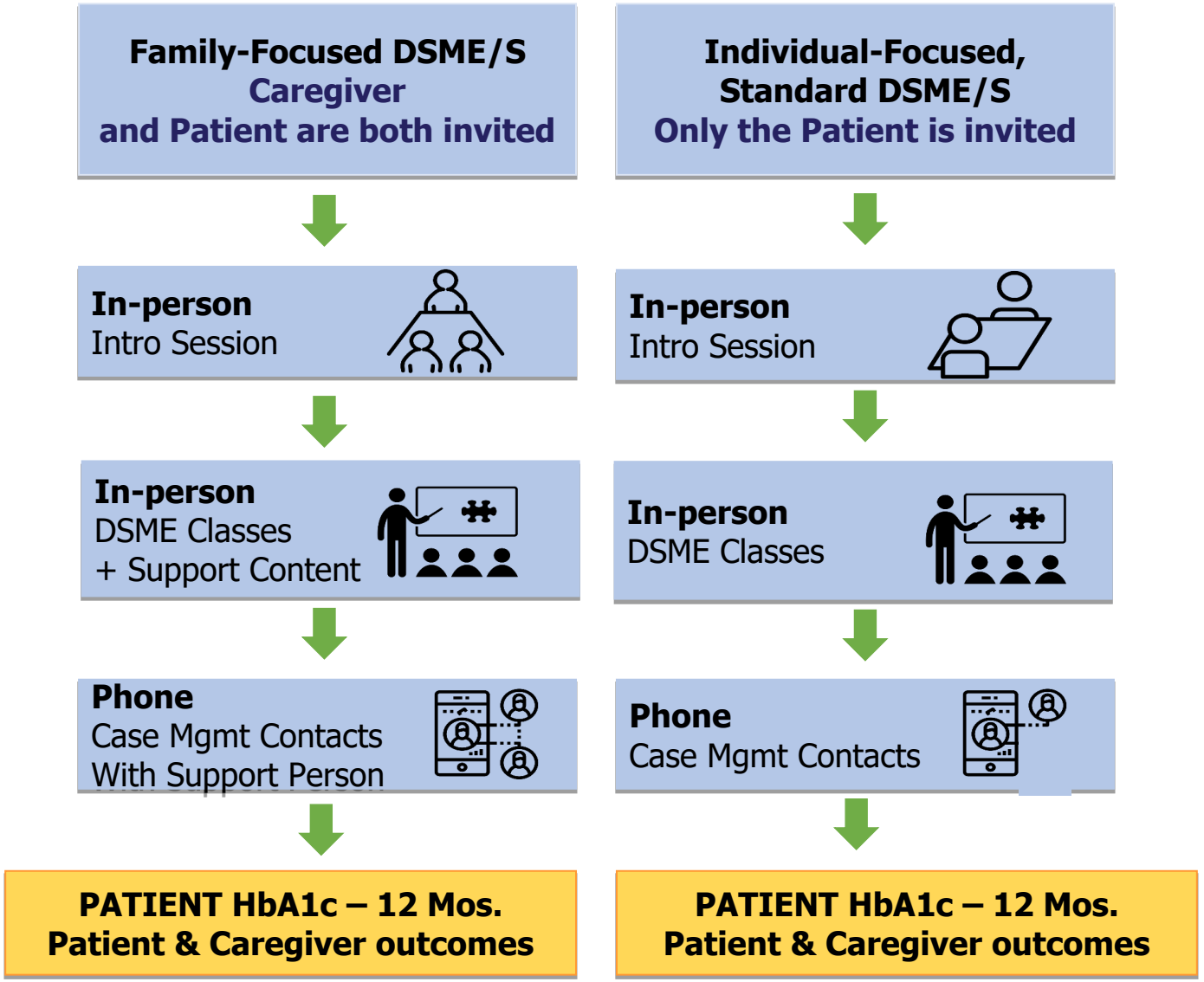
- Recruitment criteria and approach
- Intervention approach and content
- Study surveys and method of collecting data
- Analyses - goals, interpretation
- Community, professional, and policy-maker dissemination in addition to academic



Local Issues to Consider

- Family structures
  - Men come to the area without their families to work
  - Inter-generational family ties
  - Include children in health care visits, day to day activities
- Literacy, language
- Local culture – Puerto Rico, Mexico (specific regions)
- Work – construction, landscape, move to where work is
- Access to resources for childcare, transportation, healthy food
- Environmental barriers, e.g., transportation, safe places to exercise
- Legal status – impacts everyone in family

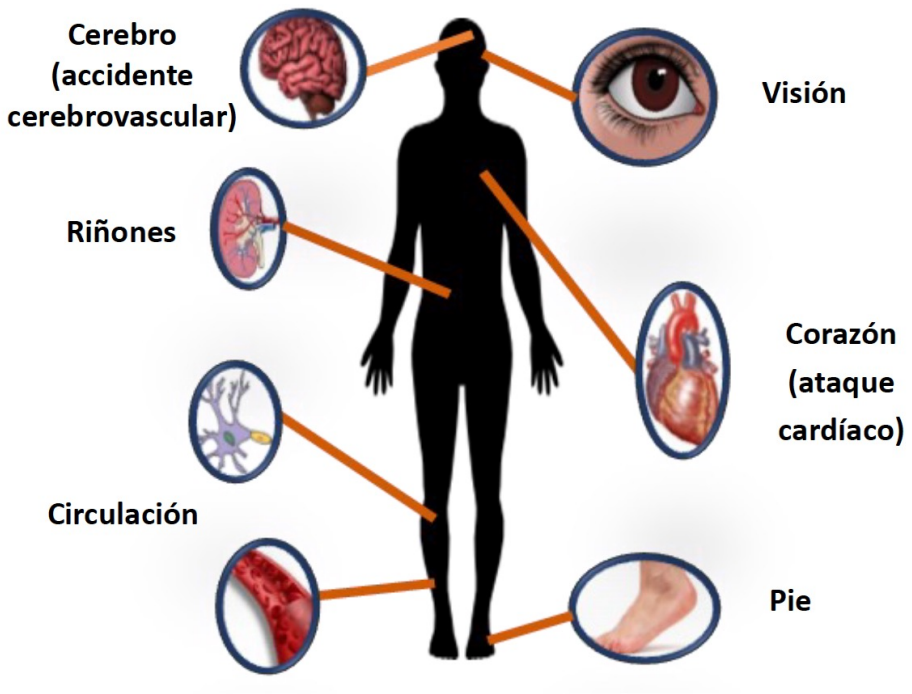
FAM-ACT Trial 1.0: Initial Design



FAM-ACT Tailoring to Culture & Community

- CHW focus groups, then during-study input
  - Latina women may put caring for family well-being above their own health; close friends are part of family
  - Training in diabetes care may reduce family distress
  - Discuss positive ways to provide support before technical aspects
  - Cultural (pictures, food, celebrations) and language tailoring
- COVID impacts on community, and changes to study
  - Personally deliver materials to doorstep
  - Tried online Docusign consent, was not trusted
  - Temporarily delivered (formerly group) intervention sessions to individuals via phone

Posibles Complicaciones de la Diabetes



La <u>buena noticia</u> es que usted puede hacer cambios para reducir sus posibilidades de desarrollar estos problemas.

Nuestro programa le enseñará maneras de reducir su riesgo de padecer complicaciones por la diabetes.

FAM-ACT

Apoyo para una Alimentación Saludable

FAM-ACT

- Haga cambios de alimentación saludable usted mismo.
- Intente hacer nuevas recetas saludables juntos.
- Aliente al paciente para que elija restaurantes que tengan opciones saludables.
- Ayúdelos a mirar de antemano el menú del restaurante.
- Ayude a que el paciente planifique qué comerá en ocasiones especiales.

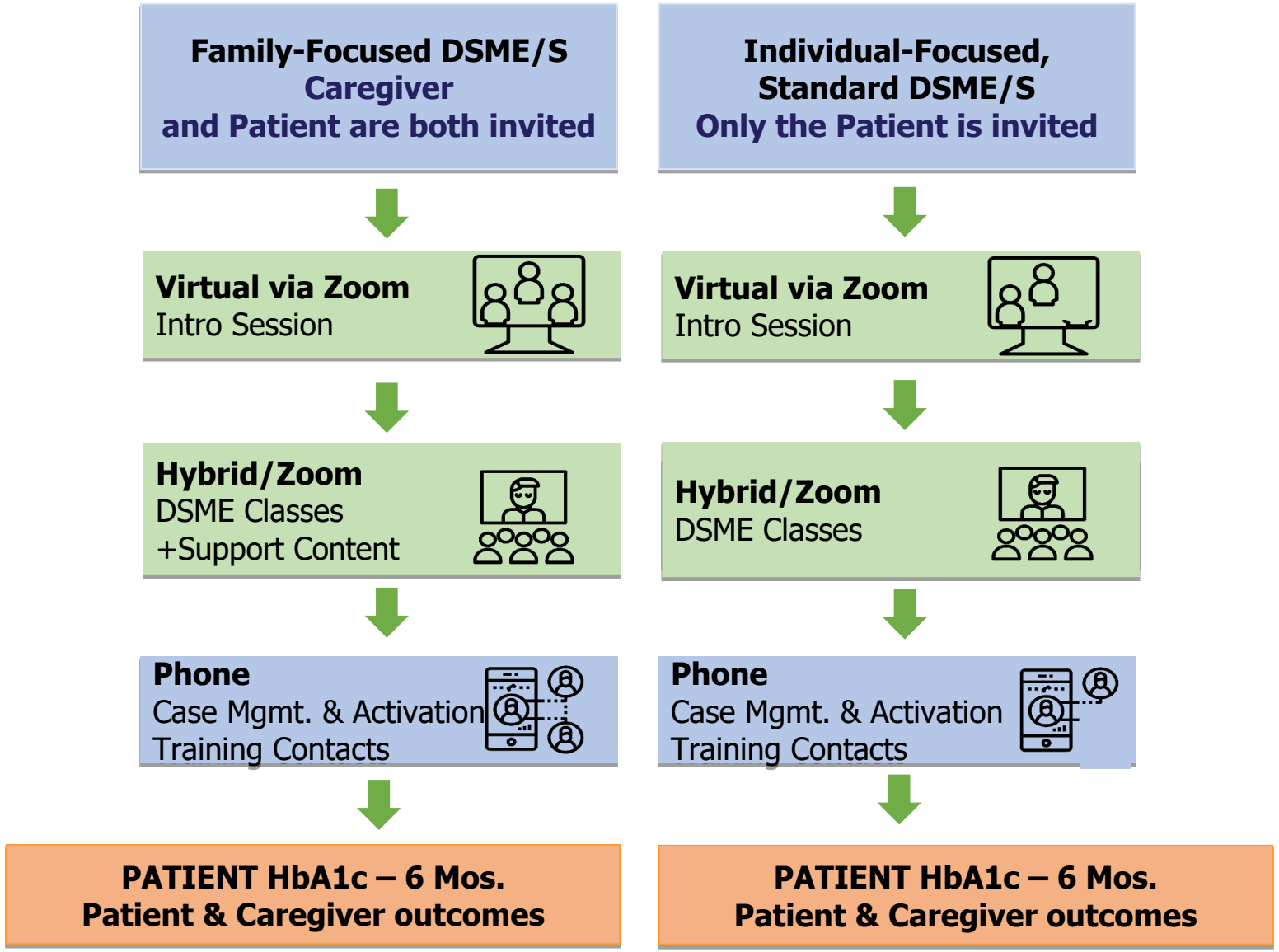


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FAM-ACT Trial 2.0: Post-Pandemic




Alcohol
BAR
Alcohol

Challenges, Lessons Learned for FAM-ACT

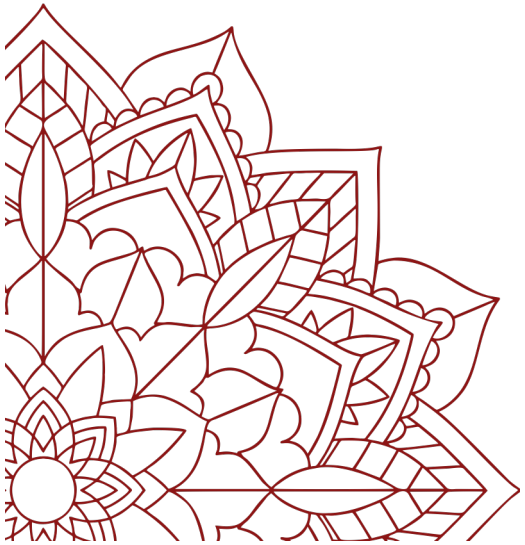
- Specific Challenges
  - Multi-caregiver roles (e.g., parents, siblings, kids, grandkids)
  - Family separation
  - COVID impacts
    - Disparate impact on this community, community clinic, and staff
    - Work roles, caring for children
    - Internet access, comfort using technology, comfort sharing over technology
- Community peer co-designs and does recruitment outreach
- Be flexible, meet people where they are at

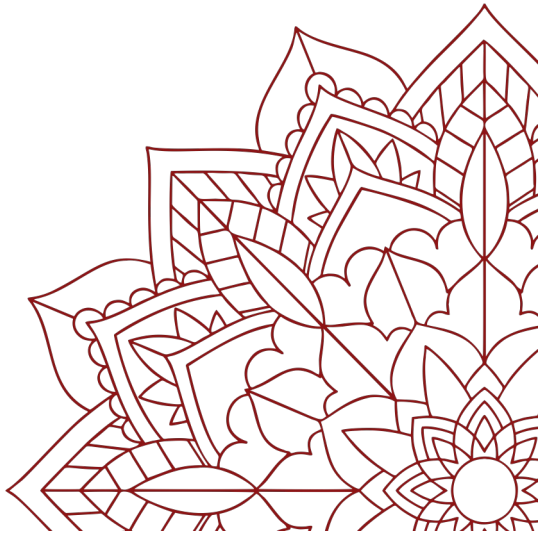
Overall Lessons Learned

- Inclusion, humility, partnership
- Time, effort, communication
- If some communities have challenges participating in research, recruiting and engaging pairs or families from these groups can be even harder!
- Learning goes both ways
  - Demands on caregivers, demands of research process
  - Share information about how research strategies can make the project stronger, and more impactful

The Unmet Cultural Needs of South Asian Breast Cancer Survivors and Caregivers

Ranak Trivedi, PhD





Diversity within South Asian Countries

- 7 countries
- 1.9 billion South Asians
- 5.4 million in the US
- 419 spoken languages
- All major world religions



- Richness of language, culture, and religion within our group

(Stretch break!)

Cultural Commonalities

- Shared cultural experiences

- Special salience in managing breast cancer
  - Role of multiple family members
  - Cancer-related stigma
  - Taboo around sex and reproductive organs

Caregiving is Culturally Determined

- South Asians are Collectivist : Group > Individual

- Motivations and expectations are culturally embedded
  - Intergenerational care
  - Gender roles: 80% caregivers are women, mainly daughter-in-law
  - Men provide financial care

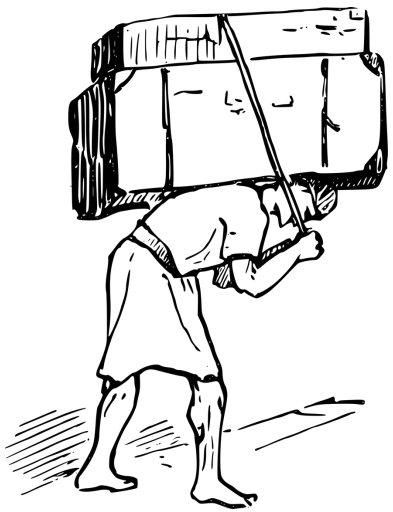
- *Seva* makes it difficult to share negative experiences

Caregiving among South Asians

- 67% of caregivers spend >10 hours per day caregiving

- >50% reported depression, especially if:
  - Cared for a spouse
  - Lived with care recipient
  - Responsible for household chores, $$, transportation
  - Provided 10+ h/day

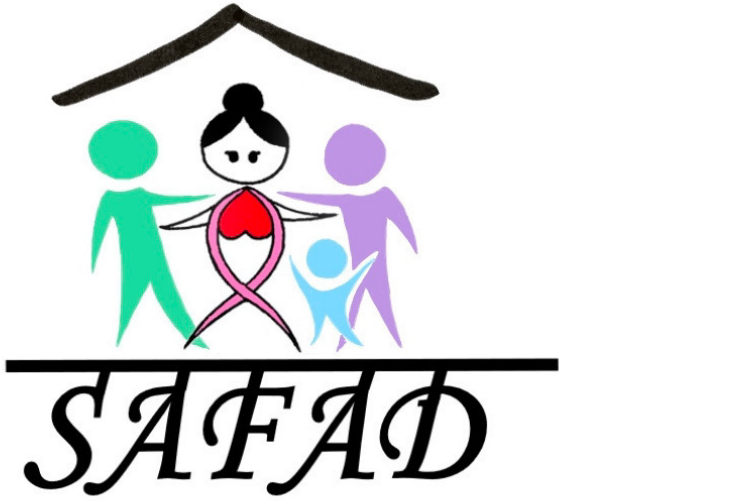
- Everyone was stressed!
  - 18% severe stress
  - 82% had moderate stress



Health Care Systems are not Culturally Attuned

- Health literacy and language barriers inhibit care
- Built environment does not accommodate multiple family members
- Default primary caregiver is assumed to be the partner
- Lack of disaggregated data inhibits data-driven questions around quality, satisfaction, utilization, and outcomes

SAFAD: South Asian Family Approaches to Diseases



STUDY GOALS



- Understand the experiences and unmet needs of **South Asian women living with breast cancer and their family members and friends**
- Understand **from providers** what the health care system can do to address cultural needs of South Asians

Mixed Methods Study

- Semi-structured interviews with
  - Breast Cancer Survivors
  - Caregivers
  - Multidisciplinary Providers
- Atlas CareMaps (posters)
- Psychosocial surveys (data analysis)

SAFAD
South Asian Family Approaches to Disease

DOMAINS

SURVIVORS/CAREGIVER

NIMHD Framework

Coping

- The way patients & caregivers have coped with the breast cancer diagnosis & experience

Cancer

- The history & diagnosis of breast cancer
- The recommended and selected treatment
- The fear of cancer recurring
- The concerns of the future (death/dying)

Acculturation

- The cultural identity of South Asian patients & caregiver who live in the United States

Stress

- The extent of which patients & caregivers have experienced stress

Cultural Background & Medical Care

- The cultural needs, support, & experiences when receiving medical care

Caregiving

- The relationship between the caregiver & the patient
- The communication between the caregiver & the healthcare providers
- The positive & negative experiences gained from caregiving

Quality of Life

- The physical function, mental state, sleep, pain, & social capabilities of patients & caregivers

Home & Community Supports

- The home & community resources used in managing breast cancer

"What are 3-5 things you need to take care of yourself?

Recruitment Strategies



- Website, fliers in the community (e.g., Indian grocery stores)
- Community talk at the Indian Community Center
- Two talks with the Bay Area Chapter of the American Association of Providers of Indian Origin (AAPIO)
- Outreach through the Community Advisory Board
- Epic Chart review based on last name

WHAT WE HAVE LEARNED

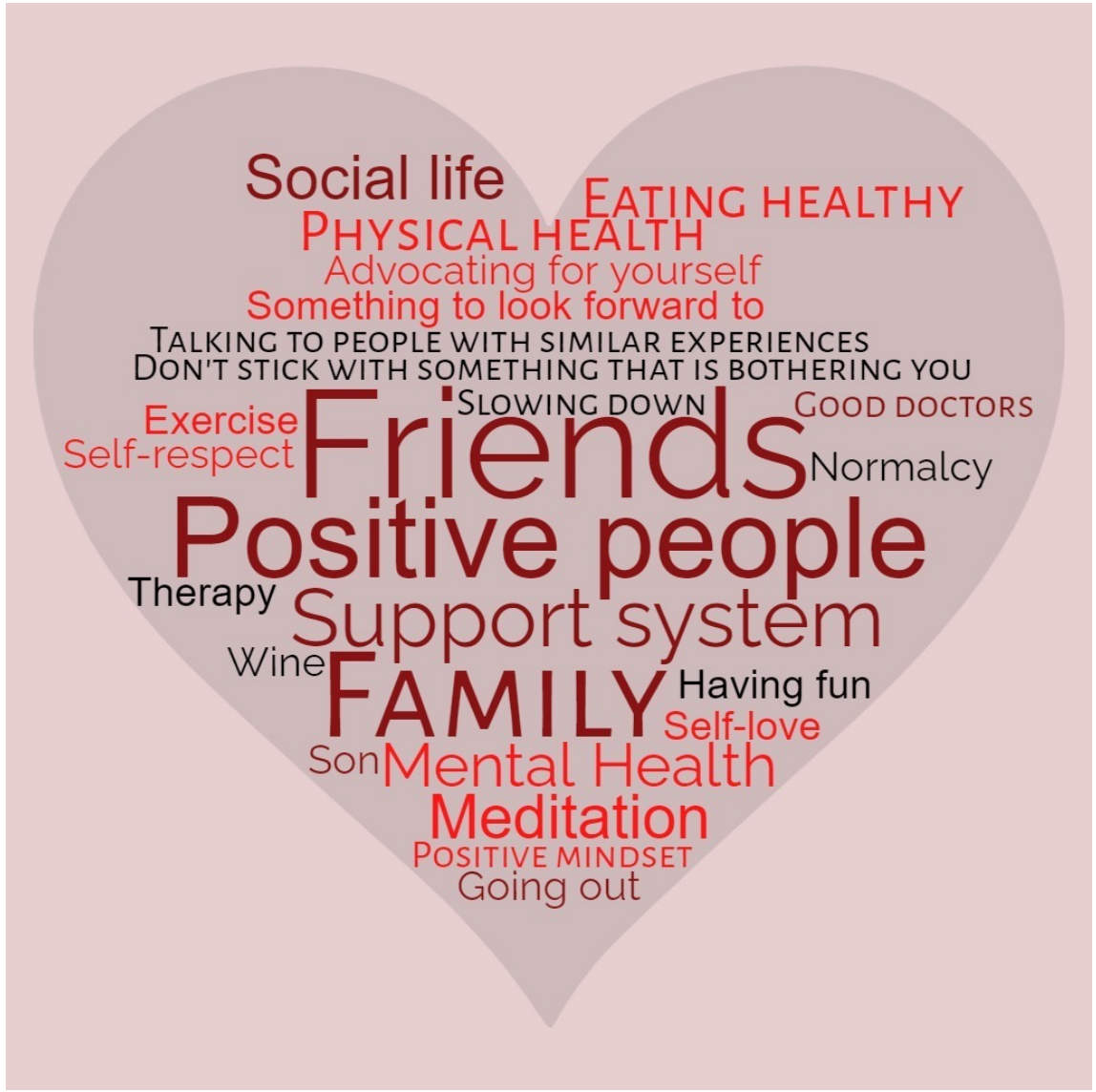
SURVIVORS CAREGIVERS



- Reluctance to share diagnosis with friends and family in India and older generations
- High levels of trust in their medical care
- Seek lifestyle recommendations to manage cancer and prevent recurrence
- Caregivers seek greater engagement with care teams, and greater support from their social networks

Survivors

"What are 3-5 things you need to take care of yourself?"



Quotations

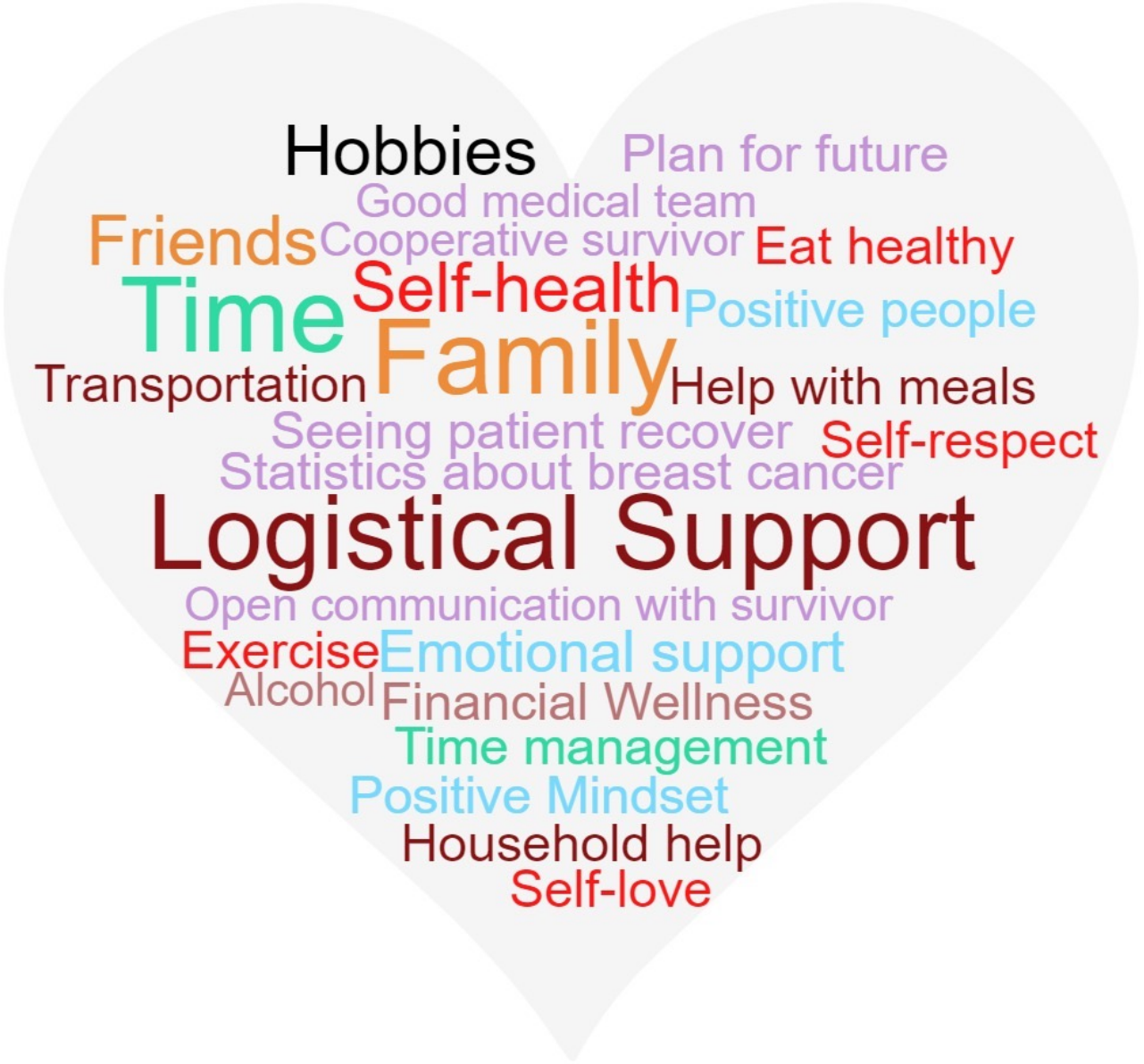
I'm not scared about anything that the cancer has made me. I believe more in God, more spiritual. And I'm ready to accept what comes.

I shared it with my sister…my sister-in-law, and one of my friends. But I did have my in-laws at our house, but I didn't share this information with them because I thought they might be too anxious or be more sad. I didn't want to share it with my parents or in-laws.

SAFAD
South Asian Family Approaches to Disease

Caregivers

"What are 3-5 things you need to take care of yourself?"



Quotations

I think it’s just the time management, like I have a full-time job, then I have to take a break in between, and then take her. But right now, at least, since it’s all remote work, it’s okay. I think I do see a challenge when I have to go back to the office and then I have to come back, take her to appointments, and all that, so that will be more inconvenient at that time than right now.

People like you and others who are in this line of work need to appreciate and understand that you're doing God's work. You're helping the patients but you're not only helping the patient you're helping everybody that's around the patient, their families, their co-workers and to keep doing what you do and continue doing it with a sense of empathy. Thank you.

SAFAD
South Asian Family Approaches to Disease

WHAT WE HAVE LEARNED

PROVIDERS

- There is a greater involvement of family and friends in South Asian patient's medical care
- Engaging with caregivers harder during COVID
- Providers recognized a stigma around cancer among South Asians patients
- Need for materials to in South Asian languages
- Providers struggle with reconciling opposing values e.g., pain management, end of life

SUMMARY

NEXT STEPS

- Key unmet needs are:
  - Lack of culturally and linguistically concordant materials
  - Lack of recognition of caregiver needs
- Developing culturally concordant care systems will involve recognizing the cultural context AND supporting health care providers
- Next steps: Developing programs to enhance connections and develop materials

CHALLENGES, LESSONS LEARNED

- South Asian minority myth
- Lack of disaggregated data in EHR
- Participating in research is not common
- Unlike many, high trust in health care
- Recruitment extra challenging by COVID19
- Community partners were willing
  - Outreach did not yield participants
  - Interested in other topics
- Limited variability in SES
- Need to expand community partnerships

FUTURE DIRECTIONS

- Moment is right to bring the lens of systemic contributors of health disparities to our work
- Understudied groups BELONG in research and their perspectives strengthen all of us
- Understanding diverse perspectives is critical to advancing science, developing educational curriculum, and to inform policy

Thank you!

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