

LIVE WEBINAR

Strengthening Complex Care Through Family Caregiver Integration

MARCH 24, 2026

1:00PM - 2:00PM ET

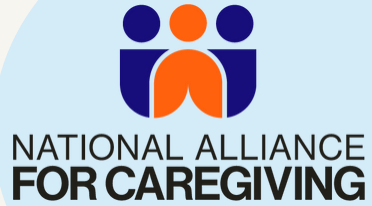


About Us

Established in 1996, the National Alliance for Caregiving (NAC) is a system change organization transforming how we value the **63 million family caregivers** through **research**, **advocacy**, and **narrative change**.

Our Network





Priorities



Champion Caregiver Health & Wellness



Drive Economic Inclusion



Foster Caregiver Friendly Communities

Caregivers as Essential Partners in Care

Yadira Montoya, Director of Programs

The **Cancer Caregiving Collaborative** is dedicated to championing systemic change that ensures cancer caregivers receive the equitable support, training, and financial relief they deserve.

Healthcare Integration

Champion the equitable integration of family caregivers into cancer care teams by optimizing reimbursement pathways to increase access to high quality training, educational resources, and support services.

Financial Health

Address the financial toxicity of cancer caregiving by advocating for smart and equitable economic policies.



Caregiving Without a Roadmap: Insights from Cancer Caregivers

February 2026



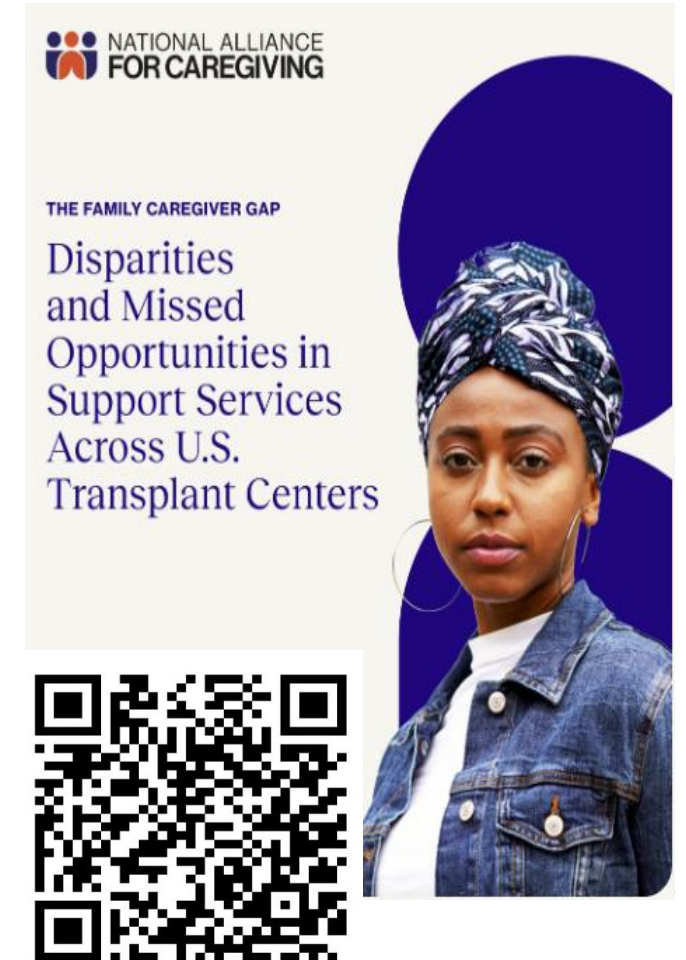
The **Transplant Caregiving Collaborative** focuses on enhancing the recognition, inclusion, and support of family caregivers within the transplant system.

Champion Practice Change

Mobilize stakeholders across the transplant ecosystem to enhance caregiver support at transplant centers.

Advocate for Federal Reform

Include caregiver support in federal reform transplant system policies



Complexity & Intensity of Caregiver Demands

- 7 in 10 caregivers monitor the severity of their recipient's health condition
- Assist with 2 of Activities of Daily Living (ADLs) and 5 Instrumental Activities of Daily Living (IADLs).
 - ➔ **Only 11% report receiving any training**
- More than half (55%) of caregivers routinely take on medical and nursing responsibilities
 - ➔ **Only 22% report receiving training**
- **This is the core challenge: high responsibility, low support**

Percentage of caregivers who report being in an intense caregiving situation

57%



The Support Caregivers Need

- **Stress & Emotional Support**
 - ➔ 30% need help managing emotional and physical stress
- **Information & Training on Safety**
 - ➔ 27% need guidance to keep their care recipient safe at home
- **Help Navigating the System**
 - ➔ 26% need assistance managing their recipient's paperwork and eligibility for services
- **Care Coordination**
 - ➔ 26% report coordinating care is “very” or “somewhat difficult”

Recognition and Support

33%

Of the family caregivers want policies that require health care professionals to assess their needs to care for their recipients

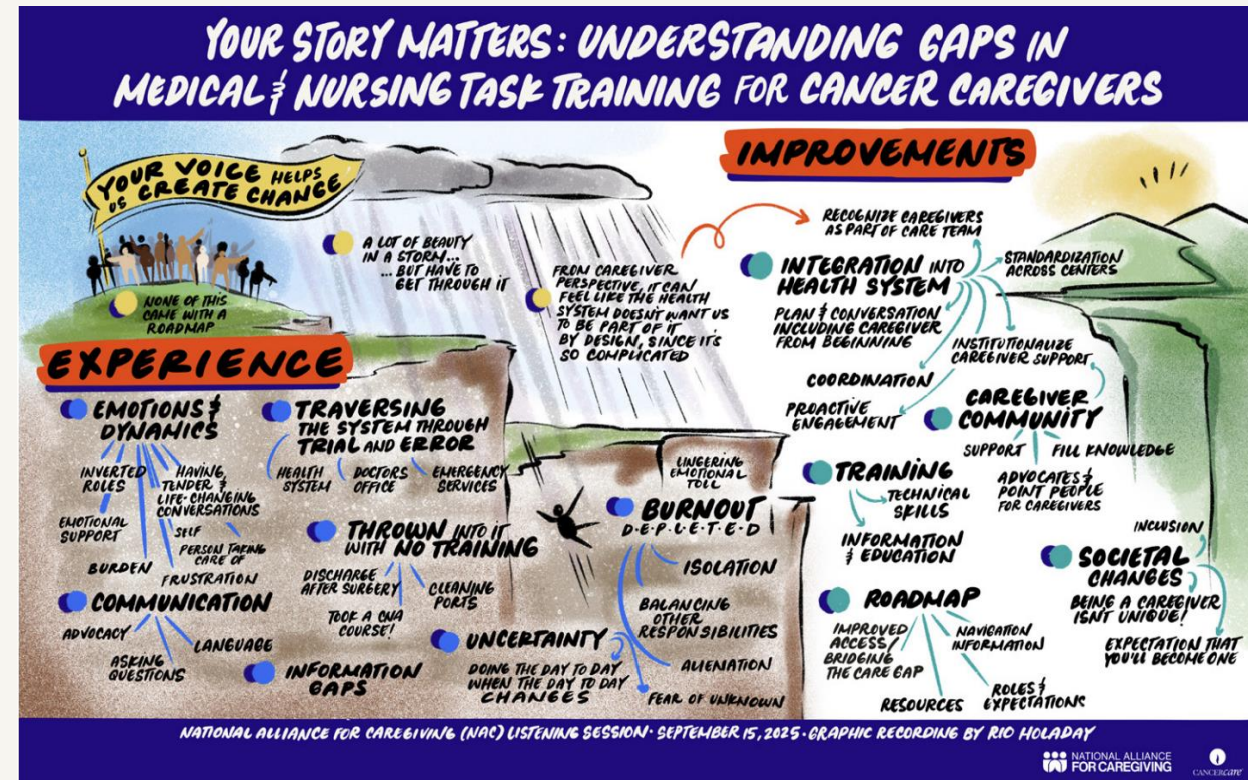


"My frustration was with information. You can't make a really informed decision if you don't have all the pieces."

- Jesus , Transplant
Caregiver

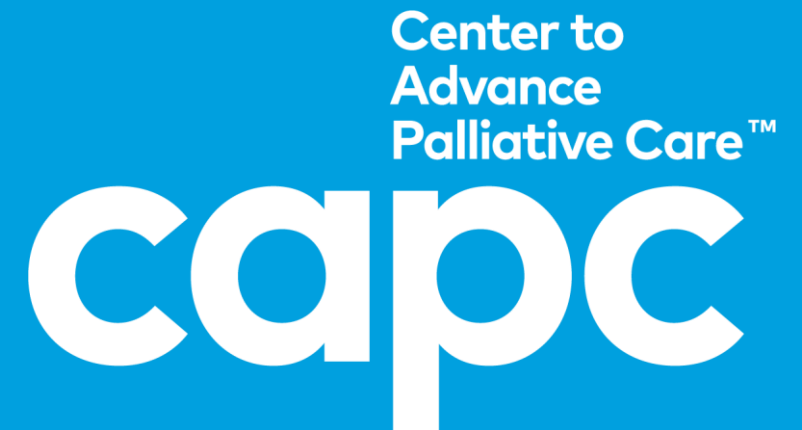
Building a System that Supports Family Caregivers

- Why Supporting Caregivers Matters
 - Caregiver support is both compassionate and cost effective, reducing strain on health systems and improving outcomes.
- The Road after Transplant
 - Even when life-saving treatments are successful, they may initiate, not conclude, a long, complex recovery journey for both patients and caregivers.
- Psychosocial Support as a Strategic Imperative
 - Caregivers emotional, social, and mental health needs influence their ability to provide effective care and maintain their own health and wellbeing.

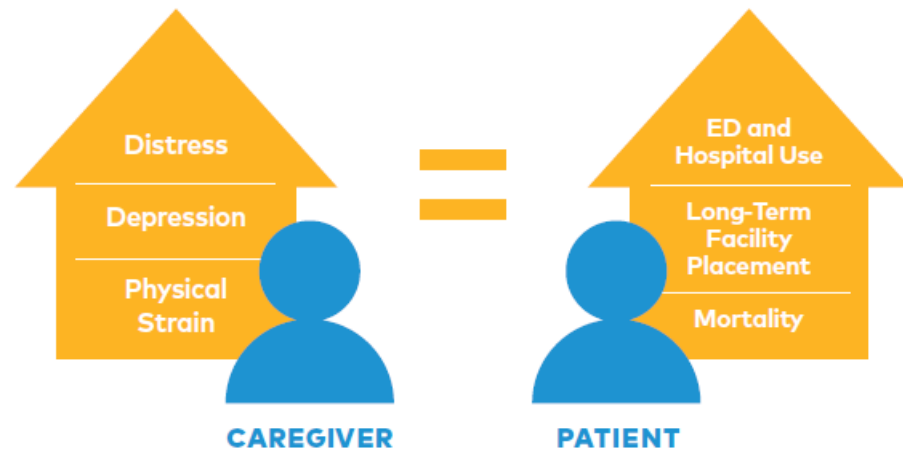


The Business Case for Supporting Family Caregivers

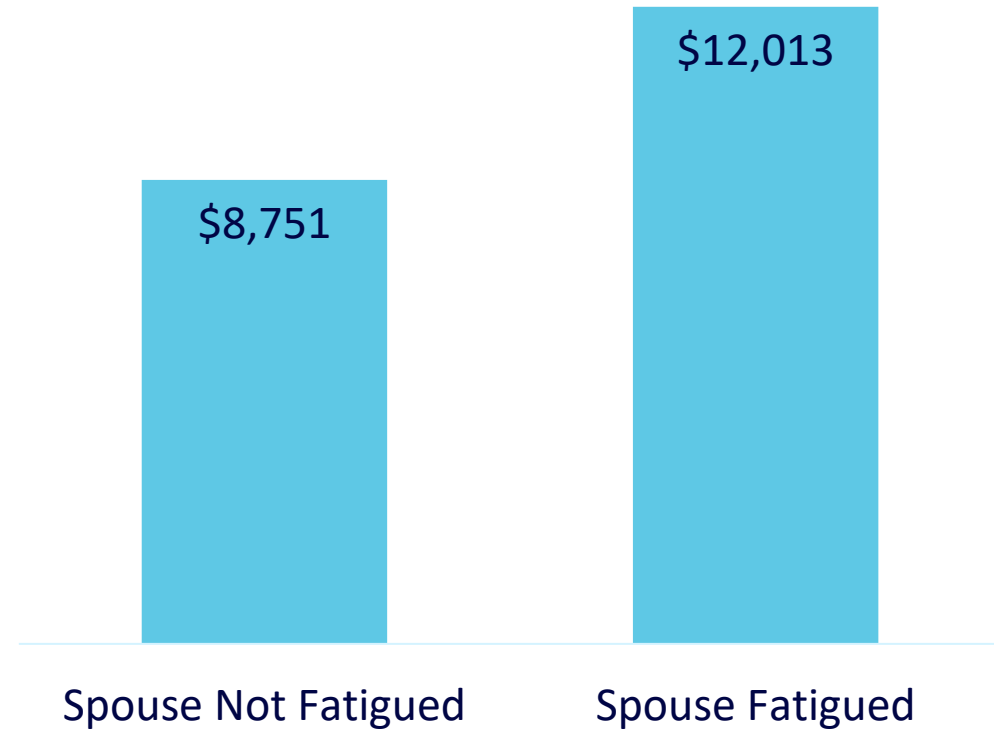
Allison Silvers, MBA
Chief, Health Care Transformation
March 24, 2026



Caregiver Well-being Drives Patient Outcomes

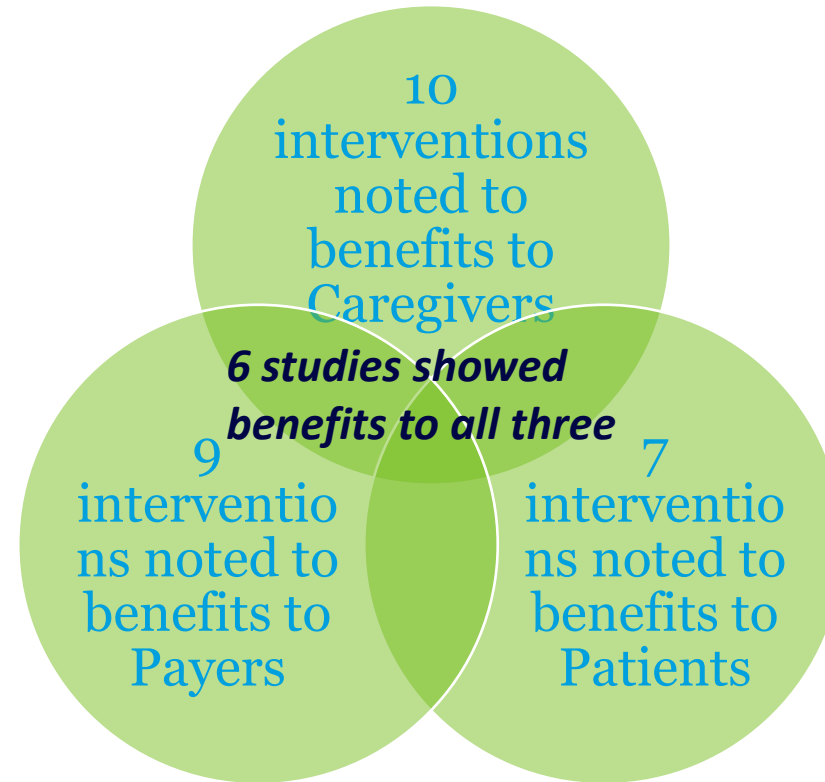


Patient's Health Care Expenditures
based on Spousal Fatigue



Healthcare Organizations Providing Caregiver Support Produce Benefits to All Parties

A recent literature review found 11 articles reporting outcomes of caregiver support interventions



Hospital-Based Psychosocial Caregiver Support Programs Can Be Financially Self-Sustaining

Annual Revenue		
Psychotherapy Services	\$	364,143
Medical Services	\$	98,690
Caregiver Training and Other Services	\$	17,071
Total Annual Revenue	\$	479,904
Annual Expenses		
Salaries (1CP, 1LCSW, 0.5NP,0.5Admin)	\$	297,500
Fringe Benefits (31%)	\$	92,225
Overhead and Allocations	\$	95,981
Total Annual Expenses	\$	485,706
Annual Net Revenue	\$	(5,802)

Caregiver must have his/her own medical record

Additional Benefits Accrue to Healthcare Organizations Providing Caregiver Support Services

- Screening for caregiver burden on its own creates a **positive perception** of the hospital
- Caregiver support services can be a positive **public relations opportunity**
- New services for new populations create **new opportunities for philanthropy and grants**
 - Grateful patients AND grateful caregivers
- Improved patient outcomes from improved caregiver well-being **enables performance bonuses** under value-based payment arrangements

The Case for Caregiver Support

Better Outcomes for People
and Organizations

Learn More

capc.org/caregiver-support-initiative/



INCITE

Increasing caregiver support
implementation through
training and education

What's in the Toolkit

Securing Organizational Support



Caregiver Support Program Development



Budget and Billing



Clinical Training for Caregiver Well-Being



Additional Resources for Caregiver Support Programs



Burdens of Therapy:

**AST's National Patient Survey of
Unmet Immunosuppressant Needs**



D. Taber¹, M. Jesse², J. Peipert³, L. Myaskovsky⁴, R. George⁵, E. Gordon⁶, M. Chisholm-Burns⁷, J. Gill⁸

¹MUSC ²HFHS ³BHAM ⁴UNM Medicine ⁵Childrens Atlanta ⁶VUMC ⁷OHSU ⁸UBC.

Background

- Organ transplant is the gold-standard treatment for end-organ disease
- **But...**
 - Transplant patients continue to die at rates **two to eightfold higher** than age matched persons from the general US population
 - Nearly half of all recipients remain **chronically disabled after transplantation**
 - Transplantation is a **treatment, not a cure**, for end-organ failure

Background

- Transplant care is never fully managed by recipients alone
- Family caregivers frequently assist with:
 - Complex immunosuppressive medication regimens (adherence)
 - Monitoring and reporting symptoms and side effects
 - Coordinating frequent clinic visits and laboratory testing
 - Supporting recovery during episodes of infection or other complications

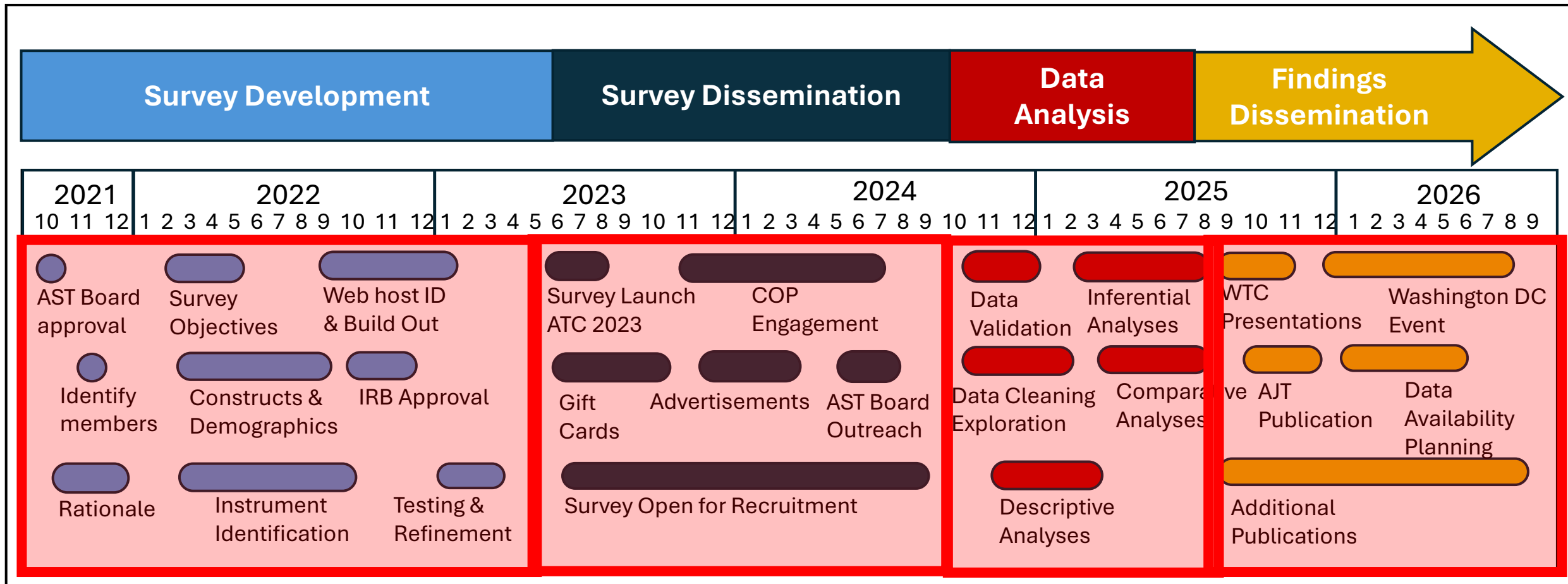
Goals and Objectives

- AST endorsed a large-scale survey be conducted among a representative cohort of transplant recipients
- The aim of this survey was to assess transplant recipient's perspectives on immunosuppressive therapies and unmet needs
- Today's presentation will provide these findings and discuss how these can potentially impact caregivers

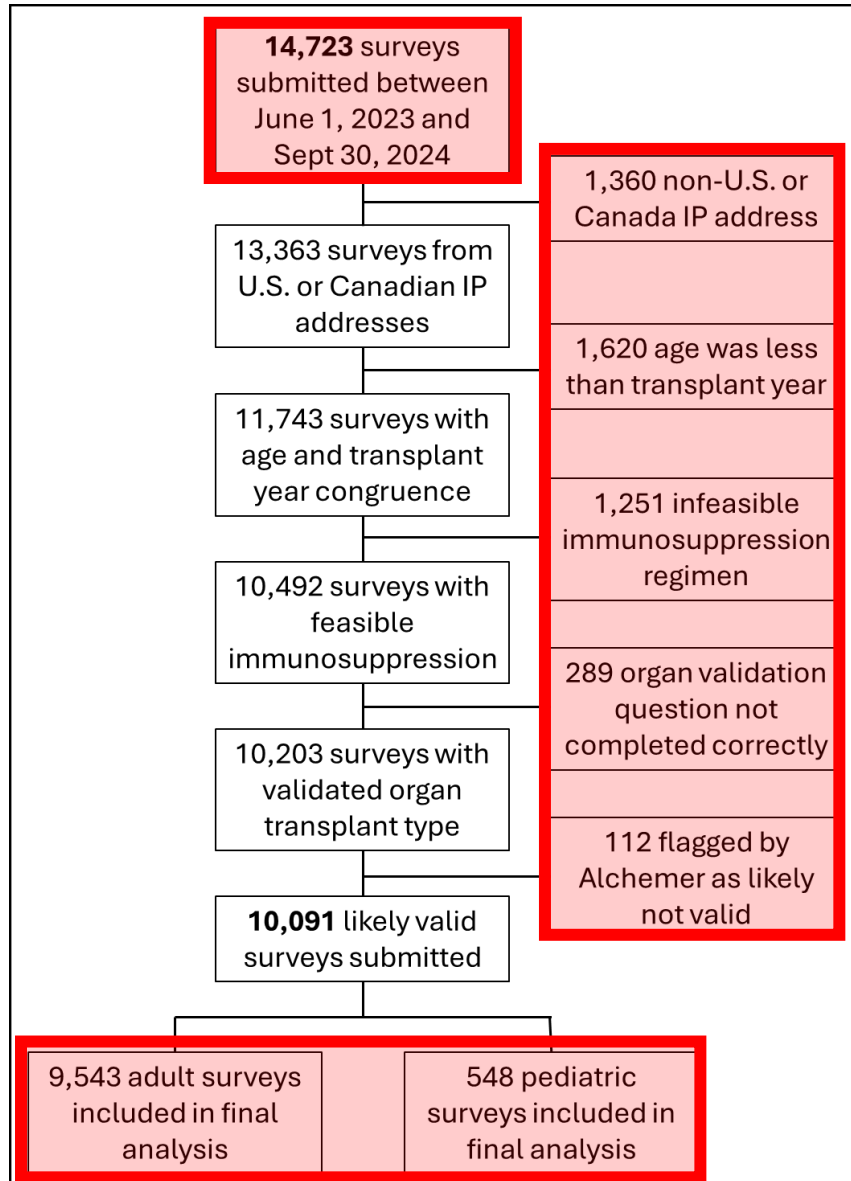
Methods – Study Design

- IRB-approved web-based survey of pediatric and adult organ transplant recipients
- Participants were recruited directly or through transplant professionals affiliated with AST
- Inclusion criteria
 1. Self-identified or identified by parent/guardian as an organ transplant recipient
 2. Legal adult, based on residence criteria (≥ 18 years of age, with the following exceptions: ≥ 19 in Nebraska and Alabama, and ≥ 21 in Mississippi)
- Exclusion criteria
 1. Not based in the U.S. or Canada
 2. Did not provide informed consent to taking and completing the survey
 3. Provided inaccurate or blatantly fake responses, based on a pre-developed survey validation system

Methods – Survey Process



Results



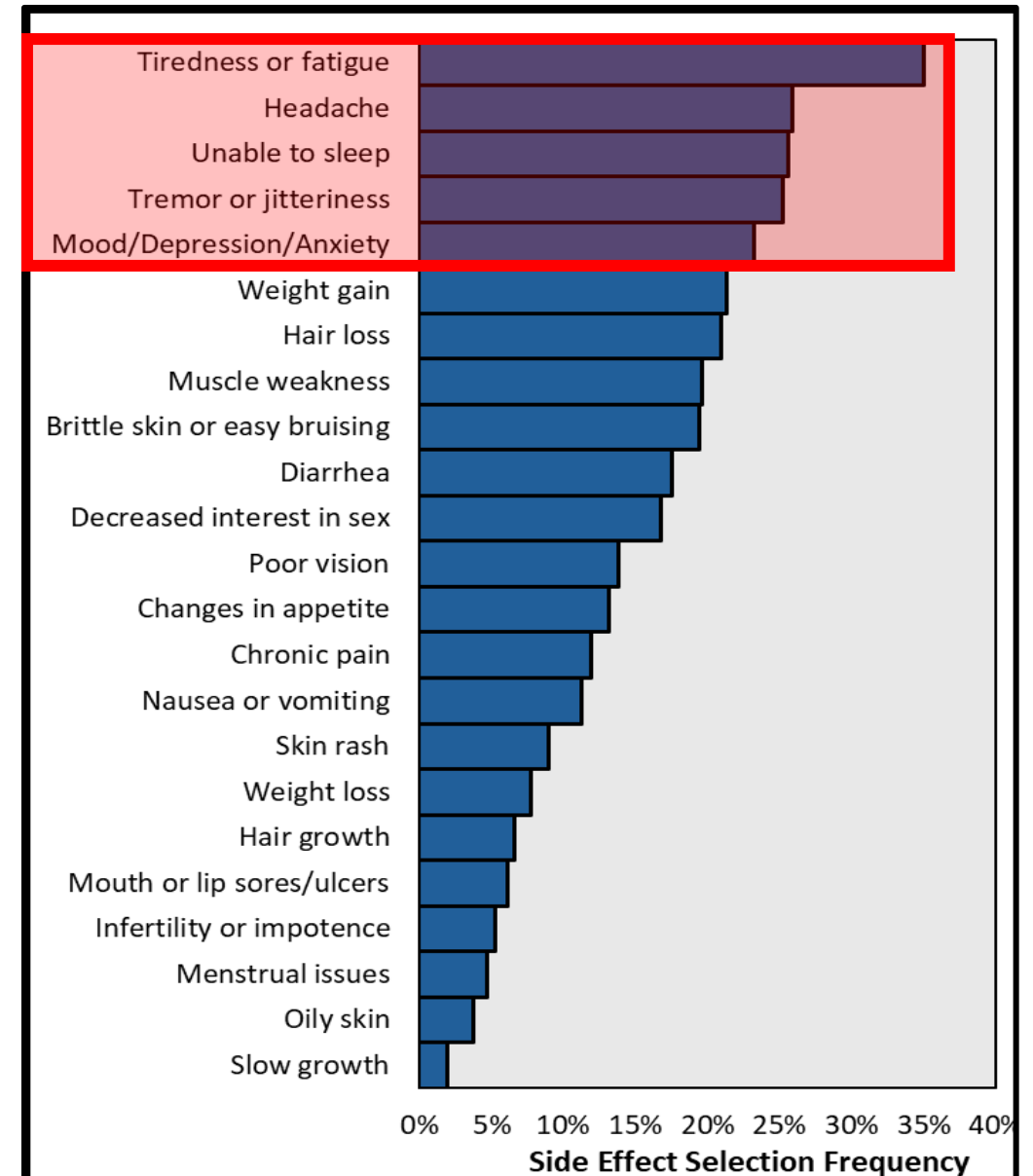
- Nearly 15,000 surveys submitted over a 16-month period
- Most were removed for being outside the US/Canada or invalid responses
- Final number of over 10,000 with a good representation of adult and pediatric recipients

Representativeness with Target Population

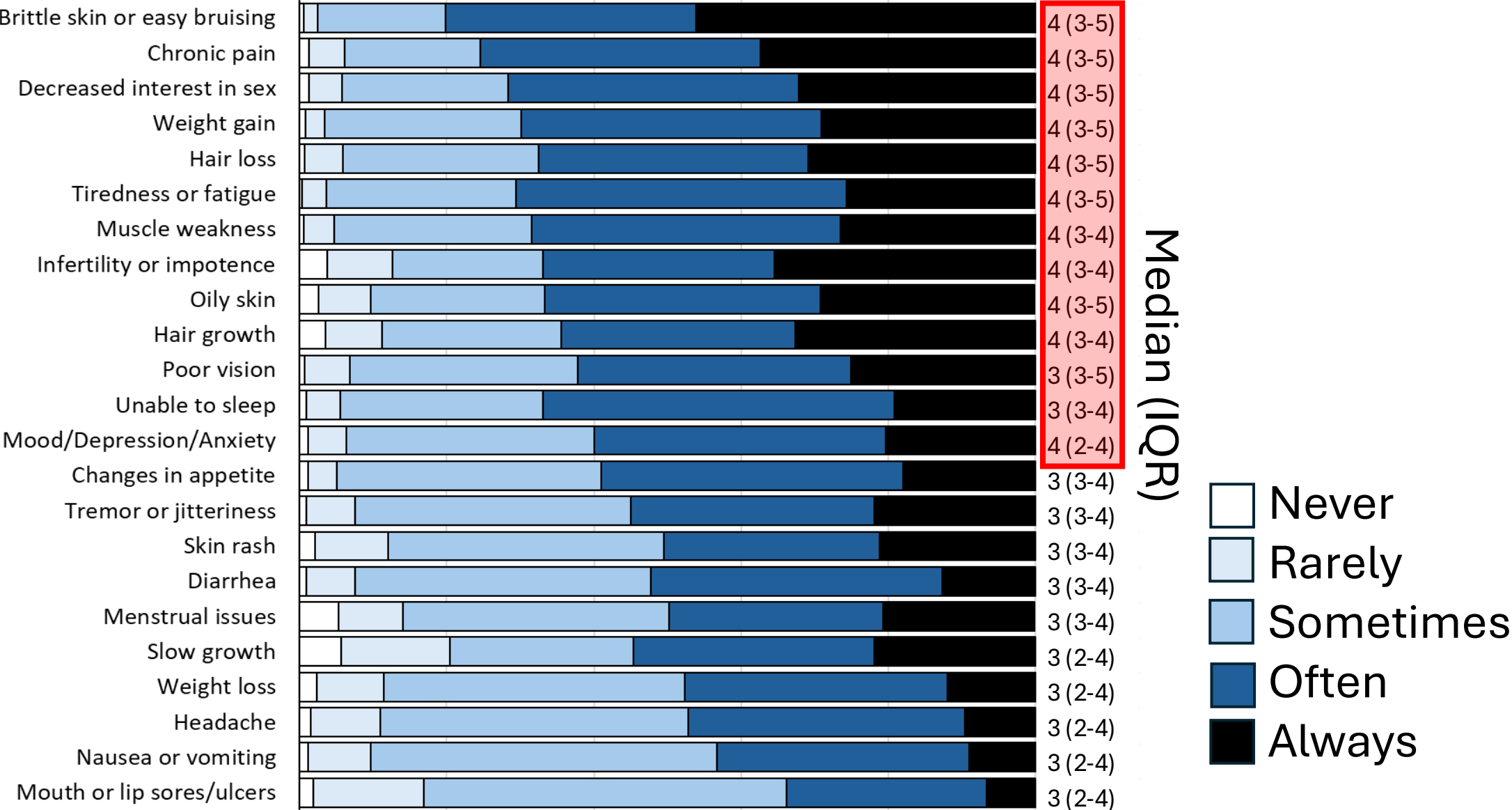
- Sample of 10,091 represents ~2.6% of last 10-years of transplants completed in the U.S.
- Mean age 47 ± 18 years
- 50% male, 50% female
- 70% White, 15% African-American, 12% Hispanic, 2% Asian
- 52% insured by Medicare, 21% Medicaid, 52% private, 1.2% uninsured

Side Effect Incidence

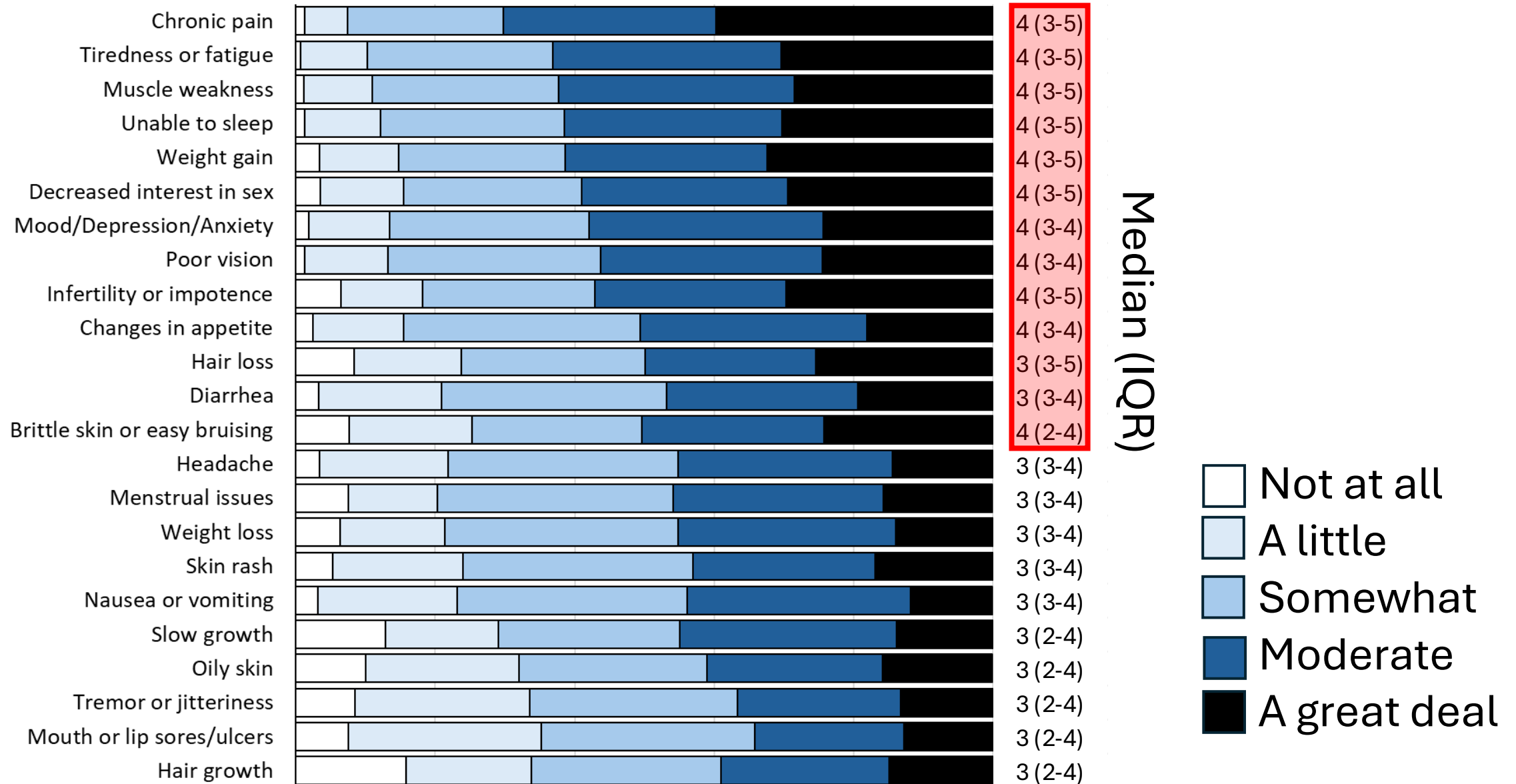
- Respondents could select up to 23 side-effects and write-in up to 3 additional side effects
- **92% selected at least one side-effect**
 - **Median of 3 (IQR 1-5) side effects selected per respondent**
- Fatigue, headaches, insomnia, tremors, and mood were the top 5 selected side-effects



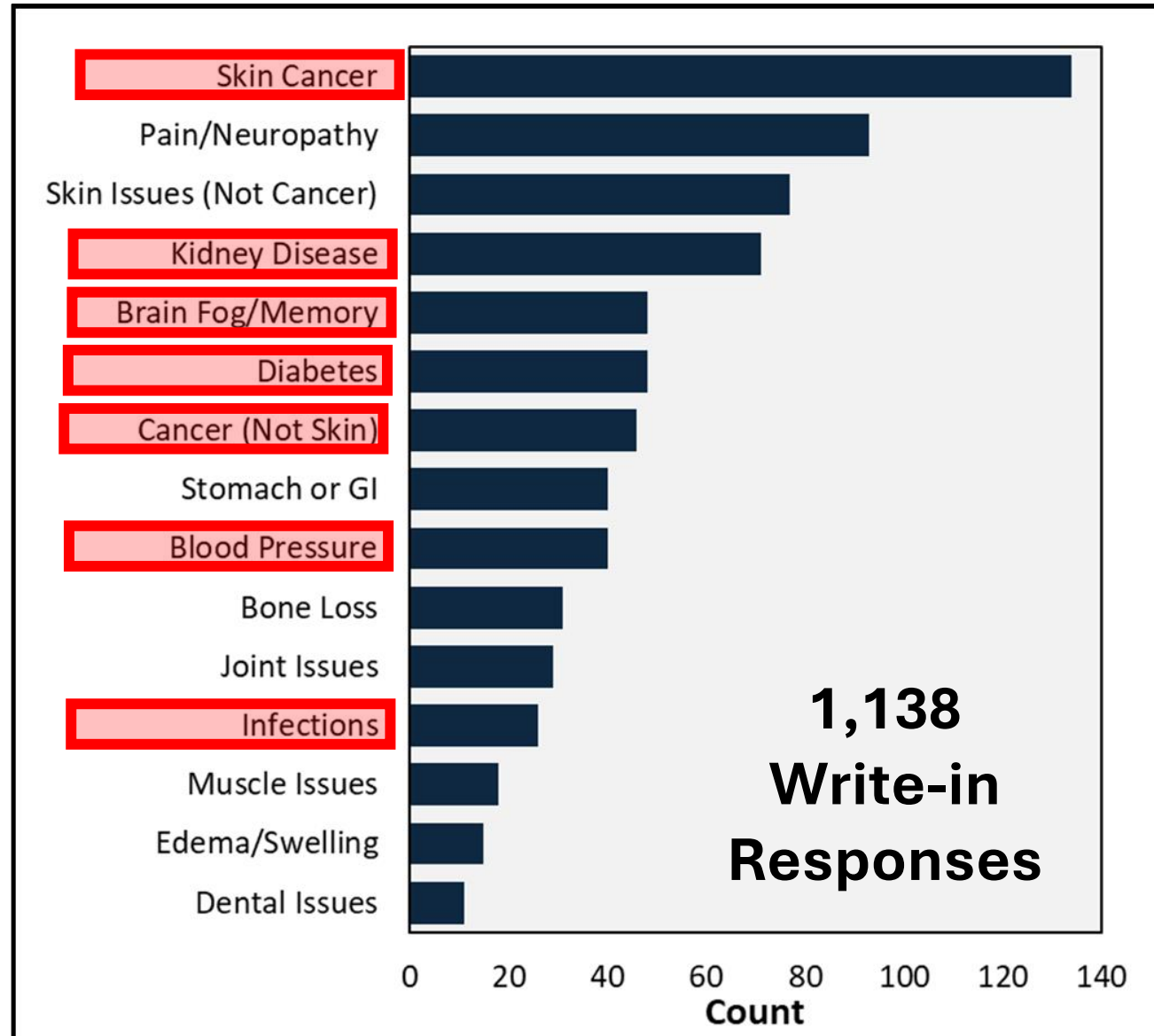
How Often is the Side Effect Occurring?



How Much is the Side Effect Impacting Daily Life?



Side Effect Burden and Write-In Responses



Quality of Life

Measure	Poor	Fair	Good	Very good	Excellent	Mean (SD)	Median (IQR)
Health-related quality of life	3%	16%	33%	29%	11%	3.30 (1.01)	3 (3-4)
Physical health	5%	22%	35%	23%	8%	3.08 (1.01)	3 (2-4)
Mental health	4%	18%	31%	27%	13%	3.30 (1.07)	3 (3-4)

- One in five transplant recipients rate QOL as fair or poor
- Physical health tended to be rated lower than mental health in adults

Treatment burden

Measure	Not applicable	Not at all	A little	Some what	Quite a bit	Very much	Mean (SD)	Median (IQR)
Schedule and keep track of medical appointments	2%	43%	15%	13%	11%	8%	2.13 (1.40)	2 (1-3)
Problem to monitor health conditions	2%	41%	16%	15%	11%	7%	2.13 (1.35)	2 (1-3)
Bothered by feeling dependent on others for healthcare needs	4%	24%	19%	18%	15%	1%	2.57 (1.46)	2 (1-4)
How much self-care interfered with ability to travel for work or vacation	3%	20%	20%	19%	17%	14%	2.74 (1.46)	3 (1-4)
Concerned transplant is losing function	2%	29%	17%	15%	15%	14%	2.59 (1.50)	2 (1-4)
Concerned about body rejecting transplant	2%	19%	22%	19%	15%	16%	2.77 (1.44)	3 (2-4)
Concerned about developing an infection	2%	12%	19%	22%	18%	19%	3.07 (1.38)	3 (2-4)
Concerned about developing a cancer of any type	2%	11%	18%	23%	18%	21%	3.14 (1.39)	3 (2-4)

What These Findings Mean for Family & Caregivers

- Medication Side Effects Create Ongoing Caregiver Responsibilities
 - 92% of recipients reported medication side effects
 - Common issues: fatigue, tremors, insomnia, headaches, mood changes
 - Caregivers often assist with:
 - Monitoring symptoms and complications
 - Encouraging medication adherence
 - Helping patients manage side effects that interfere with daily activities
- Treatment Burden Becomes a Shared Responsibility
 - Recipients reported challenges with:
 - Managing complex medication regimens
 - Coordinating frequent clinic visits and lab monitoring
 - Ongoing concern about infection, cancer, and graft failure
- Implications for caregivers
 - Increased time commitment
 - Care coordination responsibilities
 - Emotional and cognitive load of managing chronic medical complexity

Summary and Conclusions

- **This survey of more than 10,000 US and Canadian transplant recipients demonstrated:**
 - Medication side-effects are substantial issues with clear unmet patient needs
 - Infections and cancers were rated with more concern as compared to loss of graft function and rejection
 - Kidney disease, brain fog, hypertension, and diabetes were well recognized by respondents as common and debilitating side-effects of immunosuppression
- **Findings support the ongoing call for improved caregiver support programs in transplantation**
 - One that places comparable emphasis on caregiver burdens and how both support the patient AND the caregiver through the post-transplant journey



WTC 2025

World Transplant Congress
San Francisco, USA | August 2-6

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Thank You to Survey Committee Members, Transplant Community Advisory Counsel, Transplant Families, AST Staff, AST members, and most of all our Patients & Caregivers





Stanford
University

~~Enabling~~ Empowering Family Caregivers to be Valued Members of the Health Care Team

March 24, 2026

Ranak Trivedi, PhD, FSBM, FGSA

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&

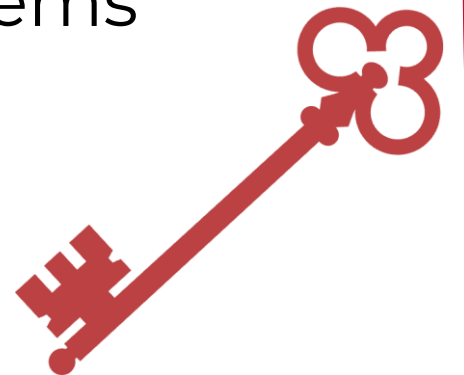
Director of Caregiving and Family Systems

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No financial conflicts of interest to disclose.

Key Takeaways

- Family caregivers can play important roles in managing the health of those with serious illnesses
- Empowering caregivers will require changes at all levels
- Micro level: mitigating individual and interpersonal barriers
- Macro level: Improving policies and health care systems





A story of dyadic caregiving

Worldwide Prevalence of Illnesses

- An estimated 95% of the world's population has health problems
- Over a third have multiple chronic conditions
 - 75% of older adults in developed countries
- Many of these are advanced and serious health conditions



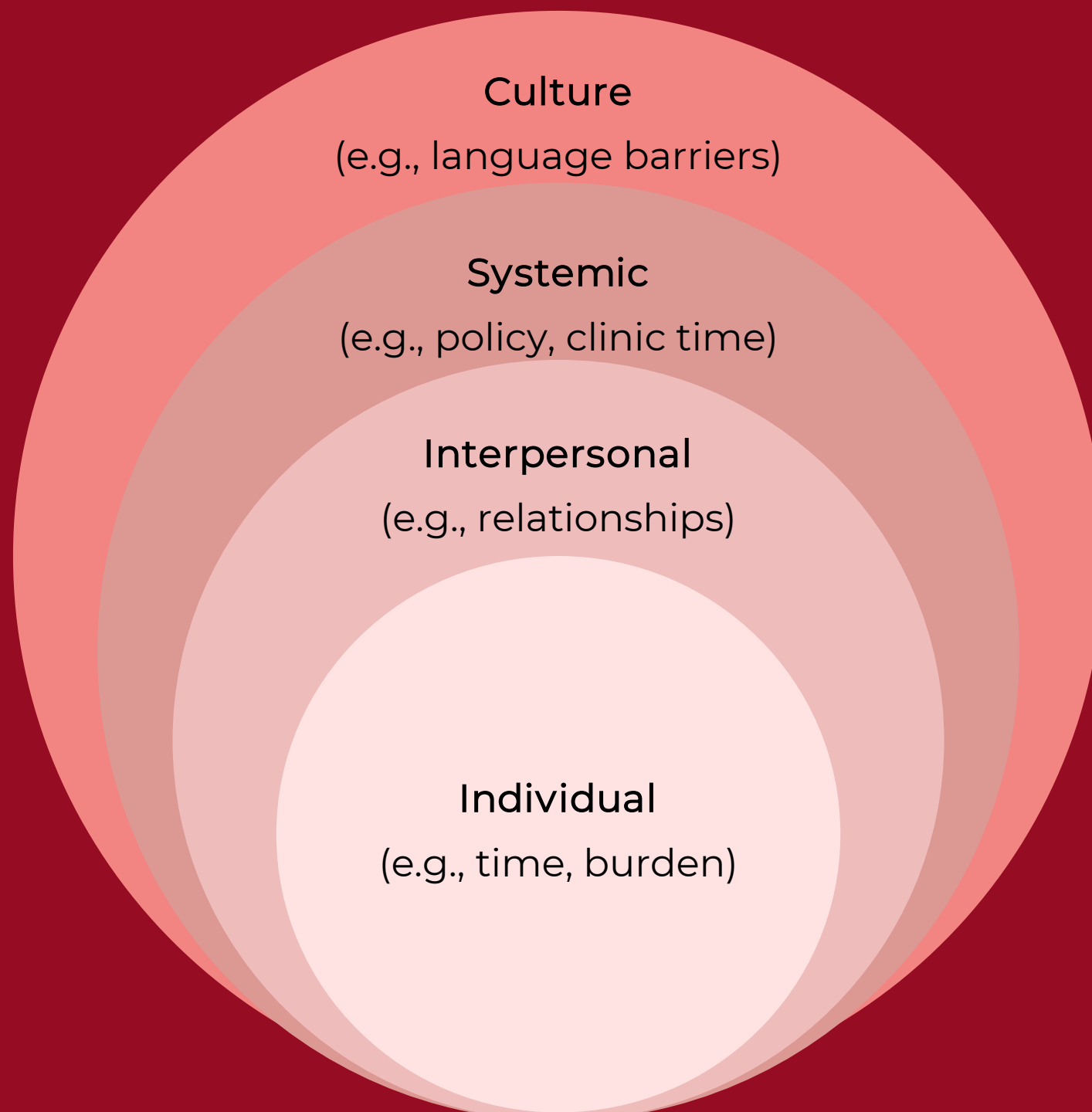
Caregiver Engagement is Critical

- Self-management outside of healthcare systems is a critical feature
- Family caregivers are often responsible for important aspects of self-management
 - Emotional support
 - Instrumental support (e.g., picking up medications, ADLs)
 - Complex medical tasks (e.g., wound care)
 - Diet and nutrition
 - Exercise



Yet, caregivers are not empowered in
healthcare.

Barriers to Empowering Caregivers



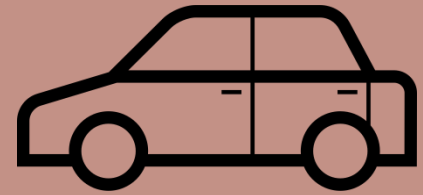
Individual Barriers



Time

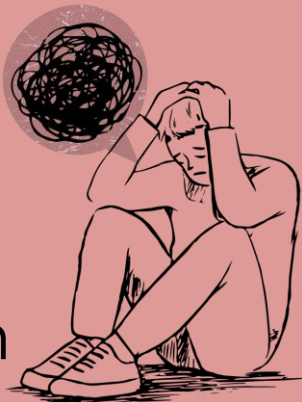


Finances

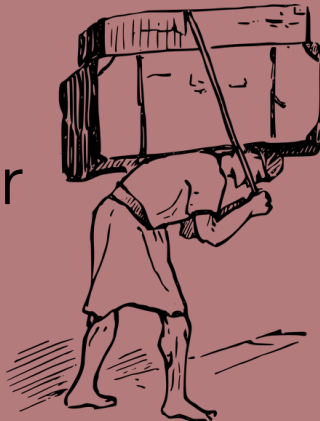


Transportation

Strain
&
Depression



Caregiver
Burden

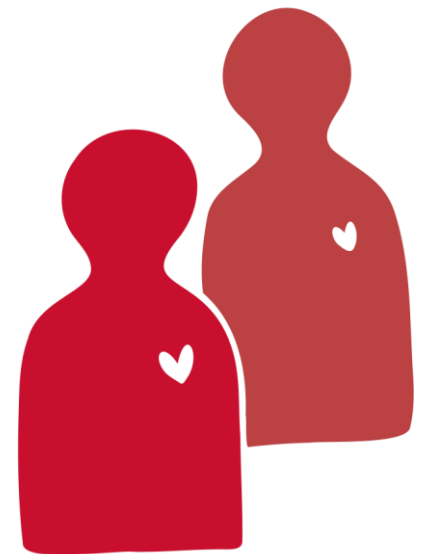


Health
Literacy



Interpersonal/Dyadic Barriers

- Patient-caregiver communication
- Clinician-caregiver communication
- Role diffusion with multiple caregivers



Dyadic Barriers

Comparing the Barriers and Facilitators of Heart Failure Management as Perceived by Patients, Caregivers, and Clinical Providers

Ranak B. Trivedi, PhD; Cindie Slightam, MPH; Andrea Nevedal, PhD; Timothy C. Guetterman, PhD; Vincent S. Fan, MD, MPH; Karin M. Nelson, MD, MS; Ann-Marie Rosland, MD; Paul A. Heidenreich, MD; Christine Timko, PhD; Steven M. Asch, MD, MPH; John D. Piette, PhD

Caregiver Experiences and Roles in Care Seeking During COPD Exacerbations: A Qualitative Study [Get access >](#)

Madhuvanthi Suresh, MS ✉, Jessica Young, MPH, MSW, Vincent Fan, MD, MPH, Carol Simons, BS, Catherine Battaglia, PhD, RN, Tracy L Simpson, PhD, John C Fortney, PhD, Emily R Locke, MPH, Ranak Trivedi, PhD

Understanding communal coping among patients and informal caregivers with heart failure: A mixed methods secondary analysis of patient-caregiver dyads

Jennalee S. Wooldridge^{2, 1} ✉, Caroline Gray², Ambri Pukhraj², Jessica Geller³, Ranak B. Trivedi^{2, 4}

The Dyadic Experience of Managing Heart Failure

A Qualitative Investigation

Kim, Juliah Shay Ryann MS; Risbud, Rashmi MS; Gray, Caroline PhD; Banerjee, Dipanjan MD, MS; Trivedi, Ranak PhD

It Takes a Village

Interpersonal Factors That Enhance Management of Heart Failure

Rashmi D. Risbud, MA; Juliah Shay Kim, MS; Ranak B. Trivedi, PhD

Research Article

Systematic Review of Dyadic Interventions for Ambulatory Care Sensitive Conditions: Current Evidence and Key Gaps

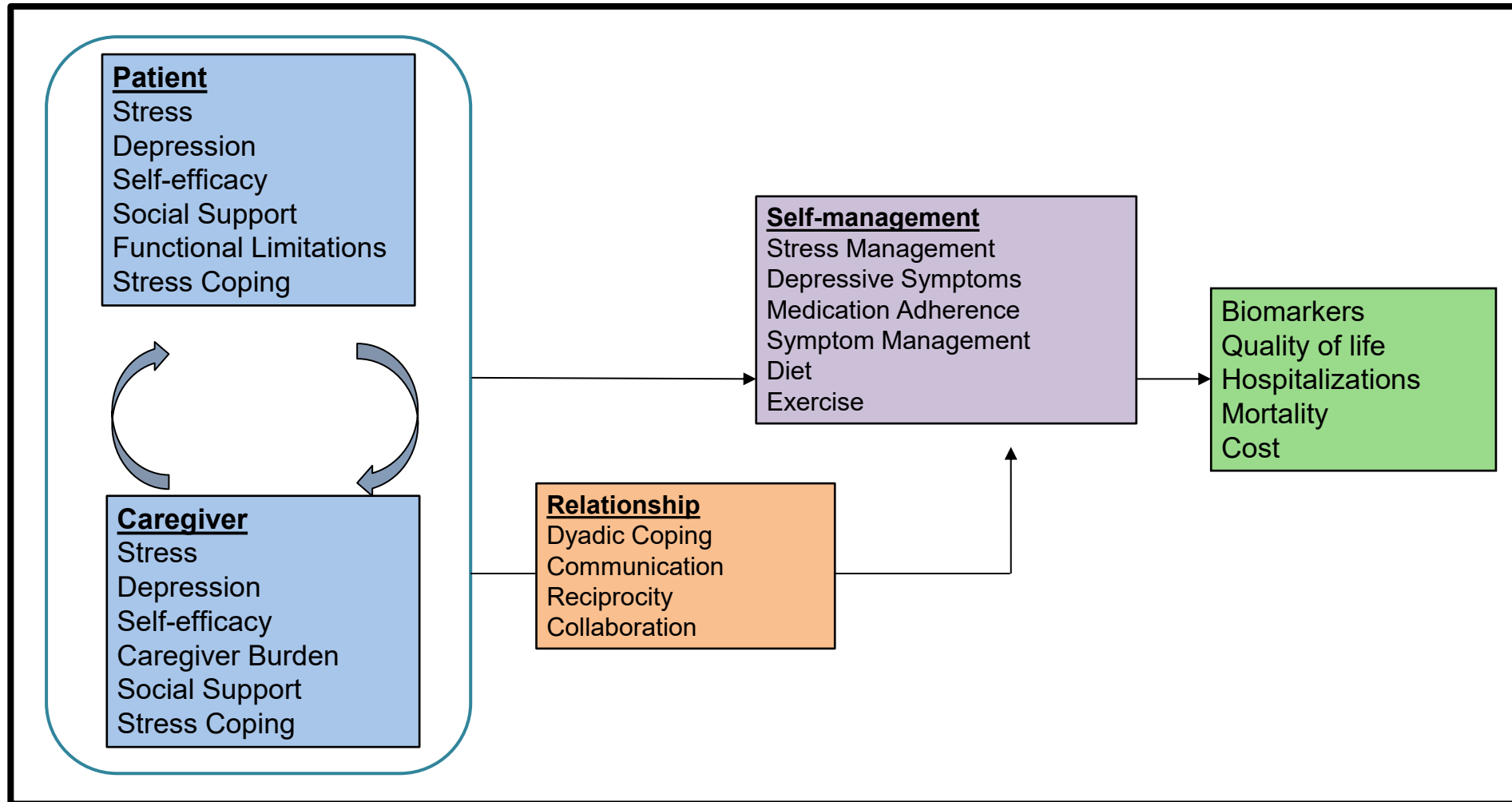
Jennalee S. Wooldridge ✉, PhD, Fernanda S. Rossi, PhD, Coral Anderson, MBChB, BSc, MRCPsych, Natalie M. Yarish, PhD, Ambri Pukhraj, MS & Ranak B. Trivedi, PhD

Published online: 17 Jun 2022

Download citation <https://doi.org/10.1080/07317115.2022.2086089>



Dyadic Health Behavior Change Model



(Trivedi et al 2016)

Systemic Barriers

- Built environment
 - Healthcare
 - Infrastructure
- Policies that are not caregiver friendly
 - Reimbursement challenges
- Institutional barriers:
 - Insufficient clinic time
 - Lack of clinical psychologists and social workers
- Employment
 - Lack of workplace accommodations
 - Limited attention to the impacts of caregiver burnout



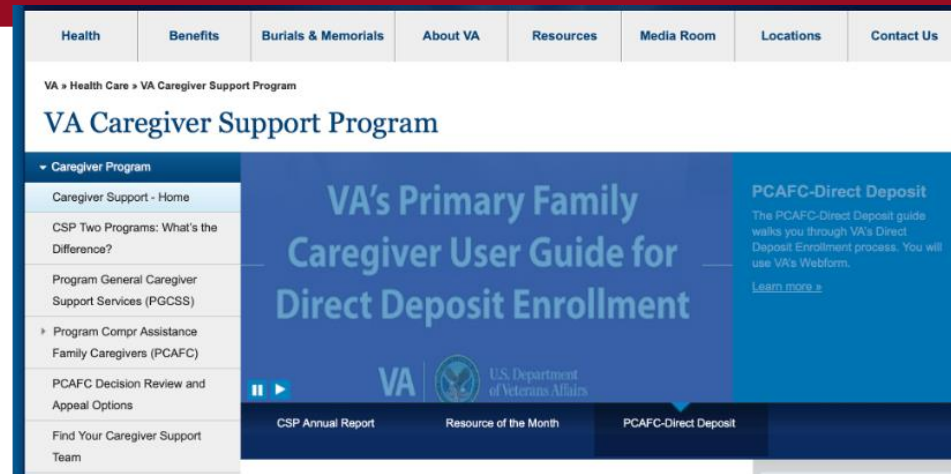
Cultural Barriers

- Caregiving is culturally embedded
 - Gender roles
 - Motivation: duty, filial piety, affection
 - Intergenerational vs. peer support
 - Individual vs. collectivist
- Language barriers
- Stigmatized conditions can add burden
- Religious beliefs that contradict evidence-based approaches

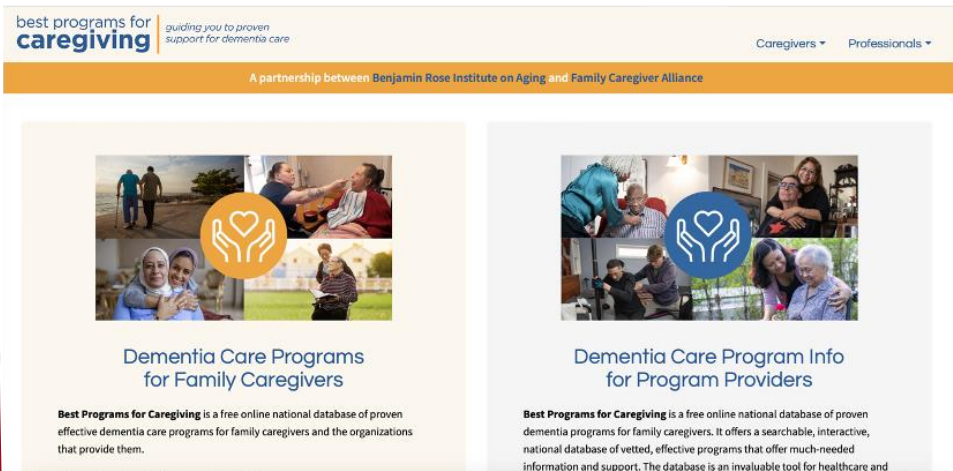


Mitigating Barriers

Caregiver Facing Programs



- BRI Care Consultation™



- SHARE for Dementia

- REACH II

Dyadic Programs

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ORIGINAL RESEARCH article
Front. Public Health, 28 August 2016
Sec. Public Health Policy
Volume 4 - 2016 |
<https://doi.org/10.3389/fpubh.2016.00171>

This article is part of the Research Topic
The Role of Financing, Delivery & Policy Innovations in Decreasing Chronic Disease Burdens
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A Couples' Based Self-Management Program for Heart Failure: Results of a Feasibility Study

 Ranak Trivedi^{1,2*}  Cindie Slightam²  Vincent S. Fan^{3,4}
 Ann-Marie Rosland^{5,6}  Karin Nelson^{3,4}  Christine Timko²
 Steven M. Asch^{1,2}  Steven B. Zeliadt^{3,4}  Paul Heidenreich^{1,2}
 Paul L. Hebert^{3,4}  John D. Piette^{5,6}

Web-SUCCEED Study

Web-based Self-management
Using Collaborative Care
Enhancement in Diseases



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Published on 16.6.2023 in Vol 7 (2023)
Preprints (earlier versions) of this paper are available at <https://preprints.jmir.org/preprint/43903>, first published October 28, 2022.



Adapting a Telephone-Based, Dyadic Self-management Program to Be Delivered Over the Web: Methodology and Usability Testing

 Ranak Trivedi¹  Sierra Kawena Hirayama²  Rashmi Risbud¹  Madhuvanthi Suresh¹  Marika Blair Humber¹  Kevin Butler³  Alex Razze³  Christine Timko¹  Karin Nelson⁴  Donna M Zulman¹  Steven M Asch¹  Keith Humphreys¹  John D Piette⁵

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ARTICLES

A Dyadic Approach to Managing Heart Failure With Confidence

Lyons, Karen S. PhD; Vellone, Ercole PhD, RN; Lee, Christopher S. PhD, RN, FAHA, FAAN; Cocchieri, Antonello PhD, RN; Bidwell, Julie T. BSN, RN; D'Agostino, Fabio PhD, RN; Hiatt, Shirin O. MPH, MS, RN; Alvaro, Rosaria MSN, RN; Vela, Raul Juarez PhD, RN; Riegel, Barbara PhD, RN, FAHA, FAAN



South Asian Family Approaches to Disease

South Asians and Breast Cancer

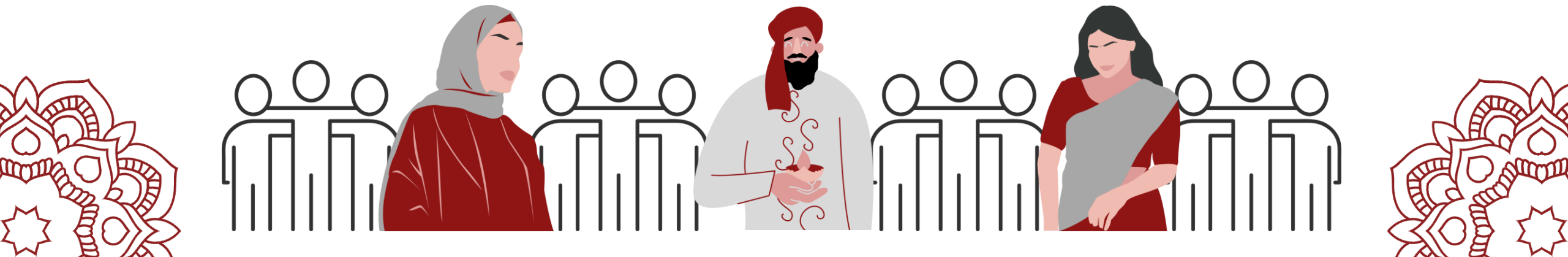
- 1 in 5 people globally have a South Asian heritage
- 5.4 million in the US

Healthcare system is not designed to
handle this cultural context

- **Taboo:** 46%- sexual taboos inhibited breast cancer awareness
- **Stigma:** No words for cancer or survivor
- **Collectivism:** Community needs > Individual needs
- **Culture of service:** inhibits caregivers asking for help
- **Gender Roles:** 80% caregiving is provided by women

Objectives

- Understand the experiences of South Asian women living with breast cancer and their family caregivers.
- Develop a program that can address unmet needs



Method

- Stanford University and surrounding communities
 - Breast cancer survivors (BCS) any stage
 - Family caregivers of BCS
- Measures:
 - ~1 hour semi-structured interviews (Stanford Zoom)
 - Psychosocial surveys (Stanford REDCap)
- Community Advisory Board
 - 7 members of South Asian heritage diverse regions/religions



Methods (contd.)

- Measurement domains based on
 - NIMHD Framework
 - Dyadic Health Behavior Change Model
- Domains: Cancer experience, Caregiving, Coping, Stress, Quality of life, Acculturation, Home and community supports
-
- Thematic analysis using deductive and inductive coding
- Descriptive analyses of psychosocial surveys



Results

Table 1: Demographics

Characteristics	Survivor (n=14)	Caregiver (n=14*)
Female, %	100.0	18.2
Age, y M (SD)	49.6 (9.3)	43.9 (13.8)
Married, %	76.9	64.6
College Education or Higher, %	92.3	64.2
Full time employment, %	76.9	64.2
Financial Status, %		
Have enough money to pay the bills and still have enough money for special things	38.5	72.7
Have enough money to pay the bills, but little spare money to buy extra or special things	30.8	18.2
Have money to pay the bills, but only because certain things have been cut back	7.7	0
Have difficulty paying bills, no matter what	0	0
Don't know/Decline	23.1	7.11
Indian heritage, %	100	100
Hindu Religion, %	76.9	81.8

Table 2: Stage of Cancer

Stage of Cancer at Diagnosis	N*
Stage 0-I	7
Stage II	5
Stage III	1
Stage IV	2



Table 3: Psychosocial Surveys

Measures	Survivor, M $\pm$ SD (n=13)	Caregiver, M $\pm$ SD (n=13)	Clinical Cutoff
Perceived Stress Scale	16.4 $\pm$ 7.37	20.3 $\pm$ 2.21	0 - 13: low, 14 - 26: moderate; 27 - 40: high
Fear of Recurrence	22.8 $\pm$ 9.2	19.6 $\pm$ 0.77	$\geq$ 17 clinically significant
Self-Management Distress Scale	3.5 $\pm$ 1.62	3.45 $\pm$ 1.65	>3 high
8-Item Loneliness	12.43 $\pm$ 6.88	13.55 $\pm$ 6.88	8 – 32; higher scores= more loneliness



Themes

Theme 1: Emotional distress, including shock, fears of recurrence, metastases, and disclosure

Theme 2: Disclosing diagnosis to family within USA but secrecy from family in India, amplified by COVID-19 travel restrictions

Theme 3: Social isolation and a desire to connect with survivors and FCG from India

Theme 4: Perception of better medical care in USA, but better logistical help in India

Theme 5: Inadequate engagement of FCG by the healthcare team

Theme 6: Need for culturally and linguistically concordant resources and services

I mean, I was terrified, actually... No one's going to come in with a cape and save the day. Like, this is real life. I could really die (BCS, 51)

I went almost silent in terms of not even talking about it because my wife was trying to brave it out (FCG, 47, Male)

I guess cancer is it's never out of your mind. I think you can never go back to being the carefree person that you were. (BCS, 39)

You feel emptiness, loneliness (BCS, 52)

Promise, don't tell your mom because then my mom will find out, (BCS, 50)

It's a chain reaction of going home, not having friends, and feeling lonely (FCG, 22, Female)

I remember my mom reading [diet recommendations] and was, like, oh, I don't even eat half these things...this is very American food. This is not the foods that we eat (FCG, 22, Female)

Steps to Empowerment

- Embrace caregivers' expertise
- Educate
 - Educate caregivers
 - Educate healthcare team with caregivers' role and needs
- Empathize and support
- Enable culturally attuned care
- Enact caregiver friendly policies

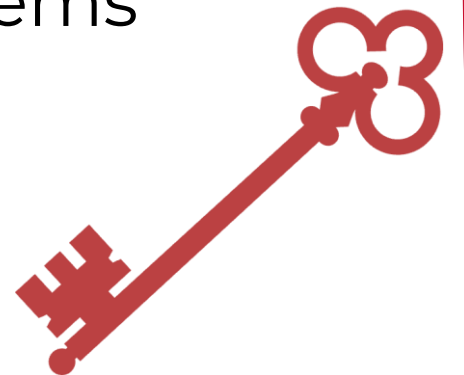


Next Steps

- NIH grant to co-design a program to address stress, social isolation and loneliness
- Building strong partnerships with community organizations to share knowledge and build trust
- Co-design workshops in the summer

Key Takeaways

- Family caregivers can play important roles in managing the health of those with serious illnesses
- Empowering caregivers will require changes at all levels
- Micro level: mitigating individual and interpersonal barriers
- Macro level: Improving policies and health care systems
- Improving culturally attuned care



Summary

- While there is momentum to empower caregivers, focused attention is needed at multiple levels
- Most attention has been on individual programs
- Onus should shift to programs that are dyadic and culturally attuned, as well as supportive policies

“

“When you ignore caregivers, you leave half the team on the bench.”

–Susannah Fox, former CTO of HHS

”

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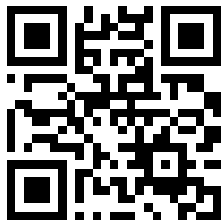
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Thank You & Questions



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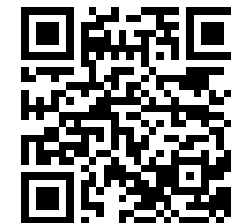
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