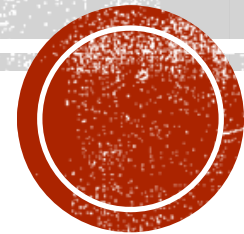


DEMENTIA CAREGIVER SELF-CARE AND EMPOWERMENT

Project ECHO Presentation

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HADI Hawai'i Alzheimer's Disease Initiative

A PROJECT OF THE UH CENTER ON AGING

www.hawaii.edu/aging/hadi

AGENDA & GOALS

- Describe the impacts of dementia caregiving on health and mental health
- Understand different aspects of overwhelm and burnout
- Discuss strategies to increase caregiver self-care and empowerment
 - Getting educated
 - Sharing the load
 - Self-care
 - Connect with resources



CAREGIVERS ARE A CRITICAL RESOURCE

- **More than 15 million Americans** (Karlavash et al., 2017) provide unpaid care for **5.5 million people with Alzheimer's Disease** (Herbert et al., 2013)
- **Estimated 27,000 people with Alzheimer's Disease in Hawai'i in 2017** (Wevue, 2015)
- **83% of care for older adults provided by family and other "informal caregivers"** (Friedman et al., 2015)
- **Majority lack access to specialized evidence-based training programs**



CAREGIVING TAKES A TOLL

- Compared to caregivers of people without dementia and non-caregivers, caregivers of PWD experience:
 - Higher levels of depression and anxiety disorders (Salim et al., 2015)
 - Increased susceptibility to illness and health complications of their own (Fonareva & Oken, 2014)
 - Higher levels of physical strain (NAC & AARP, 201)
 - Significant sleep disturbance (von Kanel et al., 2014)
 - Elevated biomarkers for cardiovascular disease and impaired kidney function (Roepke et al., 2012; von Kanel et al., 2012)
 - Reduced immune function & slower wound healing (Kiecolt-Glaser et al., 1995, 1996)
 - More negative impacts on work/employment (NAC & AARP, 2016)



CAREGIVER STRESS & BURNOUT

- Isolation and Loss of social support
 - Financial strain
 - Feeling taken for granted
 - Giving up things you love
 - Not knowing how/who to ask for help
 - Family conflict
 - Never enough time
 - Fear, guilt, frustration, self-doubt
 - Anxiety and depression
 - Illness, injury
 - *Things outside of your control*
-
- All of this on top of non-caregiving stressors!



CAUSES OF CAREGIVER STRESS

- Role changes
 - Both caregiver and care receiver may struggle with role changes
- Unrealistic expectations: of self and care receiver
- Caregivers of PWD tend to be in the caregiver role much longer than other caregivers
 - Caregiving 6+ years: 47.4% dementia caregivers vs. 29.4% non-dementia (Kasper et al., 2015)
- Communication challenges between caregiver and PWD
 - Common as dementia progresses
 - PWD may lose second language, only speaking in native tongue not always spoken by children, spouse
- Lack of training for caregiver duties
 - Nursing tasks, medication management, managing finances, knowledge of dementia

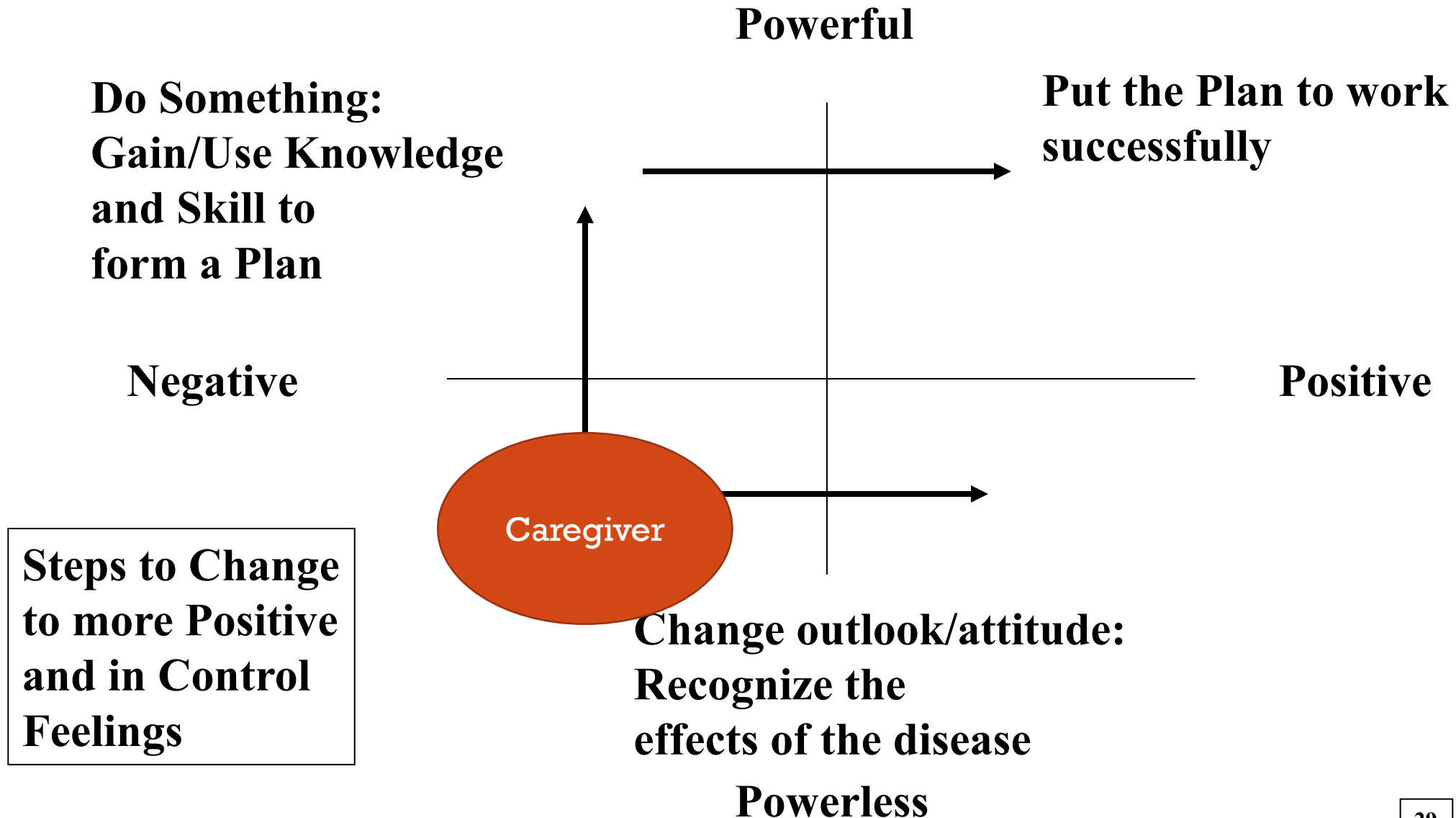


THE MANY ROLES OF CAREGIVERS

- Nurse
- Social Worker
- Guardian
- Behavior Manager
- Cook
- Companion and Comforter
- Maid and Laundry Attendant
- Safety Officer
- Administrator, Chief Financial Officer and Key Decision Maker
- Home Repair Specialist
- Activity and Tour Director
- Family Counselor and Diplomat
- Liaison with professionals -- doctors etc.
- ...Overwhelming!!



The Four Quadrants of Feeling



REDUCING CAREGIVER STRESS AND BURNOUT: GET EDUCATED!

- Knowledge is power!
- Learning more about how dementias affect a person and their behavior helps build empowerment and self-efficacy
- Helps change attitude/outlook: see challenges as part of the disease; as efforts by the PWD to feel safe, in control
- Evidence-based programs and LOTS of good books exist



EXAMPLE: SAVVY CAREGIVER TRAINING PROGRAM

- 6 weekly 2-hour group training sessions
- Aimed at building knowledge, developing skills, and shift attitude/outlook of caregivers
- Controlled studies found Savvy Caregiver participants had significantly less distress and burden at 6 months compared to control groups (Ostwald et al., 1999; Hepburn et al., 2001, 2003, 2007)
 - Improved reactions to behaviors and beliefs about caregiving
 - Significant majority "strongly agreed" to feeling more skillful, knowledgeable, and confident with their caregiving after the training
- 2017: 19 Family caregivers in Central O'ahu had high attendance, high levels of satisfaction with the course



REDUCING CAREGIVER STRESS AND BURNOUT: SHARING THE LOAD

- Speak up to friends and family
- Spread the responsibility
- Say “Yes” when someone offers assistance
 - Be willing to relinquish some control
 - Let someone help even if they might not do things exactly your way
- Daycare, hired help/home care, respite care



REDUCING CAREGIVER STRESS AND BURNOUT: SELF-CARE

- Practice the mantra: “Self-care is not selfish!”
- Maintain personal relationships
- Prioritize activities that bring you enjoyment, revitalization, or hopeful perspectives
 - Exercise
 - Mindfulness or other stress management practices
 - Spiritual/religious practices
 - Pay attention to unhelpful coping strategies
- Find ways to pamper yourself
- Get out out the house
- Take care of your health and mental health



REDUCING CAREGIVER STRESS AND BURNOUT: CONNECT WITH RESOURCES

- Executive Office of Aging/Aging and Disability Resource Centers
 - <http://health.hawaii.gov/eoa/>
 - <http://hawaiiadrc.org/> and <http://elderlyaffairs.com>
- Legal and financial advising
 - https://www.hawaii.edu/uhelp/files/DecidingWhatsNext_2011.pdf
- Elder abuse and neglect: Adult Protective Services
 - <https://www.caregiver.org/hawaii-adult-protective-services-aps-and-elder-abuse-hotline>
- Public health nurses: free in-home assessments
 - <http://health.hawaii.gov/phnb/public-health-nurses-phn/>
- Senior Companions
 - <http://humanservices.hawaii.gov/blog/senior-companion-program/>
- Dana Project services
 - <http://www.projectdana.org/>
- Mediation Center of the Pacific—Kupuna Pono Program
 - <http://www.mediatehawaii.org/>
- Psychologist/counselor
 - Hawai'i Psychological Association: <http://www.hawaiipsychology.org>
- Join a support group and connect with other resources
 - -Alzheimer's Association: <http://www.alz.org/hawaii/>



CAREGIVER TRAINING PROGRAMS

- **Child and Family Services, Gerontology Program** offers the *REACH II* in-home evidence based training for dementia caregivers as part of their Ohana Care Program. It's available to anyone taking part in their services. They can be reached on Oahu at 543-8468
 - <https://www.childandfamilyservice.org/programs/ohanacare/>
- **The Alzheimer's Association – Aloha Chapter** has offered a support-group based evidence based training called “*What's Next?*” on Oahu. They can be reached at <http://www.alz.org/hawaii/>
 - Aloha Chapter also offers dementia caregiver support groups statewide, as well as caregiver classes, care consultation, trainings and education for the public and professionals. Local contact: (808) 591-2771, alohainfo@alz.org
- **Savvy Caregiver Program:** Contact **Jody Mishan** (jmishan@hawaii.rr.com) of the Hawaii Alzheimer's Disease Initiative (HADI) for information on availability)
- **Alzheimer Association:** *essentiALZ* online training/certification
 - <http://www.alz.org/essentialz/>
- **ACT on Alzheimer's Disease Curriculum:** <http://www.actonalz.org/>



WEBSITES & BOOKS

- **National Institute of Ageing (NIA) and Alzheimer's Disease Education And Referral Center (ADEAR)** (<https://www.nia.nih.gov/alzheimers>)
- **Alzheimer's Association** (www.alz.org)
- **American Psychological Association** (www.apa.org)
- **National Alzheimer's Disease Research Center:** <https://nadrc.acl.gov>
 - Training resources toolkit: <https://nadrc.acl.gov/node/77>
 - Advance planning guides: <https://nadrc.acl.gov/node/96>
- **Administration On Ageing (AOA) & Administration for Community Living (ACL):** <https://aoa.acl.gov>
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MAHALO!

- Questions/Comments?
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