

Caring for the Caregiver

Emily Ishado, MSW, LICSW



UNIVERSITY *of* WASHINGTON



Learning Objectives

- > **Identify healthcare considerations that support dementia care partner wellness.**
 - Practical unmet needs among dementia care partners
 - Aspects of the personal journey in caregiving
 - Approaches to support dementia care partners to engage in self-care



Dementia Care Partners (DCP) Background

- > 12-15 million dementia care partners
- > 19.2 billion hours of unpaid care (~92 hours per month)
- > Majority (66%) live with person living with dementia (PLWD)
- > 60% spouse/partner and 30% are 65+ years old
- > 25% care for PLWD and own children
- > Majority are female



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Dementia Care Partners Caregiving Role and Responsibilities

- > Instrumental / Personal Activities of Daily Living
- > Treatment, medications
- > Coordination of care, medical decisions
- > Mood and behavioral support
- > Activity engagement
- > Resource utilization

Early/Mild

Middle/Moderate

Late Stage/End of Life

Care Provision

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Dementia Care Partners Social Determinants of Health

- > **Economic Stability**
 - Increased out of pocket costs
 - 41% household income <\$50,000
- > **Educational Access and Quality**
 - Level of health literacy, knowledge impact service engagement
 - 60% less than college education
- > **Healthcare Access and Quality**
 - ~7,000 geriatricians
 - Limited access to specialized healthcare services
- > **Social and Community Support**
 - Support can lessen stressful effects of care demands
 - Four in 10 have no additional support
- > **Historically Marginalized Groups**
 - Engage less in formal resources or delay care
 - Historical and current discrimination, lack of welcoming or culturally responsive services



DCP Needs Caregiving Role



DCP Unmet Needs Knowledge and Information

Disease Specific

- Diagnosis
- Prognosis
- Course of dementia

PLWD Needs

- Personal care
- Medical/Health care

Legal

- Durable Power of Attorney
- Living Will/Advance Directive



DCP Unmet Needs Training and Education

Medical and Nursing Tasks

- Medical and nursing tasks
- Verbal, written instructions
- Ongoing consultation and support

Maintaining Well-Being

- Physical and social health
- Behavioral health
- ABC (Antecedent, Behavior, Consequence)
- DICE (Describe, Investigate, Create, Evaluate)

Relationship

- Communication strategies
- Maintain connection



DCP Unmet Needs Collaboration with Healthcare Team

Rapport Building

- DCP desire time and empathy
- Trauma-informed care
- “What’s wrong with you?” vs “What happened to you?”

Communication

- Pathways – who to call for what issue and when?
- Tracking sheets for organization

Joint Decision Making

- Care priorities
- Treatment options, pros/cons
- Equal partners



DCP Unmet Needs Culturally Responsive Care

Cultural Humility

- Ongoing reflexive process
- Acknowledgement of power imbalances
- Building respectful partnerships

Cultural Knowledge

- Beliefs, values, practices
- Definition of caregiving role
- Perceptions of dementia

Accessible Services

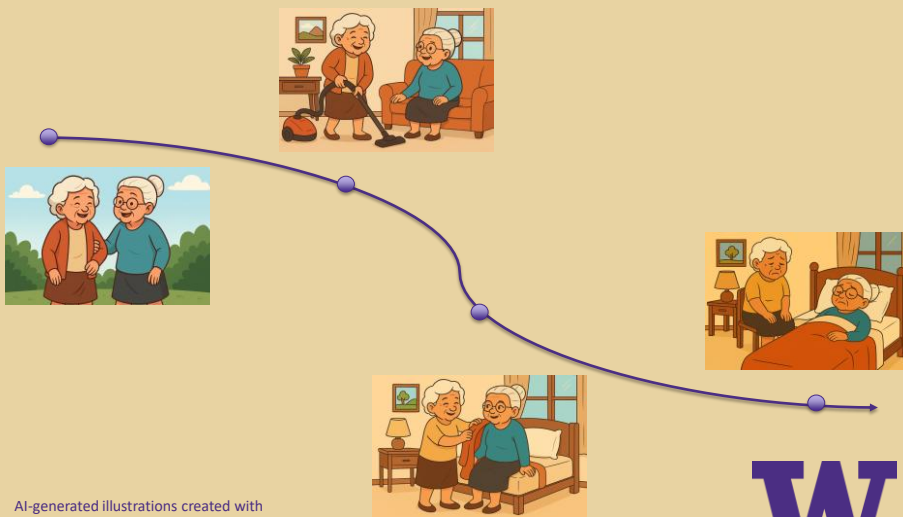
- Language interpretation
- Community integration
- Partnerships



DCP Physical Health Impact

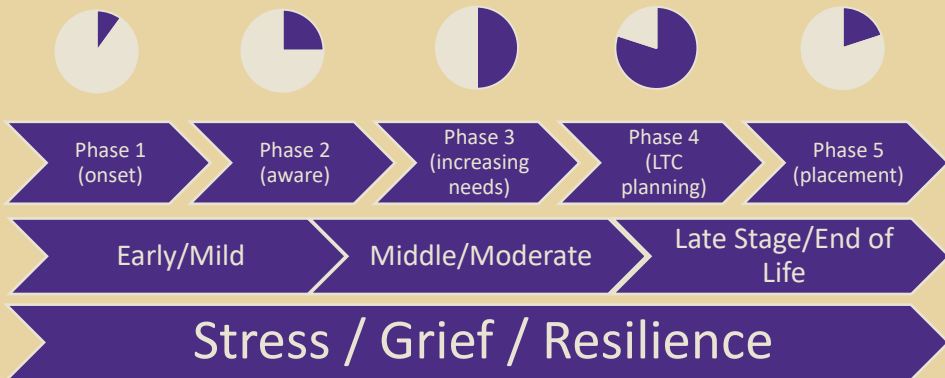


DCP - Personal Caregiving Journey



DCP Caregiving Journey Changes to Identity

Caregiver Identity Theory (Montgomery, Rowe, & Kosloski, 2007)



DCP Mental Health Impact



DCP Needs

DCP neglect
own needs

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DCP Self-Care Intervention Managing Your Own Wellness



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DCP Self-Care Practices Definition and Impact

> Orem (1991) Nursing Theory

- Activities to maintain, restore, or improve health
- 3 domains (universal, health promotion, developmental)

Self-care engagement



- Depression
- Burden
- Stress
- Anxiety
- Health risks



- Quality of life
- Positive affect
- Sleep
- Overall health
- Social support



Dementia Care Partners Self-Care Activities

Managing Your Own Wellness



DCP Self-Care Goal Development

- > **Self-care goal**
 - Motivational interviewing techniques
 - Open-ended questions
 - Pros/cons, readiness
 - Select item that is “most important and have the greatest impact on overall well-being”
 - SMART goal
 - Specific, Measurable, Achievable, Realistic, Time-Bound
- > **Habit stacking**
 - “I will do [activity] for [time/duration] AFTER [routine].”
 - Ex. “I will do mindful meditation for 5 minutes in the living room after I drink my morning coffee.”



Self-Care Intervention Sample self-care goals

**Exercise for
30+ minutes**

“After feeding myself and my dog, I will walk or use aerobic step platform in the mornings.”

**Spend time
with people I
enjoy**

“After breakfast, I will make a plan with someone to socialize for the next day, or whenever available.”

**Make
healthy food
choices**

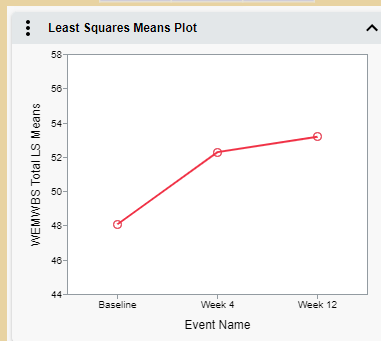
“Around 3:30 pm, after my husband is getting ready for his day, I will get a healthy snack, go outside and play my ukulele.”



Self-Care Intervention Results (N=19)

Warwick-Edinburgh Mental Well-Being Scale
(range: 14-70)

Time	Mean	Std Error
Baseline	48.1	1.65
Week 4	52.3	1.67
Week 12	53.2	1.67

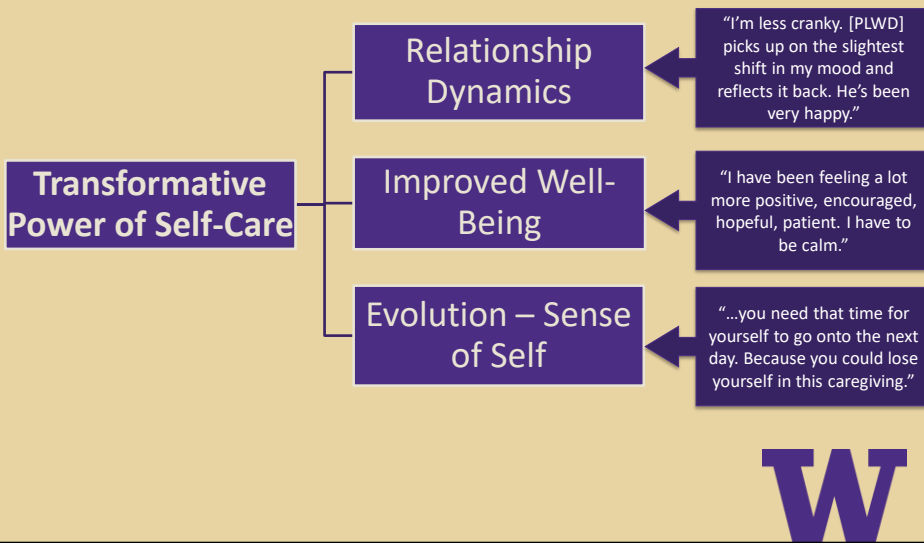


Self-Care Intervention Results – Exit Interview

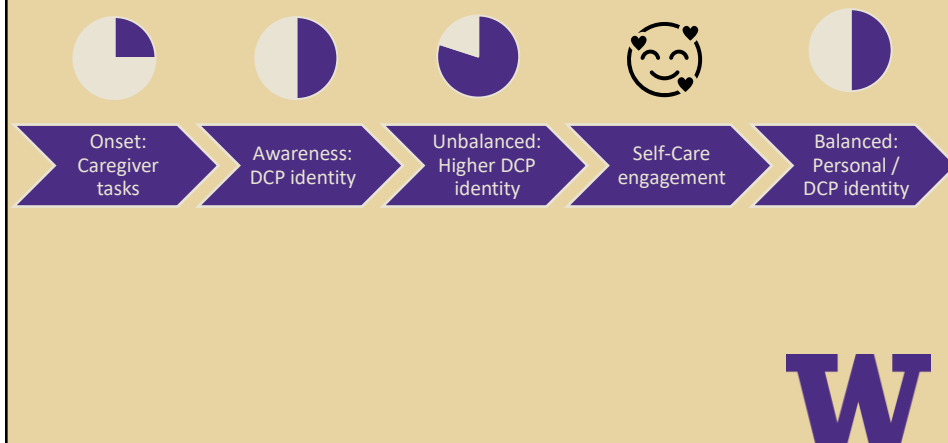
Results (N=19)	N (%) of CP
Increased patience / less frustration or irritability	18 (95%)
DCP and PLWD joint effects	16 (84%)
Acceptance of: DCP role, situation, PLWD functioning	10 (53%)
Less stress	7 (37%)
Engaging in other self-care activities	4 (21%)
Hopefulness	4 (21%)
Prioritizing self-care and own needs	3 (16%)
Back to “normal”	2 (11%)
Sense of control	2 (11%)
Slowing down / increase self-reflection	2 (11%)



Self-Care Intervention Results – Qualitative Analysis



DCP Self-Care Impact Reclaiming Identity / Sense of Self



Supporting DCP Takeaways

- > **Practical Support**
 - Knowledge and information
 - Training and education
 - Collaboration with healthcare team
 - Culturally responsive care
- > **Personal Support**
 - Self-care
 - Goal development
 - Resources



DCP Resources

- **Alzheimer's Association**
 - <https://www.alz.org/> or 1-800-272-3900
- **Eldercare Locator and Area Agency on Aging (AAA)**
 - <https://eldercare.acl.gov/> or call 1-800-677-1116
- **Family Caregiver Alliance**
 - <https://www.caregiver.org/>
- **UW Medicine Memory and Brain Wellness Center**
 - <https://depts.washington.edu/mbwc/>
- **NIA – Alzheimer's Caregiving: Caring for Yourself**
 - <https://www.nia.nih.gov/health/alzheimers-caregiving/alzheimers-caregiving-caring-yourself>
- **Dementia Palliative Education Network**
 - Partnering with Your Healthcare Provider
 - <https://dpen.nursing.uw.edu/resources/partnering-with-your-healthcare-provider/>



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Thank you!

Contact info:
Emily Ishado, MSW, LICSW
eishado@uw.edu
UW School of Nursing
UW School of Medicine

