

Making Respite More Effective

- Dale A. Lund, PhD
 - Professor & Chair
 - Department of Sociology
- California State University San Bernardino
 - dlund@csusb.edu

Making Respite More Effective

- 25 years of research on family caregiving to older adults
- 30 – 38 million caregivers to older persons
- Well over \$350 billion annual impact on economy

Why focus on making respite more effective?

1. Enhance quality of life of caregivers, families and care recipients

68% report caregiving as most stressful life experience ever.

Every aspect of a caregiver's life can be impacted by their experiences

Need much broader set of outcome measures to reflect this.

2. Accountability and future funding support

Research-to-date shows inconsistent or only moderate positive outcomes
(Why?)

Will future funding be forthcoming?

What do we already know about ways to make respite effective?

1. Begin using respite early in the “caregiving career”. (Too little, too late)
2. Use it regularly (scheduled)
3. Use it in sufficient amounts (dosage)
4. Use it along with other services
(skills, education, emotional and social support, counseling, transportation, nutrition, leisure, etc)

What else? What might be missing in studies of respite effectiveness?

Most caregivers are very satisfied with respite service providers.

- BUT –

46% report being only somewhat or not very satisfied with how they spent their respite time !

Why dissatisfied with respite time ?

1. Poor advanced planning
2. Wasted time and opportunities
3. Too much time on obligatory activities
4. Inconsistency between desired and actual time use
5. Did things that created more stress

Why is inconsistency problematic ?

When they are not satisfied with their use of time (also a discrepancy between “desired” and “actual” use of time) caregivers have been found to be;

- * more depressed
- * less satisfied with caregiving and
- * more burdened (physically, socially, emotionally, lifecourse development, and time dependency)

Need to include an examination of what caregivers do when they have respite time.

- Are specific activities beneficial ?
- Amount of discrepancy between desired and actual use of time ?
- Degree of satisfaction with respite time ?

Continuity theory of life course aging

- Those who are able to maintain or continue engaging in their preferred and most meaningful activities (and values, beliefs, preferences) or minimize the most disruption to them will have more positive adjustments to aging
- Therefore, help caregivers by finding out what activities have they discontinued as a result of caregiving and encourage them to use respite to restore them or find substitutes. (This may require assistance from objective others at a distance)

Selective Optimization with Compensation Theory

- Adjustments to life transitions often require individuals to be selective in what activities they pursue, find ways to optimize engaging in them while also recognizing the need to compensate for limitations beyond their control.
- Therefore, assist caregivers by helping them to be “selective” in identifying most desired activities to restore, “optimize” the activities by eliminating obstacles and facilitators but “compensate” by recognizing limitations out of their control. Do so through realistic goal-setting and attainment.

Recommendations for Research on Respite

- Select broader range of outcomes
- Select more realistic outcomes
- Select outcomes that match program-specific goals
- Select outcomes targeted to individual caregiver needs (consumer directed)
- Focus on intervention studies
- Share findings with others
- Be more creative

Outcomes to Consider

Physical Health

exhaustion, days sick, doctor visits, exercise, nutrition-diet, subjective ratings, medications, improvements-declines in specific conditions, etc

Mental Health

depression, anxiety, morale, subjective self-reports, satisfaction with daily life, etc

Situational

satisfaction with caregiving, perceived relationship with care-recipient, family relationships, work-related, use of other services, likelihood of institutionalization, etc.

Specific Program Objectives (goals of the service providers) identify outcomes to match each objective or goal

Goals of the Individual Caregivers (identify outcomes that match individual caregiver goals)