Respite Time-Use:
Research Findings Lead to Novel Intervention to Maximize Benefit of Respite for Caregivers

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Respite
(defined as “time away from caregiving”)

Caregiver
(informal or family caregiver)
About half of caregivers reported being “not satisfied” with their respite time.
<table>
<thead>
<tr>
<th>Respite Activities</th>
<th>Desired Time-Use (in hours)</th>
<th>Actual Time-Use (in hours)</th>
<th>% Whose Actual Time-Use was Desired Time-Use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Std Dev</td>
<td>Mean</td>
</tr>
<tr>
<td>1. Time with family</td>
<td>3.0</td>
<td>(5.8)</td>
<td>3.1</td>
</tr>
<tr>
<td>2. Housework</td>
<td>2.4</td>
<td>(4.0)</td>
<td>3.3</td>
</tr>
<tr>
<td>3. Rest and relaxation</td>
<td>2.0</td>
<td>(4.8)</td>
<td>1.3</td>
</tr>
<tr>
<td>4. Read or write</td>
<td>1.8</td>
<td>(2.5)</td>
<td>2.1</td>
</tr>
<tr>
<td>5. Help others</td>
<td>1.7</td>
<td>(3.3)</td>
<td>1.7</td>
</tr>
<tr>
<td>6. Watch TV</td>
<td>1.6</td>
<td>(3.5)</td>
<td>1.8</td>
</tr>
<tr>
<td>7. Sleep or nap</td>
<td>1.5</td>
<td>(6.2)</td>
<td>0.7</td>
</tr>
<tr>
<td>8. Cook</td>
<td>1.5</td>
<td>(2.2)</td>
<td>1.8</td>
</tr>
<tr>
<td>9. Eat</td>
<td>1.4</td>
<td>(1.9)</td>
<td>1.8</td>
</tr>
<tr>
<td>10. Shop</td>
<td>1.4</td>
<td>(2.2)</td>
<td>1.6</td>
</tr>
<tr>
<td>11. Time with friends</td>
<td>1.2</td>
<td>(1.9)</td>
<td>0.7</td>
</tr>
<tr>
<td>12. Hobby</td>
<td>0.9</td>
<td>(2.4)</td>
<td>0.5</td>
</tr>
<tr>
<td>13. Exercise</td>
<td>0.8</td>
<td>(2.0)</td>
<td>0.8</td>
</tr>
<tr>
<td>14. Personal or medical care</td>
<td>0.7</td>
<td>(1.3)</td>
<td>1.0</td>
</tr>
<tr>
<td>15. Listen to radio</td>
<td>0.6</td>
<td>(1.3)</td>
<td>0.6</td>
</tr>
<tr>
<td>16. Religious activity</td>
<td>0.5</td>
<td>(1.3)</td>
<td>0.4</td>
</tr>
<tr>
<td>17. Travel</td>
<td>0.5</td>
<td>(1.1)</td>
<td>0.6</td>
</tr>
<tr>
<td>18. Recreation</td>
<td>0.4</td>
<td>(1.1)</td>
<td>0.3</td>
</tr>
<tr>
<td>19. Attend support group</td>
<td>0.2</td>
<td>(0.7)</td>
<td>0.1</td>
</tr>
</tbody>
</table>
“I wasted my time watching television.”

“I wish I could have relaxed, but I had to help others and make visits.”

“I would like to stay home alone and work on projects that I never have time for.”
Intervention

Goal: to help caregivers maximize the benefit of respite by focusing on their time-use
“I made a greater effort to find fun things to do and ACTUALLY got around to doing them...lead to other fun things which I did and will do in the future.”

“It invigorated me. I am alive and not just living. I love feeling of success when I achieved my goals.”

“I never had time for myself but since I set my goals, I feel obligated - like a promise I can’t cut out.”

“I was unconsciously sliding into a resigned death of my own until I started this study. This program really woke me up to the fact that I needn’t give up – rather, that by setting goals, I can move forward and feel success even though my circumstances have not changed. I feel like a new, happier person!”
6 Key Areas

1. Improved research methodologies
2. Individual, family, and societal outcomes
3. Cost-benefit and cost-effectiveness research
4. Systems change that improves respite access
5. Improved respite provider competence
6. Translate research findings into best-practice models

ARCA National Respite Network
And Resource Center
A technology-delivered intervention to maximize benefit of respite

NIA R01-AG061946
Caregiver Well Being

Satisfaction with Respite Time-Use
experienced & evaluative time-use

TLC Intervention
1. **Information & Education**
   *What is Respite?*

2. **Virtual Coaching**
   *How do I use respite?*

3. **Resources & Referral**
   *How do I get more respite?*

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**Goal Setting, Goal Review Calendar**

**Selection, Optimization, Compensation (SOC)**
Pilot test for feasibility and initial efficacy

- 150 dementia caregivers
- 16-week intervention
- Randomized control trial (waitlist control)
- Community-engaged practices
http://tlc.gslc.utah.edu/