Caregiver Characteristics Associated with Use of Respite Care Results from a Texas 2012 Statewide Survey

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Texas Health and Human Services Commission
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Purpose of the Texas Respite Care Program

Enhance and expand the coordination and availability of respite services
Survey Purpose

What *knowledge and understanding* do caregivers in Texas have about respite care?
• Mixed-mode distribution:
  1. U.S. mail
     • Random sample of individuals identified as caregivers in three local data collection systems
  2. Online
     • Convenience sample
     • Newsletters, mailings, and websites
Survey Instrument

- 33 questions
- For caregivers only
- Topics:
  - Knowledge of meaning
  - Need for services
  - Help getting services
  - Demographics
  - Perceived benefits
  - Awareness of services
  - Use of respite care
- English and Spanish
Results
2,649 surveys received total (both modes)
  – 60% U.S. mail
  – 40% Online
Caregivers

- 81% female
- 75% age 40-69
- 63% were both female and age 40-69
Caregivers

- 19 years or younger
- 20 to 29 years
- 30 to 39 years
- 40 to 49 years
- 50 to 59 years
- 60 to 69 years
- 70 to 79 years
- 80 years or older
Caregivers

- 56% White
- 28% Hispanic
- 13% Black
- 3% Other
57% worked 40 or more hours per week as caregivers.
Care Recipients

- Alzheimer’s or dementia: 31%
- Physical disability: 20%
- Intellectual/developmental disability: 20%
- Chronic health condition: 11%
- All other: 18%
Care Recipients

- 59% female
- 67% age 60 or older
- 56% White, 27% Hispanic, 12% Black
Care Recipients

- 19 years or younger
- 20 to 29 years
- 30 to 39 years
- 40 to 49 years
- 50 to 59 years
- 60 to 69 years
- 70 to 79 years
- 80 years or older
• Large majority of those with Alzheimer’s/dementia, physical disabilities, chronic health conditions, heart or lung disease, and cancer were age 60 or older.

• Intellectual/cognitive/developmental disabilities:
  – 42% children/youth
  – 47% age 20-59
  – 12% age 60 or older
Relationship of Caregiver to Care Recipient

- Daughter or son: 35%
- Spouse or partner: 26%
- Parent: 21%
- Family member: 13%
- Friend or other: 5%
• Among caregivers who were age 40-69, the greatest proportion were caring for a parent (41%); smaller proportions were caring for a daughter/son, spouse, etc.

• Among caregivers who were age 70 or older, most were spouses of the care recipient (71%).
Patterns, Caregivers and Care Recipients

• Female caregivers varied in their relationship to the care recipient; male caregivers were more typically the spouse of the care recipient.

• More than half (57%) of those who were the parent of the care recipient were caring for an adult rather than a child.
Have you used respite care in the past?

- Yes: 41%
- No: 59%
• Expected higher proportion than 41% given:
  – Had applied for services or were involved with community organizations,
  – A large number of hours of caregiving,
  – Strong agreement that respite services would relieve stress, and
  – Perception that respite has many benefits.

Used Respite Care
Even among caregivers who said they needed respite care frequently, a limited proportion had used it.

<table>
<thead>
<tr>
<th>How Often Need Respite</th>
<th>Ever Used Respite Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 x/ month</td>
<td>34%</td>
</tr>
<tr>
<td>3 or more x/ month</td>
<td>51%</td>
</tr>
</tbody>
</table>
What factors are associated with the use of respite care (at any time in the past) for individuals included in our sample?
## Chi Square Test of Independence

<table>
<thead>
<tr>
<th></th>
<th>Got into Special Club (200)</th>
<th>Did Not Get In (800)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green Hair (500)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purple Hair (500)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Chi Square Test of Independence

<table>
<thead>
<tr>
<th></th>
<th>Got into Special Club (200)</th>
<th>Did Not Get In (800)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green Hair</td>
<td>100</td>
<td>400</td>
</tr>
<tr>
<td>(500)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purple Hair</td>
<td>100</td>
<td>400</td>
</tr>
<tr>
<td>(500)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

No relationship between hair color and club
Chi Square Test of Independence

Is a relationship between hair color and club

<table>
<thead>
<tr>
<th></th>
<th>Got into Special Club (200)</th>
<th>Did Not Get In (800)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green Hair (500)</td>
<td>175</td>
<td>325</td>
</tr>
<tr>
<td>Purple Hair (500)</td>
<td>25</td>
<td>475</td>
</tr>
</tbody>
</table>
Analysis Methods

• **Statistically significant:** A measure that would be unlikely to have occurred by chance

• **Effect size:** The magnitude of the relationship between variables
  – Small effect size: weak relationship
  – Large effect size: strong relationship
Who were the caregivers who used respite care?
## Significant Association with Respite Care Use, Small/Very Small Effect Size

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Associated with use of respite care:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>-</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Age 40 or older (highest among 70 or older)</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Age 39 and younger</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>White (compare to non-White)</td>
</tr>
<tr>
<td>Care recipient</td>
<td>White (compare to non-White)</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Urban (compare to rural)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Associated with use of respite care:</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Relationship</td>
<td>Parent of the care recipient</td>
</tr>
<tr>
<td>Care recipient’s condition</td>
<td>Disability related to cognition*</td>
</tr>
<tr>
<td>Length of time caring</td>
<td>More years of caregiving</td>
</tr>
<tr>
<td>Time spent caring</td>
<td>More hours per week caregiving</td>
</tr>
<tr>
<td>Access to internet</td>
<td>Had access to internet (took the online survey OR took the paper survey and said they had access to the internet).</td>
</tr>
</tbody>
</table>

*"Disability related to cognition" includes Alzheimer’s/dementia, Traumatic Brain Injury, and cognitive/intellectual/developmental disabilities."
Significant Associations with Use of Respite Care

- Not statistically significant:
  - Gender of caregiver
Significant Association with Respite Care Use, Medium/Large Effect Size

Associations that had the greatest effect size with having used respite care services were:

- Knowing meaning of respite care (medium),
- Actually looking for services (large), and
- Getting help from someone to locate and apply for services (large).

These three variables were also highly correlated with each other.
Conceptual Model

Know Meaning of Respite Care

Look for Respite Services

Get Help Accessing Respite Services

Use Respite Services

- Race
- Age
- Gender
- Health Condition
- Relationship
- Years of Caregiving

- Hours per Week of Caregiving
- Urban/Rural
- Region
- Access to Internet
Conceptual Model

Know Meaning of Respite Care

Look for Respite Services

Get Help Accessing Respite Services

Use Respite Services

- Race
- Age
- Gender
- Health Condition
- Relationship
- Years of Caregiving
- Hours per Week of Caregiving
- Urban/Rural
- Region
- Access to Internet
Significant Associations with Knew Meaning of Respite Care

• 64% of survey respondents knew the meaning of respite care.
### Significant Association with Knew Meaning of Term, Small/Very Small Effect Size

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Associated with knew meaning of respite care:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Female</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Age 40-69</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Child/youth (19 or younger)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>White</td>
</tr>
<tr>
<td>Care recipient</td>
<td>White</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Urban</td>
</tr>
</tbody>
</table>
**Significant Association with Knew Meaning of Term, Small/Very Small Effect Size**

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<tr>
<th>Characteristic</th>
<th>Associated with knew meaning of respite care:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship</td>
<td>Parent of care recipient</td>
</tr>
<tr>
<td>Care recipient’s condition</td>
<td>Disability related to cognition</td>
</tr>
<tr>
<td>Length of time caring</td>
<td>More years of caregiving</td>
</tr>
<tr>
<td>Time spent caring</td>
<td>-</td>
</tr>
<tr>
<td>Access to internet</td>
<td>Had access to internet</td>
</tr>
</tbody>
</table>
Significant Associations with Knew Meaning of Respite Care

- Not significant:
  - Hours/week caregiving
Significant Associations with Knew Meaning of Respite Care

• 53% of those who knew the meaning of respite care used these services.

• In comparison, only 20% of those who did not know the meaning of the term used respite care.
Conceptual Model

Know Meaning of Respite Care

Look for Respite Services

Get Help Accessing Respite Services

Use Respite Services

- Race
- Age
- Gender
- Health Condition
- Relationship
- Years of Caregiving

- Hours per Week of Caregiving
- Urban/Rural
- Region
- Access to Internet
• 49% of respondents had looked for respite care.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Associated with looked for respite care:</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>-</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Age 70 or older</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Child/youth (19 or younger)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>-</td>
</tr>
<tr>
<td>Care recipient</td>
<td>-</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Urban</td>
</tr>
</tbody>
</table>
Significant Association with Looked for Respite, Small/Very Small Effect Size

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<th>Characteristic</th>
<th>Associated with looked for respite care:</th>
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<td>Relationship</td>
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<td>Care recipient’s condition</td>
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<tr>
<td>Length of time caring</td>
<td>More years of caregiving</td>
</tr>
<tr>
<td>Time spent caring</td>
<td>More hours of caregiving</td>
</tr>
<tr>
<td>Access to internet</td>
<td>-</td>
</tr>
</tbody>
</table>
Significant Associations with Looked for Respite Care

• Not significant:
  • Gender (caregiver)
  • Race (caregiver or care recipient)
  • Caregiver access to internet
73% of those who looked for respite care used these services (ever). There was a strong relationship between looking for services and ever having used them.

However, looking for respite care was not necessarily sufficient to find it consistently.

It is also true that 64% of those who looked for respite care had the experience of not finding the right service at some point.
Conceptual Model

Know Meaning of Respite Care

Look for Respite Services

Get Help Accessing Respite Services

Use Respite Services

- Race
- Age
- Gender
- Health Condition
- Relationship
- Years of Caregiving

- Hours per Week of Caregiving
- Urban/Rural
- Region
- Access to Internet
• 41% of all respondents said that someone helped them access respite care (referral, helped scheduling).
## Significant Association with Got Help, Small/Very Small Effect Size

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Associated with got help accessing respite care:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>-</td>
</tr>
<tr>
<td>Care recipient</td>
<td>-</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Age 70 or older</td>
</tr>
<tr>
<td>Care recipient</td>
<td>Child/youth (19 or younger)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
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</tr>
<tr>
<td>Caregiver</td>
<td>-</td>
</tr>
<tr>
<td>Care recipient</td>
<td>-</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Urban</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Associated with got help accessing respite care:</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Relationship</td>
<td>Parent or spouse of care recipient</td>
</tr>
<tr>
<td>Care recipient’s condition</td>
<td>Disability related to cognition</td>
</tr>
<tr>
<td>Length of time caring</td>
<td>More years of caregiving</td>
</tr>
<tr>
<td>Time spent caring</td>
<td>More hours of caregiving</td>
</tr>
<tr>
<td>Access to internet</td>
<td>-</td>
</tr>
</tbody>
</table>
Significant Associations with Got Help Accessing Respite Care

- Not statistically significant:
  - Gender (caregiver or care recipient)
  - Race (caregiver or care recipient)
  - Caregiver access to internet
• 75% of those who used respite care said they had received help accessing the services.

• Among those who did not receive help, only 18% used respite services.
Conceptual Model

Know Meaning of Respite Care

Look for Respite Services

Get Help Accessing Respite Services

Use Respite Services

- Race
- Age
- Gender
- Health Condition
- Relationship
- Years of Caregiving

- Hours per Week of Caregiving
- Urban/Rural
- Region
- Access to Internet
Strengths and Limitations
Strengths

• Large sample size (>2,500)
• Statewide
• Detailed questions in survey
• Variety of care recipients’ disabilities and ages represented
• Captured responses of caregivers providing many hours of caregiving
Limitations

• Selection bias:
  – Respondents were those who had applied for services or were involved with community organizations
  – No random selection in online survey

• Non-response bias

• Over-sampling in the San Antonio area

• Missing data
Conclusions
Conclusions

- These respondents were less likely to have accessed respite care:
  - Non-White
  - Rural communities
  - Relationship other than parent of care recipient
  - Care for someone who has physical disabilities, chronic health conditions, or functional limitations due to older age.

- Effect size (strength of relationship) is small.
Conclusions

• Most respondents had never used respite care, despite saying they would find it beneficial.

• Knowing the meaning of respite care, looking for it, and getting help accessing it had a significant association with using respite care services with a medium to large effect size.
• Because these steps were more strongly associated with use of respite care than any other characteristics examined, it is important to:
  – Make sure people know what respite care is
  – Make it easy to look for respite care
  – Make sure that people get help accessing respite care.
Acknowledgements and Contact Information

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Questions? Please feel free to e-mail Alison.Little@hhsc.state.tx.us.