

Has the use of Tailored Caregiver Assessment and Referral® System Impacted the Well-being of Caregivers in Washington?

Report to the Washington Aging and Long-Term Support Administration

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SUMMARY

Data Source:

Data used for this report were obtained from the Washington State Department of Social and Health Services (DSHS) Aging and Long-Term Support Administration (AL TSA) were taken from records for caregivers participating in the Family Caregiver Support Program (FCSP). The data were collected via the use of the Tailored Caregiver Assessment and Referral® (TCARE®) system assessment tool between March 2010 and December 2013.

Key Findings:

- 84% of caregivers who remained in the program for six months reported improved levels of stress and depression.
- The 16% of caregivers who did not show improvement were providing more assistance of all types and were caring for family members who engaged in more problem behaviors. There was also a decline in the functional level of the persons for whom they provide care.
- After 12 months of participation in the program, caregivers continued to have statistically significant lower levels of stress and depression than they did at the time of initial enrollment.
- As a group, caregivers who placed the care recipient in a long term care facility prior to the six-month follow-up had the highest levels of stress and depression at the time of the of the initial assessment. Their scores on all measures of stress and depression were higher than those of caregivers who continued in the program and those of caregivers whose care recipient died prior to the six-month follow up.
- The group of caregivers whose care recipient died prior to the six-month follow-up was providing the most assistance for care recipients with the greatest functional impairment, but did not have higher levels of stress. They had the lowest scores of relationship burden and the highest levels of uplifts or positive feelings about caregiving.

A. Background

This report provides a summary of findings from analyses of records for 11,101 informal caregivers who participated in the Family Caregiver Support Program (FCSP) administered by the Aging and Long-Term Support Administration (AL TSA) in the Washington State Department of Social and Health Services. The Tailored Caregiver Assessment and Referral® (TCARE®) system was adopted by AL TSA in 2009 in response to a directive from the Washington State Legislature to identify and use an evidence based assessment and referral tool for use within the Family Caregiver Support Program (FCSP).

As part of TCARE® implementation, the DSHS developed a three tiered eligibility and authorization process. Level 1 provides unpaid caregivers with information and referrals to community resources and, if needed, services up to \$250. Caregivers who choose to participate in level 2 of the program complete the short TCARE® screen which includes: three measures of caregiver burden (i.e. objective burden, relationship burden, stress burden), a measure of the caregivers' positive feelings about caregiving (uplifts), a measure of the caregivers' acceptance of the caregiving role (identity discrepancy) and measures of the caregivers' depression and their intention to place the care recipient in a long term care facility. Caregivers who score low or medium on most of the measures may receive up to \$500 in services. Caregivers who have scores that are in the medium and high range are invited to complete the full TCARE® in-depth assessment. Caregivers' responses to the assessment questions are processed by a computer software that uses a decision algorithm to provide a profile of the caregiver and suggestions for a service plan that are used by the care managers to tailor a care plan to the caregivers' current needs.

B. Caregivers Served With TCARE® Protocol (March 2010 through December 2013)

Between March 2010 and December 2013, 11,101 family caregivers completed the TCARE® screening process. Half (49.5%) of the caregivers were husbands (15.8%), wives (31.9%), or partners (1.7%) of the care recipient; 40.8% were sons (8.7%) or daughters (32.1%); and distant relatives and friends accounted for the remaining 9.7%. The mean age of caregivers was 64 and the mean age of care recipients was 77. The majority (85%) of caregivers were white, but the sample did include small numbers of Asians, Blacks, Latinos, Pacific Islanders, and Native Americans. Scores for 25% of these caregivers on the five measures of caregiver stress and depression did not meet the threshold to be eligible for level 3 services. The remaining 8,314 caregivers completed the full-in-depth structured TCARE® interview. A greater proportion of spouse caregivers (79%) completed the full assessment than did adult children (72%) or more distant relatives (65%). This report provides detailed information about the 5,592¹ spouse and adult children caregivers who completed the full TCARE® assessment between March 15, 2010 and December 15, 2013 and would be eligible for a six-month follow up assessment.

C. Outcomes for Caregivers Who Completed a Six-Month Follow-Up

Current policy of the FCSP requires follow-up with a TCARE® screening to be conducted with caregivers after six months of enrollment. If a caregiver's scores on the measures of stress and depression have improved over the course of six months, only minor adjustments are made to the care plan, if needed. If a caregiver's scores on key measures have not improved, the full TCARE® assessment is completed with the caregiver. A six-month follow-up assessment was conducted with 57.4% of the caregivers who were eligible for the follow-up assessment. Data from these assessments provide strong evidence for the benefits of the TCARE® process. Most important, the levels of stress and burden for 84% of these caregivers had diminished over the six month period. The mean scores for this group decreased by 13% for stress burden, 10% for objective burden, 8% for relationship burden, 7% for identity discrepancy (i.e. comfort with caregiving role), and 9% for depression. Equally important, scores for uplifts, or caregivers' positive feelings, increased by 4%.

A full follow-up assessment was deemed appropriate for the 16% of caregivers whose scores on the key outcomes had not improved at the time of follow-up. Although there are potentially numerous idiosyncratic reasons for this lack of improvement, two possible explanations should be considered as they have implications for practice and policy decisions. It is possible that the care plans created for these caregivers did not effectively meet their needs. It is also possible that the care plan was initially

effective, but the care plan became obsolete due to changes in the condition of the care recipient or the resources of the caregiver.

Findings from two analyses provide support for the latter explanation. First, it is useful to look at differences between the two groups of caregivers (those who improved and those who did not) at the time of enrollment. At the time of the initial assessment, there were no differences between the two groups in the functional levels of the care recipients nor in the level any of the three types of caregiver burden or and depression reported. However, caregivers in the group that failed to improve were caring for persons who engaged in more problem behaviors and were providing more assistance with ADLs (eating, bathing, dressing and toileting functions), transportation and money and legal matters. Moreover, there was a statistically significant decline over the six month period in the functional level of the person for whom they were providing care. In short, the 16% of caregivers whose stress and depression levels were not improved, were providing the most care for care recipients whose condition continued to decline. Given that these caregivers were already providing the greatest number of hours of care, it is highly likely that the increase in functional disability of the care receiver translated to a need for more or different support services. Consequently, the initial care plans were no longer meeting the needs of the caregiver. Together these findings underscore the importance and the efficiency of conducting follow-ups to identify the small group of caregivers in need of the more in-depth follow-up.

D. Outcomes for Caregivers Who Completed a 12-Month Follow-Up Assessment

Current policy for the FCSP requires a full assessment to be conducted with caregivers on an annual basis regardless of the caregiver's scores on the key measures of stress or burden. Data for 1,381 caregivers who completed the full TCARE[®] assessment 12 months after enrollment in the program provide evidence that the positive impact of the TCARE[®] protocol persists over time. Over a one year period, the condition of the care recipients deteriorated as indicated by increased need for assistance with all types of daily activities including help with personal care. In response, caregivers increased the number of hours they spent providing help with eating, bathing and dressing. Yet, despite these statistically significant increases in disability of the care recipient and in the hours providing care, the mean scores for the caregivers on all measures of caregiver burden and depression decreased. **In short, with the support of TCARE[®], caregivers served by the FCSP over a one year period were able to maintain their health and improve their emotional and mental health while providing more assistance to care recipients who experienced a decline in functional abilities.**

E. Caregivers Who Left the Program Prior to Six-Month Follow-Up

Reasons for leaving

To gain a full understanding of the benefits and limitations of the FCSP program, a detailed analysis was conducted that focused on characteristics of 1,665 caregivers who dropped out of the program prior to the six-month follow-up. The majority (66%) of these caregivers left the program because the care recipient was placed in a long term care facility (24%), the care receiver died (34.7%) or the caregiver was no longer available due to death, moving, or illness (5.7%). The remaining 34% of caregivers who did not complete a follow-up chose not to participate in the program or the care managers were unable to contact them.

Differences in characteristics between caregivers who continued and caregivers who left the program

Given the emphasis of the FCSP on promoting continued community living, an important question to ask is: *Did the caregivers who made the decision to place the care recipient in a long term care facility*

differ in any significant way from those who continued to be served in the program? The answer is yes, they did differ in several important ways. Caregivers whose family members moved to a long term care facility were more likely to be caring for an individual who had memory problems, the majority (60.5%) of whom had a medical diagnosis of Alzheimer’s disease or other dementia. These care recipients engaged in more problem behaviors and required more assistance with everyday activities such as meal preparation, laundry and household tasks, than did the care recipients of caregivers who continued in the program to the 6-month follow-up. However, their caregivers did not spend more time providing assistance with these tasks, but they did spend more time providing assistance with ADLs (bathing, dressing, eating, and toileting). The biggest difference between the group of caregivers who continued to provide care and those whose care recipient moved to a care facility was their level of stress and depression. The mean scores for all measures of caregiver burden, depression and intentions to place the care recipient in a care facility were highest for caregivers who ultimately did place the care recipients in a long term care facility.

Two observations that have policy implications can be made about these differences between the two groups. First, it is highly likely that the caregivers who placed their care recipient in a long term care facility were seeking and receiving help too late in the caregiving process. The levels of caregiver burden and depression that these caregivers were experiencing was so high that they were already considering or seeking placement of the care recipient in a facility when they first made contact. This is the group of caregivers that is often in crisis and unable or unwilling to consider other options. In short, the services offered by the FCSP were too little, too late. This pattern suggests that the FCSP is most effective when services are offered to caregivers before their stress levels become very high.

The second observation concerns the challenge of caring for individuals with memory problems and problem behaviors. Although these individuals are often physically able to perform daily tasks and chores, their memory and behavior problems create a situation that requires constant vigilance on the part of caregivers. The difficulty of maintaining constant vigilance is not captured by measures of functional ability or the number of hours that a caregiver spends performing tasks. They must be constantly vigilant and in many ways they are “on call” 24 hours a day, 7 days a week. It is, therefore, not surprising that the caregivers who ultimately moved the care recipient to a care facility were more likely to be caring for someone with memory and/or problem behaviors.

The final analysis that was conducted focused on caregivers whose family members died prior to a scheduled six-month follow-up assessment. The analysis provides two findings that are informative. Family members caring for an adult at the end of life were providing the most care for individuals who were the most physically impaired. Yet, despite this greater workload, their mean scores for relationship burden, stress burden, and identity discrepancy did not differ from those of caregivers who continued in the program to the six-month follow up. They also expressed no greater intention to place the care recipient in a long term care facility than did caregivers who continued in the program and reported experiencing the most positive feelings about caregiving. Clearly these findings underscore the fact that the physical work of caregiving is not the most important factor that influences caregiver’s ability and willingness to continue to provide care. Rather, it is the emotional well-being of the caregiver that is the driving force.

End Note

¹ 25% (1,910) of the 7,502 spouse and adult-children caregivers in had not been enrolled in the TCARE® program long enough to be eligible for a six-month follow-up assessment.

F. Technical Appendix

Table 1. Frequencies of Characteristics of Washington TCARE® Caregivers (Mar 2010-Dec 2013)
(*n=11,101*)

| | Full Sample (N=11,101) | Full Assessment Completed (N=8,314) | Screen Only Completed (N= 2,787) |
|---|---------------------------|---|--|
| | N (%) | N (%) | N (%) |
| Gender | | | |
| Male | 3020 (27.2) | 2215 (26.6) | 805 (28.9) |
| Female | 8079 (72.8) | 6097 (73.3) | 1982 (71.1) |
| Other | 2 (.0) | 2 (.0) | 0 (0.0) |
| Race | | | |
| White | 9407 (84.7) | 7184 (86.4) | 2223 (79.8) |
| Black or African American | 364 (3.3) | 285 (3.4) | 79 (2.8) |
| Native Hawaiian/Other Pacific Islander | 50 (0.5) | 34 (0.4) | 16 (0.6) |
| American/Alaskan Native | 248 (2.2) | 113 (1.4) | 135 (4.8) |
| Asian | 471 (4.2) | 375 (4.5) | 96 (3.4) |
| Unreported | 195 (1.8) | 96 (1.2) | 99 (3.6) |
| Other | 322 (2.9) | 210 (2.5) | 112 (4.0) |
| Hispanic/Latino | 468 (4.2) | 325 (3.9) | 143 (5.1) |
| Two or More Races Indicated | 488 (4.4) | 342 (4.1) | 146 (5.2) |
| Employment Status ** | | | |
| Employed | - | 2125 (25.6) | - |
| Not Employed | - | 5630 (67.7) | - |
| Relationship to the care recipient | | | |
| Spouse/Partner | 5498 (49.5) | 4357 (52.4) | 1141 (40.9) |
| --Husband | 1759 (15.8) | 1340 (16.1) | 419 (15.0) |
| --Wife | 3545 (31.9) | 2877 (34.6) | 668 (24.0) |
| --Partner | 194 (1.7) | 140 (1.7) | 54 (1.9) |
| Adult Child | 4525 (40.8) | 3259 (39.2) | 1266 (45.4) |
| --Son | 966 (8.7) | 682 (8.2) | 284 (10.2) |
| --Daughter | 3559 (32.1) | 2577 (31.0) | 982 (35.2) |
| Other | 1078 (9.7) | 698 (8.4) | 380 (13.6) |
| Live with Care Receiver** | | | |
| Yes | - | 6855 (82.5) | - |
| No | - | 989 (11.9) | - |
| Self-reported health ** | | | |
| Very Poor | - | 158 (1.9) | - |
| Poor | - | 841 (10.1) | - |
| Fair | - | 2767 (33.3) | - |
| Good | - | 3544 (42.6) | - |
| Very Good | - | 1004 (12.1) | - |
| Care recipient memory loss | | | |
| No memory problem | 1952 (17.6) | 1298 (15.6) | 624 (22.4) |
| Memory or cognitive problem suspected | 3351 (30.2) | 2440 (29.3) | 908 (32.6) |
| Probable Alzheimer's, not medically diagnosed | 1729 (15.6) | 1292 (15.5) | 427 (15.3) |
| Yes, Alzheimer's, medically diagnosed | 4069 (36.7) | 3284 (39.5) | 828 (29.7) |

** indicates variable only found in assessment

**Table 2. Descriptive Statistics of Characteristics of Washington TCARE® Caregivers (Mar 2010-Dec 2013)
(n=11,101)**

| | Full Sample (N=11,101) | Full Assessment Completed (N=8,314) | Screen Only Completed (N= 2,787) |
|--|---------------------------|---|--|
| | Mean (SD) | Mean (SD) | Mean (SD) |
| Caregiver Age (in years) | 63.81 (14.15) | 64.51 (13.79) | 61.87 (15.07) |
| Care recipient Age (in years) | 77.57(12.41) | 78.02 (12.10) | 76.39 (13.26) |
| Caregiver annual income** | - | 1990.36 (1613.35) | - |
| <i>Missing Data - N(%)</i> | - | 2299 (27.7) | - |
| Caregiver assistance (hours per week) ** | | | |
| Eating, bathing, dressing or toilet functions | - | 14.17 (15.46) | - |
| Meal preparation, laundry or light housework | - | 20.82 (12.99) | - |
| Provide transportation to/from appointments | - | 6.49 (5.99) | - |
| Legal matters, banking, money matters | - | 3.40 (4.88) | - |
| Care recipient ADLs (0-44)** | - | 8.55 (7.17) | - |
| Care Recipient IADLs (0-24)** | - | 18.51 (4.73) | - |
| Care Recipient Problem Behaviors (0-45)** | - | 11.90 (7.28) | - |
| Intention to Place (1-4) | 1.79 (.94) | 1.82 (.94) | 1.77 (.98) |
| Relationship Burden (5-25) | 11.13 (5.15) | 11.81 (5.16) | 9.66 (4.87) |
| Objective Burden (6-30) | 21.73 (6.47) | 23.21 (5.64) | 18.09 (7.02) |
| Stress Burden (5-25) | 15.52 (5.45) | 16.57 (5.06) | 12.99 (5.53) |
| Depression (10-40) | 24.24 (7.09) | 25.55 (6.63) | 21.18 (7.21) |
| Identity Discrepancy (6-36) | 24.61 (7.11) | 26.10 (6.26) | 21.13 (7.88) |
| Uplifts (6-30) | 15.03 (6.18) | 14.48 (5.94) | 16.38 (6.57) |

** indicates variable only found in assessment

**Table 3. Paired T-test for Follow-Up Screen Key Outcomes- Time 1 and Time 2
(n=2702)**

| Outcome | Time 1 | Time 2 | t | df | % Change |
|----------------------------|--------|--------|-----------|------|-------------|
| <i>Relationship Burden</i> | 11.54 | 10.59 | 11.157*** | 2701 | 8.0% |
| <i>Objective Burden</i> | 23.03 | 20.79 | 20.347*** | 2701 | 10.0% |
| <i>Stress Burden</i> | 16.21 | 14.16 | 22.652*** | 2701 | 13.0% |
| <i>Uplifts</i> | 14.41 | 14.92 | -5.438*** | 2701 | 4.0% |
| <i>Depression</i> | 25.29 | 22.92 | 19.441*** | 2701 | 9.0% |
| <i>Discrepancy</i> | 25.79 | 24.05 | 13.466*** | 2701 | 7.0% |

Note; Asterisks denote significant differences between times at the levels specified below

* = p<.05, **=p<.01, ***p<.001

Table 4. Time 1 With Assessment & Screen Follow-Up- Chi Square (n=3212)

| | Time 1 With Screen Follow-Up (N=2702) | Time 1 With Assessment Follow-Up (N=510) |
|---|---|---|
| | N (%) | N (%) |
| Gender | | |
| Male | 763(28.2) | 136 (26.7) |
| Female | 1938 (71.7) | 374 (73.3) |
| Other | 1 (.0) | 0 (.0) |
| Race | | |
| White | 2353 (87.1) | 450 (88.2) |
| Black or African American** | 115 (4.3) | 9 (1.8) |
| Native Hawaiian/Other Pacific Islander | 10 (0.4) | 0 (.0) |
| American/Alaskan Native | 26 (1.0) | 6 (1.2) |
| Asian | 127 (4.7) | 25 (4.9) |
| Unreported | 14 (0.5) | 6 (1.2) |
| Other | 66 (2.4) | 15 (2.9) |
| Hispanic/Latino | 104 (3.8) | 23 (4.5) |
| Two or More Races Indicated | 113 (4.2) | 24 (4.7) |
| Employment Status | | |
| Employed | 617 (22.8) | 119 (23.3) |
| Not Employed | 1940 (71.8) | 358 (70.2) |
| Relationship to the care recipient | | |
| Spouse/Partner | 1674 (62.0) | 312 (61.2) |
| Adult Child | 1028 (38.0) | 198 (38.8) |
| Live with Care Receiver | | |
| Yes | 2373 (87.8) | 439 (86.1) |
| No | 201 (7.4) | 46 (9.0) |
| Self-reported health ** | | |
| Very Poor | 45 (1.7) | 11 (2.2) |
| Poor | 248 (9.2) | 69 (13.5) |
| Fair | 916 (33.9) | 161 (31.6) |
| Good | 1179 (43.6) | 199 (39.0) |
| Very Good | 314 (11.6) | 70 (13.7) |
| Care recipient memory loss | | |
| No memory problem | 415 (15.4) | 88 (17.3) |
| Memory or cognitive problem suspected | 708 (26.2) | 137 (26.9) |
| Probable Alzheimer's, not medically diagnosed | 396 (14.7) | 86 (16.9) |
| Yes, Alzheimer's, medically diagnosed | 1183 (43.8) | 199 (39.0) |

Note; Asterisks denote significant differences between categories at the levels specified below.

* = p<.05, **=p<.01, ***p<.001

Table 5. Time 1 With Assessment & Screen Follow-Up- T-Tests (n=3212)

| | Time 1 With Screen Follow-Up (N=2702) | Time 1 With Assessment Follow-Up (N=510) |
|---|---|---|
| | Mean (SD) | Mean (SD) |
| Caregiver Age (in years) | 66.24 (12.86) | 65.93 (12.54) |
| Care Recipient Age (in years) | 78.79 (10.40) | 78.60 (10.14) |
| Caregiver annual income*** | 1986.76 (1550.67) | 1676.32 (1457.99) |
| <i>Missing Data - N(%)</i> | 695 (25.7) | 142 (27.8) |
| Caregiver assistance (hours per week) | | |
| Eating, bathing, dressing or toilet functions* | 13.96 (15.02) | 15.46 (15.96) |
| Meal preparation, laundry or light housework | 21.82(12.59) | 23.05 (13.91) |
| Provide transportation to/from appointments*** | 6.21 (5.74) | 7.70 (6.38) |
| Legal matters, banking, money matters** | 3.17 (4.42) | 3.80 (4.57) |
| Care recipient ADLs (0-44) | 8.26 (6.81) | 8.57 (7.45) |
| Care Recipient IADLs (0-24) | 18.52 (4.54) | 18.75 (4.62) |
| Care Recipient Problem Behaviors (0-45)* | 11.46 (6.91) | 12.20 (7.43) |
| Intention to Place (1-4) | 1.68(.85) | 1.66 (.87) |
| Relationship Burden (5-25) | 11.54 (4.97) | 11.61 (5.38) |
| Objective Burden (6-30) | 23.03 (5.59) | 22.89 (5.78) |
| Stress Burden (5-25) | 16.21 (4.96) | 16.28 (5.30) |
| Depression (10-40) | 25.29 (6.44) | 25.02 (6.94) |
| Identity Discrepancy (6-36) | 25.79 (6.31) | 25.77 (6.68) |
| Uplifts (6-30) | 14.41 (5.89) | 14.43 (5.91) |

Note; Asterisks denote significant differences between categories at the levels specified below.
 * = p<.05, **=p<.01, ***p<.001

Table 6. Paired T-test Comparing Initial Assessment (T1) and Second Assessment Follow-Up (T3) Outcomes (n=1,381)

| Outcome | Time 1 | Time 3 | t | df | % Change |
|----------------------------|--------|--------|----------|------|----------|
| <i>Relationship Burden</i> | 11.75 | 11.51 | 1.929* | 1380 | 2.1% |
| <i>Objective Burden</i> | 23.22 | 22.03 | 7.650*** | 1380 | 5.1% |
| <i>Stress Burden</i> | 16.53 | 15.34 | 8.940*** | 1380 | 7.2% |
| <i>Uplifts</i> | 14.34 | 14.58 | -1.797 | 1380 | - |
| <i>Depression</i> | 25.75 | 24.19 | 8.848*** | 1380 | 6.1% |
| <i>Discrepancy</i> | 26.04 | 25.60 | 2.471* | 1380 | 1.7% |

Note; Asterisks denote significant differences between times at the levels specified below

* = p<.05, **=p<.01, ***p<.001

Table 7. Paired T-test Comparing Initial Assessment (T1) and Second Assessment Follow-Up (T3) Key Characteristics (n=1,381)

| | Time 1 | Time 3 | t | df | % Change |
|--|--------|--------|-----------|------|----------|
| <i>ADLs</i> | 8.23 | 9.38 | -9.282*** | 1380 | -14.0% |
| <i>IADLs</i> | 18.67 | 19.16 | -5.579*** | 1380 | -3.0% |
| <i>Problem Behaviors</i> | 11.75 | 11.30 | 2.831** | 1380 | 4.0% |
| <i>Hours spent assisting eating, bathing, dressing, or helping with toilet functions</i> | 13.85 | 15.14 | -3.405** | 1380 | -9.0% |
| <i>Hours spent assisting meal preparation, laundry, or light housework</i> | 21.75 | 21.69 | .177 | 1380 | - |
| <i>Hours spent assisting providing transportation to appointments and/or shopping</i> | 6.32 | 5.86 | 2.636** | 1380 | 7.0% |
| <i>Hours spent assisting legal matters, banking or money matters</i> | 3.14 | 3.06 | .613 | 1380 | - |
| <i>Self-rated Health</i> | 3.52 | 3.50 | .875 | 1379 | - |
| <i>Memory Problems</i> | 1.51 | 1.47 | 1.291 | 1380 | - |

Note; Asterisks denote significant differences between times at the levels specified below
 * = p<.05, **=p<.01, ***p<.001

Table 8. Paired T-test Comparing Initial Assessment (T1) and Assessment Follow-Up (T2) Outcomes (n=510)

| Outcome | Time 1 | Time 2 | t | df | % Change |
|----------------------------|--------|--------|--------|-----|----------|
| <i>Relationship Burden</i> | 11.61 | 11.83 | -1.035 | 509 | - |
| <i>Objective Burden</i> | 22.89 | 22.55 | 1.198 | 509 | - |
| <i>Stress Burden</i> | 16.28 | 15.84 | 1.856 | 509 | - |
| <i>Uplifts</i> | 14.43 | 14.59 | -.703 | 509 | - |
| <i>Depression</i> | 25.02 | 24.73 | .952 | 509 | - |
| <i>Discrepancy</i> | 25.77 | 25.94 | -.577 | 509 | - |

Note; Asterisks denote significant differences between times at the levels specified below
 * = p<.05, **=p<.01, ***p<.001

Table 9. Paired T-test Comparing Initial Assessment (T1) and Assessment Follow-Up (T2) Key Characteristics (n=510)

| | Time 1 | Time 2 | t | df | % Change |
|--|--------|--------|-----------|-----|----------|
| <i>ADLs</i> | 8.57 | 10.04 | -6.134*** | 509 | -17.1% |
| <i>IADLs</i> | 18.75 | 19.35 | -3.617*** | 509 | -3.3 |
| <i>Problem Behaviors</i> | 12.20 | 12.32 | -.421 | 509 | - |
| <i>Hours spent assisting eating, bathing, dressing, or helping with toilet functions</i> | 15.46 | 16.47 | -1.329 | 509 | - |
| <i>Hours spent assisting meal preparation, laundry, or light housework</i> | 23.05 | 21.99 | 1.590 | 509 | - |
| <i>Hours spent assisting providing transportation to appointments and/or shopping</i> | 7.70 | 7.26 | 1.285 | 509 | - |
| <i>Hours spent assisting legal matters, banking or money matters</i> | 3.80 | 3.86 | -.235 | 509 | - |
| <i>Self-rated Health</i> | 3.49 | 3.47 | .527 | 504 | - |
| <i>Memory Problems</i> | 1.53 | 1.58 | -.932 | 509 | - |

Note; Asterisks denote significant differences between times at the levels specified below

* = $p < .05$, ** = $p < .01$, *** = $p < .001$

Table 10: Comparison of Caregiver and Care Receiver Characteristics by Follow-Up Completion Type

| | Time 1 With Screen Follow-Up (N=2702) N (%) | Time 1 With Assessment Follow-Up (N=510) N (%) | Time 1 With No Follow-Up CR Death (N=577) N (%) | Time 1 With No Follow-Up CR Placement (N=397) N (%) |
|---|--|--|---|---|
| Gender + ∞ | | | | |
| Male | 763(28.2) | 136 (26.7) | 128 (22.2) | 122 (30.7) |
| Female | 1938 (71.7) | 374 (73.3) | 449 (77.8) | 275 (69.3) |
| Other | 1 (.0) | 0 (.0) | 0 (.0) | 0 (.0) |
| Race | | | | |
| White +*◇□ | 2353 (87.1) | 450 (88.2) | 534 (92.5) | 371 (93.5) |
| Black or African American ^ +* | 115 (4.3) | 9 (1.8) | 5 (0.9) | 6 (1.5) |
| Native Hawaiian/Other Pacific Islander | 10 (0.4) | 0 (.0) | 3 (0.5) | 1 (0.3) |
| American/Alaskan Native | 26 (1.0) | 6 (1.2) | 6 (1.0) | 2 (0.5) |
| Asian +*◇□ | 127 (4.7) | 25 (4.9) | 14 (2.4) | 8 (2.0) |
| Unreported | 14 (0.5) | 6 (1.2) | 7 (1.2) | 1 (0.3) |
| Other◇ | 66 (2.4) | 15 (2.9) | 7 (1.2) | 9 (2.3) |
| Hispanic/Latino +◇ | 104 (3.8) | 23 (4.5) | 10 (1.7) | 9 (2.3) |
| Two or More Races Indicated | 113 (4.2) | 24 (4.7) | 15 (2.6) | 10 (2.5) |
| Employment Status | | | | |
| Employed | 617 (22.8) | 119 (23.3) | 116(20.1) | 85 (21.4) |
| Not Employed | 1940 (71.8) | 358 (70.2) | 416(72.1) | 295 (74.3) |
| Relationship to the Care Recipient | | | | |
| Spouse/Partner | 1674 (62.0) | 312 (61.2) | 358 (62.0) | 241 (60.7) |
| Adult Child | 1028 (38.0) | 198 (38.8) | 219(38.0) | 156 (39.3) |
| Live with Care Recipient | | | | |
| Yes | 2373 (87.8) | 439 (86.1) | 519 (89.9) | 348 (87.7) |
| No | 201 (7.4) | 46 (9.0) | 44 (7.6) | 39 (9.8) |
| Self-Reported Health ^◇ | | | | |
| Very Poor | 45 (1.7) | 11 (2.2) | 7 (1.2) | 6 (1.5) |
| Poor | 248 (9.2) | 69 (13.5) | 50 (8.7) | 49 (12.3) |
| Fair | 916 (33.9) | 161 (31.6) | 210(36.4) | 120 (30.2) |
| Good | 1179 (43.6) | 199 (39.0) | 242(41.9) | 172 (43.3) |
| Very Good | 314 (11.6) | 70 (13.7) | 68(11.8) | 50 (12.6) |
| Care Recipient Memory Loss +*□∞ | | | | |
| No memory problem | 415 (15.4) | 88 (17.3) | 94 (16.3) | 22 (5.5) |
| Memory or cognitive problem suspected | 708 (26.2) | 137 (26.9) | 188 (32.6) | 67 (16.9) |
| Probable Alzheimer's, not medically diagnosed | 396 (14.7) | 86 (16.9) | 75 (13.0) | 68 (17.1) |
| Yes, Alzheimer's, medically diagnosed | 1183 (43.8) | 199 (39.0) | 220 (38.1) | 240 (60.5) |
| | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) |
| Caregiver Age (in years) +*◇□ | 66.24 (12.86) | 65.93 (12.54) | 67.45 (12.42) | 68.09 (13.12) |
| Care Recipient Age (in years) +*◇□ | 78.79 (10.40) | 78.60 (10.14) | 80.43(9.97) | 80.81 (8.28) |
| Caregiver Annual Income ^◇□∞ | 1986.76 (1550.67) | 1676.32 (1457.99) | 1882.45 (1495.13) | 2121.72 (1589.68) |
| Missing Data - N(%) | 695 (25.7) | 142 (27.8) | 151 (26.2) | 104 (26.2) |
| Caregiver Assistance (hours per week) | | | | |
| Eating, bathing, dressing or toilet functions ^+*◇∞ | 13.96 (15.02) | 15.46 (15.96) | 21.40 (17.01) | 17.52 (16.40) |
| Meal preparation, laundry or light housework + | 21.82(12.59) | 23.05 (13.91) | 23.52 (12.59) | 22.90 (11.97) |
| Provide transportation to/from appointments ^◇□ | 6.21 (5.74) | 7.70 (6.38) | 5.99 (5.66) | 6.58 (5.32) |
| Legal matters, banking, money matters ^+* | 3.17 (4.42) | 3.80 (4.57) | 3.37 (4.32) | 3.87 (5.83) |
| Care Recipient ADLs (0-44) +*◇∞ | 8.26 (6.81) | 8.57 (7.45) | 13.23 (7.66) | 9.02 (6.42) |
| Care Recipient IADLs (0-24) *◇□ | 18.52 (4.54) | 18.75 (4.62) | 20.49 (3.61) | 20.24 (3.67) |
| Care Recipient Problem Behaviors (0-45) ^*□∞ | 11.46 (6.91) | 12.20 (7.43) | 11.86 (7.19) | 14.74 (8.13) |
| Intention to Place (1-4) *□∞ | 1.68(.85) | 1.66 (.87) | 1.73(.85) | 2.42 (1.05) |
| Relationship Burden (5-25) *□∞ | 11.54 (4.97) | 11.61 (5.38) | 11.20 (5.18) | 12.55 (5.26) |
| Objective Burden (6-30) +*◇□∞ | 23.03 (5.59) | 22.89 (5.78) | 23.90(5.16) | 24.83 (4.92) |
| Stress Burden (5-25) *□∞ | 16.21 (4.96) | 16.28 (5.30) | 16.48 (5.02) | 17.78 (4.83) |
| Depression (10-40) +*◇□∞ | 25.29 (6.44) | 25.02 (6.94) | 25.88 (6.54) | 26.92 (6.68) |
| Identity Discrepancy (6-36) *◇□∞ | 25.79 (6.31) | 25.77 (6.68) | 25.84 (6.20) | 27.91 (5.32) |
| Uplifts (6-30) +*□∞ | 14.41 (5.89) | 14.43 (5.91) | 15.08 (6.08) | 12.75 (5.32) |

- ^ Denotes a significant difference between T1 With Screen Follow-Up and T1 With Assessment Follow-Up.**
- + Denotes a significant difference between T1 With Screen Follow-Up and T1 With No Follow-Up CR Death.**
- * Denotes a significant difference between T1 With Screen Follow-Up and T1 With No Follow-Up CR Placement.**
- ✦ Denotes a significant difference between T1 With Assessment Follow-Up and T1 With No Follow-Up CR Death.**
- Denotes a significant difference between T1 With Assessment Follow-Up and T1 With No Follow-Up CR Placement.**
- ∞ Denotes a significant difference between T1 With No Follow-Up CR Death and T1 With No Follow-Up CR Placement.**