

Rock County Caregivers

A Brief Report Regarding
Survey of Rock County Caregivers
August 2010- December 2010

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Background

The Rock County Council on Aging (RCCOA) conducted a survey of informal caregivers who resided in their county. The goal of the survey, conducted between August 2010 and December 2010 was three-fold. The council was interested in: (1) identifying the caregiver population, (2) identifying the tasks and types of activities caregivers performed; and (3) identifying the unique needs of their caregivers. The council was particularly interested in the needs of family caregivers who cared for adult relatives or those ages 18 and older.

RCCOA approached the University of Wisconsin-Whitewater evaluation team and requested assistance with analyzing the survey data. The evaluation team agreed and conducted exploratory analysis to address three questions: (1) who comprises the population that cares for adults; (2) what types of activities are performed by caregivers; and (3) what are the unique needs of caregivers.

Methods

Data Analysis

Descriptive statistics was utilized to address the three research questions. A series of univariate analyses were performed and information is presented in tables. Qualitative responses provided by caregivers were also examined and are presented.

Sample

During the enrollment period, 268 informal caregivers (i.e., unpaid or family member) completed a caregiver questionnaire developed by the Rock County Council on Aging. The questionnaire includes questions that ask caregivers about the things they do, level of care they provide, and ability level of their care receivers. Caregivers were recruited multiple ways, including flyers, word of mouth, and through community agencies that served older adults. The survey was available for completion electronically and in paper format.

Two-hundred twelve caregivers (79%) completed the survey via *Survey Monkey*, an online surveying tool. Fifty-six respondents (21%) completed a paper version of the survey. The majority of caregivers in the sample (n=257) were caring for family members age 18 or older. Because RCCOA was particularly interested in the needs of family caregivers caring for adults, information present below includes only data for caregivers who provided care for someone over the age of 18 (n=257).

Caregiver Sample

Table 1 includes demographic information for the 257 caregivers caring for a relative age 18 or older.

Table 1. Caregiver demographics (n=257).

| Characteristic | Frequency Number (%) |
|--|-------------------------|
| Age | |
| 18-21 | 3 (1.2) |
| 26-35 | 8 (3.1) |
| 36-45 | 27 (10.5) |
| 46-55 | 63 (24.5) |
| 56-65 | 77 (30) |
| 66-75 | 40 (15.6) |
| 76-80 | 17 (6.6) |
| 81-85 | 6 (2.3) |
| 86-90 | 3 (1.2) |
| Missing | 13 (5.1) |
| Gender | Number (%) |
| Female | 202 (78.6) |
| Male | 43 (16.7) |
| Missing | 12 (4.7) |
| Race | Number (%) |
| White | 236 (91.8) |
| Hispanic/Latino | 2 (.8) |
| African American | 1 (.4) |
| Asian/Pacific Islander | 0 |
| American Indian/Alaskan Native | 4 (1.6) |
| More than one race | 1 (.4) |
| Missing | 13 (5) |
| Marital Status | Number (%) |
| Married (living with spouse/partner) | 180 (70) |
| Married (not living with spouse/partner) | 5 (1.9) |
| Divorced/separated | 26 (10.1) |
| Widowed | 12 (4.7) |
| Single (never married) | 22 (8.6) |
| Missing | 12 (4.7) |

| | | |
|--------------------------------------|--------------------|----------------------|
| Employment | Number (%) | |
| Working full time | 92 (35.8) | |
| Working part time | 30 (11.7) | |
| Not working/unemployed | 20 (7.8) | |
| Retired | 81 (31.5) | |
| Not applicable | 3 (1.2) | |
| Missing | 31 (12.1) | |
| Residence Location | Number (%) | |
| City of Janesville | 115 (44.7) | |
| City of Beloit | 30 (11.7) | |
| City of Milton | 15 (5.8) | |
| City of Edgerton | 7 (2.7) | |
| City of Evansville | 15 (5.8) | |
| City of Footville | 3 (1.2) | |
| City of Orfordville | 1 (.4) | |
| Rural Janesville | 15 (5.8) | |
| Rural Beloit | 5 (1.9) | |
| Rural Milton | 7 (2.7) | |
| Rural Clinton | 2 (.8) | |
| Rural Edgerton | 6 (2.3) | |
| Rural Evansville | 3 (1.2) | |
| Rural Footville | 1 (.4) | |
| Rural Orfordville | 1 (.4) | |
| Other rural (not listed) | 8 (3.1) | |
| Not in Rock County | 9 (3.5) | |
| Not in Wisconsin | 2 (.8) | |
| Missing | 12 (4.7) | |
| Relationship to Care Receiver | <u>Male</u> | <u>Female</u> |
| | Number (%) | Number (%) |
| Spouse/partner | 17 (41.5) | 46 (25.1) |
| Mother or father | 13 (31.7) | 89 (48.6) |
| Mother in law or father in law | 3 (7.3) | 9 (4.9) |
| Grandparent | 0 (0) | 3 (1.6) |
| Adult son or daughter | 4 (9.8) | 15 (8.2) |
| Other relative | 2 (4.9) | 12 (6.6) |
| Friend or neighbor | 2 (4.9) | 4 (2.2) |
| Other | 0 (0) | 5 (2.7) |
| Residence Relationship | Number (%) | |
| Live with them | 121 (47.1) | |
| Less than 20 minutes away | 76 (29.6) | |
| Between 20 and 60 minutes away | 23 (8.9) | |
| More than 2 hours away | 2 (.8) | |
| Live in another state | 1 (.4) | |
| Missing | 34 (13.2) | |
| Length of Caregiving | Number (%) | |
| Less than one year | 23 (8.9) | |
| 1-5 years | 111 (43.2) | |
| 6-10 years | 52 (20.2) | |
| 11-15 years | 9 (3.5) | |
| Over 15 years | 32 (12.5) | |
| Missing | 30 (11.7) | |

The majority of caregivers are between the ages of 46 and 65 (54.5%). Of the 257 caregivers, 202 are female (78.6%) and 43 are male (16.7%). The majority of the respondents are married (70%), white (91.8%), working full-time (35.8%), and live in the city of Janesville (44.7%).

Almost half (44.4%) of the caregivers provide care for a parent or parent-in-law (n=114), which is overwhelmingly provided by females (n=98). A quarter of caregivers (24.5%) provided care for their spouse or partner. In terms of gender and care, patterns were similar to those observed in the adult children distribution. Forty-six women (73%) care for their spouse or partner and 17 men (27%) care for their spouse or partner.

With regard to living arrangement, 121 (47%) caregivers report the care receiver resides in the same household.. In instances where the care receiver resides outside the caregiver's home, 76 (29.6%) live less than 20 minutes away, and 23 (8.9%) live between 20 and 60 minutes from the caregiver.

In terms of length of time caregiving, there was substantial variation. The majority of caregivers have been caring for a family member between 0-5 years (52.1%). Many caregivers have also been providing care between 6-10 years (20.2%). Just over an eighth of the caregivers have been providing care for over 15 years (12.5%).

Care Receiver Sample

Table 2 includes demographic information for care receivers or those being cared for by the 257 caregivers.

Table 2. Care Receiver demographics (n=257).

| Characteristic | Frequency Number (%) |
|---|-------------------------|
| Age | |
| 18-21 | 4 (1.6) |
| 22-25 | 5 (1.9) |
| 26-35 | 7 (2.7) |
| 36-45 | 5 (1.9) |
| 46-55 | 12 (4.7) |
| 56-65 | 20 (7.8) |
| 66-75 | 36 (14) |
| 76-80 | 38 (14.8) |
| 81-90 | 67 (26.1) |
| 91 + | 30 (11.7) |
| Missing | 33 (12.9) |
| Gender | Number (%) |
| Female | 122 (47.5) |
| Male | 98 (38.1) |
| Missing | 37 (14.4) |
| Illness/Diagnosis/Condition | |
| Alzheimer's disease/Memory loss | 94 (36.6) |
| Parkinson's disease | 19 (7.4) |
| Arthritis | 70 (27.2) |
| Diabetes | 51 (19.8) |
| Heart Disease | 58 (22.6) |
| Cancer | 25 (9.7) |
| Stroke | 28 (10.9) |
| Frail Elder | 66 (25.7) |
| Short Term (broken arm, hip replacement) | 17 (6.6) |
| AIDS | 0 (0) |
| Traumatic Brain Injury | 10 (3.9) |
| Mental Illness | 17 (6.6) |
| Developmental Disability (mental retardation) | 19 (7.4) |
| Sensory Impairment | 42 (16.3) |
| Physical Impairment (vision, hearing) | 21 (8.2) |
| Epilepsy | 6 (2.3) |
| Autism | 6 (2.3) |
| Multiple Health Issues | 27 (10.5) |
| Other | 57 (22.2) |

The majority of care receivers (74.3% or 191 individuals) are 56 years or older. Thirteen percent of the care receivers are under the age of 55. Of those 56 years or older, 36 (18.8%) are

between the ages of 66-75 years, 38 (19.9%) are between the ages of 76-80 years, 67 (35.1%) are between the ages of 81-90, and 30 (15.7%) are age 91 or older.

Females comprise the majority of care receivers (47.5%). The top five illnesses reported by caregivers about their care receiver included: Alzheimer's Disease/memory loss (36.6%), Arthritis (27.2%), Diabetes (19.8%), Heart Disease (22.6%), and Frail Elder (25.7%). Twenty-seven respondents (10.5%) reported their care receivers had multiple health issues

Results

Hours, Activities, Outcomes

Table 3 provides information regarding the hours of care and the activities performed.

Table 3. Caregiver Hours and Activities (n=257).

| Characteristic | Frequency Number (%) |
|---|-------------------------|
| Hours of Supervision or Care | |
| 0-7 | 51 (19.8) |
| 8-14 | 39 (15.2) |
| 15-21 | 23 (8.9) |
| 22-36 | 20 (7.8) |
| 36-50 | 20 (7.8) |
| More than 50 | 23 (8.9) |
| 24 hours /7 days a week | 50 (19.5) |
| Missing | 31 (12.1) |
| Activities | |
| Assist with Scheduling Appointments | 212 (82.5) |
| House Chores | 177 (68.9) |
| Manage Diet | 145 (56.4) |
| Personal Care | 105 (40.9) |
| Do Shopping | 197 (76.7) |
| Managing/Administering/Filling Meds | 165 (64.2) |
| Managing Person's Financial and Legal Affairs | 165 (64.2) |
| Providing Emotional Reassurance/ Companionship | 203 (79) |
| Assistance with Transferring (such as bed to chair) | 75 (29.2) |
| Providing/Arranging Transportation | 198 (77) |
| Mow Lawn, Shovel, Outside Homecare | 122 (47.5) |
| Home Maintenance/Repair | 149 (58) |
| Providing Healthcare Procedures | 74 (28.8) |
| Managing Socialization | 155 (60.3) |
| Managing Pastoral Care | 62 (24.1) |
| Arranging/Monitoring Outside Help or Services | 133 (51.8) |
| Other | 30 (11.7) |

The majority of caregivers report providing between 0-14 hours of supervision or care (35%). A large portion of caregivers (19.5%) also report providing around the clock care 7 days a week for their care receiver. In terms of activities performed, caregivers were asked to check all tasks they perform. The data clearly documents caregivers assist their care receivers with a wide variety of activities important for daily living (ADLs) and instrumental for daily living (IADLs). Assistance with personal care was provided by almost half the caregivers (40.9%).

Assistance with IADLs was quite high. Almost all caregivers (n=212) assist their care receiver with scheduling appointments. The overwhelming majority assists with scheduling appointments (82.5%), provide companionship (79%), arrange or provide transportation (77%), assist with shopping (76.7%), managing medications (64.2%), and manage their care receivers' financial or legal affairs (64.2%). One hundred-thirty three (51.8%) arranges or monitors outside help.

The outcomes associated with caregiving vary among caregivers. Table 4 documents both positive and negative outcomes experienced by caregivers.

Table 4. Caregiver outcomes associated with caregiving (n=257).

| Characteristic | Frequency Number (%) |
|----------------------------------|-------------------------|
| Experience of Aspects | 146 (56.8) |
| Fulfillment of obligation | 159 (61.9) |
| Gaining satisfaction | 121 (47.1) |
| Feeling positive | 144 (56) |
| Feeling appreciated | 177 (68.9) |
| Caring for someone love/care for | 106 (41.2) |
| Having additional time with them | 101 (39.3) |
| Gaining knowledge and skills | 131 (51) |
| Giving back | 87 (33.9) |
| Improving relationship-receiver | 54 (21) |
| Reconnecting- receiver | 53 (20.6) |
| Improving relationship-family | 62 (24.1) |
| Getting to know receiver better | 115 (44.7) |
| Learning about self and growing | 82 (31.9) |
| Having a purpose | 9 (3.5) |
| No positive aspects | 13 (5.1) |
| Other | |

| Challenges of Caregiving | Not at all Number (%) | Some Number (%) | Quite a bit Number (%) | A great deal Number (%) |
|----------------------------------|--------------------------|--------------------|---------------------------|----------------------------|
| Physical strain | 28 (10.9) | 102 (39.7) | 62 (24.1) | 16 (6.2) |
| Financial strain | 76 (29.6) | 80 (31.1) | 29 (11.3) | 19 (7.4) |
| Emotional upset/guilt | 24 (9.3) | 105 (40.9) | 53 (20.6) | 26 (10.1) |
| Interference w/ social life | 34 (13.2) | 99 (38.5) | 47 (18.3) | 29 (11.3) |
| Interference w/ family | 58 (22.6) | 90 (35) | 44 (17.1) | 16 (6.2) |
| Interference w/ free time | 17 (6.6) | 108 (42) | 55 (21.4) | 31 (12.1) |
| Interference w/work | 83 (32.3) | 79 (30.7) | 15 (5.8) | 11 (4.3) |
| Physical health changes | 60 (23.3) | 105 (40.9) | 28 (10.9) | 10 (3.9) |
| Reluctance to ask for help | 47 (18.3) | 97 (37.7) | 39 (15.2) | 20 (7.8) |
| Lack of assistance | 51 (19.8) | 85 (33.1) | 41 (16) | 25 (9.7) |
| Unappreciated | 73 (28.4) | 80 (31.1) | 32 (12.5) | 18 (7) |
| Feeling guilty about asking help | 76 (29.6) | 66 (25.7) | 27 (10.5) | 23 (8.9) |

The data documents caregivers' experience of caregiving is both uplifting and challenging. Regarding positive aspects, caregivers were asked to check from a series of possible responses. In terms of positive feeling about providing care, almost two-thirds (61.9%) report "gaining satisfaction" from providing care. Over half report feeling appreciated (56%) and just under half report feeling positive (47.1%). Many caregivers report they provide care due to sense of obligation (56.8%). A third report having a purpose (31.9%) and the experience as providing an opportunity to improve the relationship with the care receiver (20.6%).

There are also many challenges of caregiving. The majority of negative outcomes tend to center around stress burden and time burden. Negative effects on caregiver health also are present. Almost three-quarters of caregivers (184 or 71.5%) identify emotional stress. Interference with own life or responsibilities is also experienced by the majority of caregivers. One hundred ninety-four (75.5%) report interference with free time, 175 caregivers (68.1%) report interference with their social life, 150 (58.4%) report interference with attending to their own family, and 105 (41.%) report interference with their work. Physical health changes were documented for 143 (55.6%) of the caregivers.

Qualitative Comments

Caregivers were asked to respond to a series of open-ended questions. These questions were designed to capture “deeper” meaning and experiences regarding caregiving. Table 5 displays caregiver responses recorded in the “other” or “comments” section of the survey questionnaire.

Table 5. Qualitative responses included in survey questionnaire.

| Question | Similar Responses/Themes |
|---|---|
| What kinds of activities or assistance do you perform for your care receiver? | <ul style="list-style-type: none"> • Caring for receiver’s pet(s) • Attending medical appointments • Digitally remove fecal matter • Feed • Finding/hiring staff to come to home and assist with care receiver |
| Which of these challenges have you experienced as a result of your caregiving responsibilities? | <ul style="list-style-type: none"> • Lack of time to do it all (to complete tasks, work, personal/family care, caregiver meetings) • Emotional toll • Money/Finances |
| When employed/working, did you (or do you) do any of the following because of your caregiving responsibilities? | <ul style="list-style-type: none"> • Work longer hours at night to keep up on work (missed because of caregiver responsibilities) • Retired/Self employed • No longer work outside of home |

| | |
|---|---|
| What is the person's illness/diagnosis/condition that you are caring for? | <ul style="list-style-type: none"> • Both parents require help • Caring for more than one person • There was no option for caring for more than one person on survey • Cerebral Palsy • COPD • Pulmonary Fibrosis |
| How do you feel about your current situation as a family caregiver? | <ul style="list-style-type: none"> • Tough • Overwhelmed • Siblings do not offer support |
| To what extent do you experience the following challenges as a result of your family caregiving responsibilities? | <ul style="list-style-type: none"> • Family members don't get involved • Eating healthier because of preparing diabetic meal plan for receiver • Fortunate for nieces that help • Not enough information • Activities planned around receiver's schedule |
| As a caregiver, have you experienced any of the following aspects of family caregiving? | <ul style="list-style-type: none"> • Not an obligation/honor privilege despite big demands |
| Which of the following resources do you currently use, or would you find useful if they were available? | <ul style="list-style-type: none"> • Help and information that doesn't cost a lot • Care receiver does not like/want help in the home • What care receiver wants differs from what caregiver wants • Finding right help/agency for needs |

Similar responses or themes of the responses were given in the right hand column to better display the needs caregivers may not have had as a choice for their response to the question. Overall trends in responses were lack of time, lack of funds, and lack of family support. However, there was also a common response that included positive feelings, such as the care of the receiver was not an obligation to the caregiver.

Discussion

The goals of the survey research conducted by Rock County Council on Aging were to identify the population of caregivers in their county, identify the tasks they perform, and further identify their unique needs. The findings from this report provide a snapshot of the Rock County caregivers. Caregivers in the county are representative of the larger population. Similar to national data, the majority of caregivers are female and adult children of the care receiver. National data also documents similar outside obligations. The large majority of Rock County caregivers are full time adult-children who are full-time employees faced with the challenges of caregiving, working, and attending to the needs of their own families (Wolff & Kasper, 2006). The types of tasks, length of time caregiving and outcomes of family caregiving are also quite similar to the larger population of family caregivers. National studies document significant assistance with care receiver ADLs and IADLs (Wolff & Kasper, 2006).

The outcomes experienced by caregivers in Rock County also mirror data reported in other studies. Caregiving is both uplifting and stressful (Schulz & Sherwood, 2008). Many caregivers in this study experienced both positive and negative impacts of caregiving. Major concerns expressed by caregivers includes the infringement caregiving has had on time to attend to their own activities, negative emotional effects, and changes in physical health. Qualitative comments provided by caregivers confirm both the positive and negative effects.

Conclusion

There is great variation in caregiving and the experience. Caregivers vary in the intensity and types of tasks they perform. The outcomes of caregiving also vary. For some caregiving is uplifting and rewarding. For others, negative physical, mental, and financial outcomes are experienced. It is hoped the information presented will be help guide RCCOA in their continued efforts to serve family caregivers.

References

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