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Caregivers of Adults with Psychological
and/or Physical Deficits: A Needs Assessment

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Abstract

This study identified specific characteristics of caregivers in Washington and Idaho's Whitman and Latah counties and examined how well their needs are being met by local service agencies. The survey included 32 respondents from both counties and used both qualitative and quantitative methods. Findings showed that caregivers in these two counties were primarily white, female and retired. Fifty-three percent had an educational attainment of a bachelors degree or greater. The qualitative data indicated that caregivers would benefit from respite services and more group activities for people with dementia. Implications for social work practice are discussed.

Caregivers of Adults with Psychological and/or Physical Deficits: A Needs Assessment

Approximately 4 million people in the United States have some kind of dementia and the number is expected to increase four times in the next fifty years (cited in McCallion, Toseland, Gerber & Banks, 2004). The National Council on Aging cites a Consumers Union report that 25 percent of people over the age of forty care for an aging family member. The value of this “free” care was estimated in 2002 to be about \$257 billion dollars annually in the United States (cited in National Council on Aging [NCA]). The United States Congress currently funds the National Family Caregiver Support Program through the Older Americans Act, at \$156.2 million, but this funding falls significantly short of supporting the actual needs of caregivers.

The care giving population is especially vulnerable to stress-related health issues as they take on more unpaid care giving responsibilities for aging parents and grandparents. Among the care giving population, 17% reported their health as being fair to poor, and among those doing intensive care giving 35% reported their health as fair to poor (NCA, 2007). The conservative estimate of cost to business for losses related to employee caregivers is \$17.1 billion a year (NCA, 2007).

This problem is of special concern to people living in Whitman County in the state of Washington and Latah County in the state of Idaho. According to the U.S. Census of 2000, 39.8% of the population over the age of 65 in Latah County has a disability. Of those ages 21-64, 11.7% have a disability. In Whitman county 37.9 % of the population age 65 and over have a disability, and of those ages 21-64, 11.7% are disabled (US Census Bureau, 2000). State wide, Idaho’s population over age 60 is expected to increase 147.4% by the year 2030 (Idaho Commission on Aging, 2006). In Washington the State Plan on Aging projects an increase from 696,555 persons over age 65 to 1.6 million by 2030. This could significantly increase the strain

on caregivers, both in the private and public sectors. According to a report by the National Family Caregivers Association and Family Caregiver Alliance, Washington State has 616,302 persons providing care for a family member. In Idaho 132,600 family members are providing care. The annual market value of this care in Washington totals over \$6.5 million and in Idaho over \$1.4 million (National Family Caregiver Association & Family Caregiver Alliance, 2006).

Many older rural Americans have strong values about self-reliance, conservatism, distrust of outsiders, and family orientation, which can impact their willingness to use formal services. Formal services were defined for this study as services offered by paid individuals through agencies, while informal services refers to help provided by family members and neighbors. (Dibartlo & McCrone, 2003). In a 2001 study, over two thirds of rural dwelling older adults relied exclusively on informal help for their service needs as opposed to 13% that relied exclusively on formal services (Blieszner, Roberto, & Singh).

The Family Caregiving Alliance (FCA) found that informal caregivers provide an average of 20.6 hours per week of care. Care is defined as help with activities of daily living (ADL), including taking medications, eating, walking, grooming, bathing, and eating and/or instrumental activities of daily living (IADL) including money management, driving, meals, housework or using the telephone. In Idaho, 30.5 % of informal caregivers did not know whom to call to arrange help for their family member in the home, in case of their absence. Twenty three percent said that they would call medical support, and 22.3% said that they would call a relative or friend (2006). In Washington 18.6% of informal caregivers did not know who to call to arrange for help in the home, 25.6% would call a relative or friend and 25.1% would call medical support (FCA, 2006). This indicates a need for education for informal caregivers about potential resources and an expansion of resources to reach areas that are more rural.

The persons receiving care is defined as someone with a chronic condition, disability or an older person who requires assistance with activities of daily living in order to function. In Idaho, the Family Caregiver Alliance research found that 46.1% people over the age of 65 who had a disability and 13.3 % ages 21-64 had a disability that required someone to provide care. In Washington 39% age 65 and older and 13.2 % ages 21-64 and had a disability requiring care (FCA, 2006).

Because of these issues, social workers must be prepared to provide services that will help rural caregivers provide the best care possible, ensuring that loved ones are not placed in long-term care prematurely. These services must be tailored to fit the community they intend to serve so that caregivers can have confidence that their individual needs and concerns will be addressed when they access services.

As the populations of Whitman and Latah Counties shift in the coming years, more families will be seeking respite and health related services to assist them in ensuring quality of life for their loved ones. This research will help social service agencies design programs and develop services that can aid families of vulnerable adults in the most effective way possible. The size of this problem has just recently begun to be recognized by researchers and government agencies, and is projected to continue to cost families, businesses, and government more and more in the years to come. By being aware of the issue and planning appropriately, service providers can help families through tough times without letting our vulnerable citizens fall through the cracks.

Literature Review

In the past, care giving was thought to be a family problem and was primarily performed by women not in the workforce. Historically many people did not live long enough to require ongoing care because of a lack of modern medicine. Today people are living longer, and women who work are also taking on the majority of care giving responsibilities. In 1999, the Supreme Court's *Olmstead* decision mandated that care for elderly and disabled individuals be given in the least restrictive environment possible. This put more pressure on families to care for loved ones at home at a time when the number of aging Americans is reaching an all time high. The number of people over 65 is expected to double by 2030. As caregivers become a larger part of the population care giving can be viewed as a public health issue that requires the attention of legislators, health providers, social workers and the public (Tally and Crews).

Many caregivers suffer significant stress and stress related illness as the strain of caregiving increases. Studies show that support from family, friends and formal services can decrease the stress from which caregivers suffer. One study shows that instrumental support, whether formal or informal, increases physical wellness in primary caregivers. This study also demonstrates that simply having someone who understands is less likely to reduce stress and stress related illness than instrumental support. This study went on to say that while severity of the care recipients illness negatively impacted the caregivers' health, sometimes formal supports did not improve the health of the caregiver because of stress related to accessing and negotiating with the formal service provider. The example given was of stress related to dealing with in-home care providers that the family did not fully trust. Outcomes were better when the caregiver relied on family members and trusted friends for help (Parminder, McIntyre, Zhu, McDowell, Santaguida, Kristjansson, Hendricks, Massfeller & Chambers, 2004).

A 2004 study focused on an intervention to help families get information and referrals to health and human services organizations. In a partnership with the Alzheimer's Association (AA), this group of researchers compiled a list of caregivers and invited them to participate. One third of those in the study agreed to a referral to services after an interview that included questions about demographics and services needed. The findings indicated that participants with less education were more likely to want a referral to an Alzheimer's Association chapter for support. Those who felt that they could keep their family member home longer or that AA would make it easier to care for their loved one were also more likely to accept referrals. Spouse caregivers were the least likely to accept referrals. This study suggests that information be tailored to fit the needs of single less educated caregivers when providing education about available services. It also recommends that social workers be sure that spouse caregivers understand that it is acceptable for them to ask for help and encourage them to access services designed for caregivers. The study significantly increased the use of the local AA, where caregivers began seeking more information simply because they had answered the questions on the questionnaire. This research highlights the important role social workers play as information providers (McCallion, Toledano, Gerber & Banks).

One Canadian study examined the relationship between spousal care of a person with long-term illness and public health care dollars this saved. Findings indicated that a spouse caregiver reduced the amount of publicly funded care by 4.7 hours per week. There was no difference between male and female care providers. The other significant indicator for receiving less publicly funded care was having a caregiver living with the recipient. The total savings to the state amounted to 242 hours per year per individual in need of care, saving the government \$518 million dollars per year. The implications of this research support providing some financial

relief to family care providers (Hayward, Davies, Robb, Denton, & Auton, 2004). The research is supported by similar findings in the United States where the value of family caregiving is estimated at \$257 billion dollars a year (NCA, 2007).

Unfortunately, caring for a chronically ill spouse, especially with dementia, can have a negative impact on the caregivers' well being, leading to problems in providing appropriate care. A 2006 study found that spouse caregivers suffered concerns about the uncertainties and consequences of the illness, concerns about providing enough of the right kind of care, feelings of resentment and anger toward the recipient and concerns about the illness's impact on their own lives. The care recipients' emotional lability (defined as something constantly undergoing change or something that is likely to undergo change) had more impact on the well being of the caregiver than cognitive impairment, since it led to increased feelings of resentment and anger toward the impaired person. When care recipients exhibited higher levels of destructive behavior, caregivers felt more restriction on their personal time, also leading to more feelings of anger and resentment. In fact, 41% of the caregivers surveyed described having these feelings sometimes or frequently. Results were not significantly different according to the gender of the caregiver. This report recommends providing more support for caregivers to alleviate feelings of social isolation and restriction in order to help decrease feelings of anger and resentment toward the patient, especially for caregivers of dementia clients who are more emotionally unstable and have unpredictable behaviors (Croog, Burlison, Sudilovsky, & Baume, 2006).

A similar study that tracked caregiver/ care recipient dyads over time, showed that as behavioral and cognitive problems increased over time, caregiver well being decreased over time. More rapid progression of the disease was more difficult for caregivers than a steady progression. In this study, a psycho-educational intervention was implemented for one half of the

participants. The participants in the intervention group were encouraged to find social support and to use respite care as well as being offered eight weekly sessions that educated them about the disease, encouraging them to care for themselves and helping them find ways to optimize their relationship with the person they provided care for. The group that received treatment was able to maintain their state of well being over a year's time as opposed to a decrease in the well being of those in the control group. At two years the effect was no longer significant, however the research highlights the important role education and support can play in decreasing negative feelings for caregivers (Perren, Schmid, & Wettstien, 2005).

Caregiver characteristics and their impact on the neuropsychiatric symptoms (NPS) of dementia were evaluated in a 2006 study of community dwelling dementia patients and their caregivers. The study was designed to determine which traits in caregivers increased the symptoms exhibited by people with dementia. The findings were that older, better educated caregivers were correlated with fewer hyperactive symptoms, including wandering, in the client. This study also suggests that caregivers who were more burdened and more depressed were associated with an increase in NPS. After controlling for other factors it appears that the interpersonal dynamic between caregiver and care recipient can influence the symptoms exhibited by the dementia patient. This underscores the importance of education and support for caregivers tailored to fit their needs and careful observation by the social worker when assessing the needs and severity of the dementia client (Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006).

In some cases caregiver's increasing stress and decreasing health can have a negative impact on how they care for their loved one. This 2006 study identifies several risk factors that can contribute to poor caregiving. When caregivers are at risk for depression, and report an

increase in physical symptoms over the week, they were more likely to yell, use a harsh tone of voice, insult or swear at the care recipient. In this study, nearly 26% of the care recipients reported being yelled at in some way during the study. The risk factors for this behavior are identified as being the spouse of the care recipient, care recipients requiring more help, older caregivers with more impairments of their own, caregivers with poorer self-reported health, and caregivers at risk for clinical depression. The implications are that caregivers need a variety of services to meet their needs if they are to provide quality care at home. Such services include a combination of formal and informal support, including respite and appropriate health care. Early interventions for caregivers could decrease the potential for verbal abuse. Providers need to be aware that sometimes the caregiver's health may be worse than the care recipients, and provide for screening and interventions for the caregiver (Beach, Schulz, Williamson, Miller, Weiner, & Lance, 2005).

A 2002 study using random digit dialing to find caregivers and then offering a 24 minute questionnaire, found that as many as 36% of caregivers were vulnerable. For this study, vulnerable was defined as being in fair to poor health or having a serious health condition. Vulnerable caregivers were more likely to be over 65 and have less than 12 years of education. They were also more likely to be providing more care and a greater variety of care. While there was no difference between vulnerable and non-vulnerable care providers regarding the amount of professional services they received, vulnerable caregivers were more likely to have difficulty providing care and to be providing more care than their non-vulnerable peers. This research notes that recent changes in Medicare policy regarding when they provide in home care, has shifted the burden of providing services to family members. This is having a notable impact on vulnerable caregivers. The implication is that caregivers are being put at risk for becoming

dependant as well, further burdening the fragile system of support, and this could be a preventable situation (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). When conceptualizing the type of interventions that could ease the plight of caregivers, it could be helpful to think of some simple creative methods of providing support. Canadian researchers provided 66 new caregivers with phone support through a group of 27 experienced family caregivers. The idea was to provide a one-on-one peer support intervention and measure the participants' perception and satisfaction with the intervention. The support people offered information, affirmation and emotional support to the new caregivers in weekly telephone contact sessions. The caregivers that participated were very satisfied with the intervention and reported that it benefited them by providing them with information, helping them feel that they were doing a good job, helped them feel less burdened, and made them feel less lonely and isolated. One of the most encouraging things about this intervention is that it can be used in more rural areas where it could be difficult for caregivers to attend support groups or access other types of support (Stewart, Barnfather, Neufeld, Warren, Letourneau, & Liu, 2006).

Many rural caregivers experience barriers to accessing the services they need to provide quality care for their loved ones. Research on these barriers was conducted in 2006 to discover what was preventing older rural adults from using any of 7 common programs. Predisposing factors were also measured as were need factors. Predisposing factors are defined as factors that make an individual more at risk for developing a need. Interestingly, 83.6% of caregivers reported having barriers to the use of respite care, 75% to transportation services and 57.7% reported barriers to homemaker services. The leading barriers to accessing these services were reported as being "service not available," "not aware of service," and "service not affordable." This is not surprising since many of these services are underdeveloped and under supported in

rural areas. The study also indicates that rural people on Medicaid have better access to services and are also provided with more education about what is available to them. Home modification was found to be the most difficult for rural people with less education to access or find out about, which indicates a need for an improvement of services in this area. This research encourages social workers to focus their assessment on services needed when interviewing impaired rural adults and their caregivers. It also recommends forming service coalitions to help close the gaps in services and to advocate for more support for these services in rural areas (Li, 2006).

This research indicates that services for caregivers are in short supply and often expensive, fragmented or inaccessible to the people who are most vulnerable especially in rural areas. This represents a public health problem because of the large numbers of people that it affects and because as the health of current caregivers fail more people and resources are needed to care for the increasing numbers of care recipients. Care for caregivers is important to ensure the care recipient is getting good care. Interventions that have been shown to be effective in the past include respite care, education for caregivers, support groups, social support networks and peer support via weekly phone calls. These interventions, coupled with quality health care for the caregivers and service coordination for the care recipient, can improve outcomes for families and save money for both businesses and governments. What services do caregivers of adults with psychological and/or physical deficits in Latah and Whitman counties, need the most to provide quality care and keep their family member at home?

Methods

Caregiver research has surveyed caregivers of people with differing problems in a variety of communities and geographical areas. Other care giving research has focused on the characteristics of caregivers, characteristics of care recipients or the relationships between care giving dyads and professionals. Previous research has pointed to a lack of support services and education for caregivers leading to poor health outcomes for caregivers and poor care provided to recipients. This research looked at the needs of caregivers in Whitman and Latah counties so that services could be directed where they are needed most.

Paradigm

I value the National Association of Social Workers Code of Ethics and believe that an emancipatory approach can be used effectively to integrate new research into a culturally appropriate supports and interventions. One of the values in the Code of Ethics that is important to me is equality, which can be implemented through interventions designed through research, to fit the people they are created for. The theoretical basis for this research is ecological theory. In this framework, people are more likely to thrive when the environment they live in meets their needs. Ecological theory recognizes that humans are shaped by their interactions within a given environment and that the fit between an individual and the environment affects the individuals' experience. People are micro systems that have demands placed on them by the larger system and in turn, demand products or services from the system. In order for a person to do well, the system must be responsive to the needs of the individual and the individual must adapt to the system to some degree (Lehmann & Coady, 2001). Based on this idea services are best provided within the framework of the community environment where there are fewer barriers to accessing support.

I am a lifelong resident of Benewah County and have served as a volunteer Emergency Medical Technician for ten years in Fernwood Idaho. I have a close relationship and deep understanding of many of our elderly citizens. I am also a senior Social Work student at Lewis-Clark State College.

Study Design

This research used a mixed methods survey entitled Needs of Caregivers Evaluation. The survey contained both qualitative and quantitative questions, including eight demographic questions. Other questions included what types of services caregivers are aware of, what types of services caregivers use and what types of services caregivers need. There was also an open-ended question about the caregivers experience accessing services.

Population and Sample

This sample was a purposive convenience sample of 150 recipients gathered from the Caregivers mailing list, maintained by Gritman Adult Day Health. This agency provides day services for people who require ongoing assistance with activities of daily living as well as education, resources and support groups for caregivers in Whitman County, Washington and Latah County, Idaho.

Investigative techniques

This research employed a structured questionnaire with closed and open ended questions, Likert scale questions and questions that ask the respondent to check all that apply, e.g. which services have you accessed in the past?

Instrumentation

This research used an instrument that included questions about which available services caregivers have accessed, what their relationship with the recipient was, and Likert scale questions regarding the effectiveness of services used.

Data Collection

The survey was mailed to the 150 recipients. The survey was also available online for those who have internet access and prefer to do the survey this way.

Data Analysis Plan

The quantitative data collected was analyzed for central tendencies and variability. Qualitative data was analyzed and central themes were identified and reported.

Ethical considerations

This research was approved by the Institutional Review Board at Lewis-Clark State College in January 2008. The participants were informed of their right to informed consent and confidentiality. They were also informed that they had the right to withdraw from the study at any time. Because it was a mailed questionnaire the subjects were not subjected to an interviewer nor had any pressure on them to answer questions they were not comfortable with. This research was not apparently harmful in any way, however participants were informed of their right to withdraw or to decline filling out the survey if they were not comfortable doing so. Participants were informed in the cover letter that if they had any questions or concerns they could contact Gisella Quigley at 208-883-6483, or by email at gsquigley1@llcwarriormail.com; Dr. Brian L. Christenson at (208) 792-2476 or blchristenson@lsc.edu, or the Internal Review Board of Lewis-Clark State College at (208) 792-2461.

Ethnic diversity does exist in Whitman and Latah Counties to a higher degree than in surrounding counties due to the presence of universities. It was beyond the scope of this survey to ensure that the sample adequately represented cultural and ethnic diversity of caregivers.

Bias

Biases affecting this research were that I have not cared for a loved one in my home who has significant deficits for any period of time longer than a week. This could have influenced how I conceptualized the questions in the questionnaire. However I did consult with individuals that have been in the care giving situation when producing the questions and also relied on the existing research to inform my process.

Assumptions

The assumptions made by this research were that the participants would be honest when answering the questions and that they represented the typical caregiver in Whitman and Latah Counties. The assumption that they represent typical caregivers is of concern because they are caregivers who were connected enough with resources to come to a support group and sign up for a mailing list. In fact there may be many rural caregivers that do not have access to support groups or mailing lists.

Limitations

The limitations of this study were that it did not adequately address the issue of cultural and ethnic diversity in Latah and Whitman counties. Another limitation is that this study did not represent caregivers in especially isolated areas, who may not have accessed any kind of professional services.

Results

Sample

The caregivers that responded to this survey were primarily from Latah County (31%) (Table 1) and 37.5% were over 70 years of age (Table 2). Of the respondents 78% indicated that they were female (Table 3) and 98.3% of them indicated that they were white (Table 4). Their occupations included 28% other, 25% professional, and 12.4% sales/service (Table 5). The majority of the respondents were retired (37.5%) and 31.3% had incomes of over \$60,000 per year (Tables 6&7). Over half of the respondents (53.1%) had a bachelors degree or higher in educational attainment (Table 8).

Table 1

Demographic Variable of Respondents by County (n=32).

Measure and variable	Frequency	Percent
Latah	10	31.2
None marked	18	56.2
Whitman	4	12.5

Table 2

Demographic Variable of Respondents By Age (n=32).

Measure and variable	Frequency	Percent
18	1	3.1
40	4	12.5
50	9	28.1
60	6	18.8
70	9	28.1
80	3	9.4

Table 3

Demographic Variable of Respondents by Gender (n=32).

Measure and variable	Frequency	Percent
None	2	6.2
Female	25	78.1
Male	5	15.6

Table 4

Demographic Variable of Respondents by Race (n=32).

Measure and variable	Frequency	Percent
White	30	93.8
Other	2	6.2
Total	32	100.0

Table 5

Demographic Variable of Respondents by Occupation (n=32).

Measure and variable	Frequency	Percent
Government	2	6.2
Professional	8	25.0
Management	1	3.1
Education	2	6.2
Labor industry	2	6.2
Technical	2	6.2
Sales/Service	4	12.5
Other	9	28.1

Table 6

Demographic Variable of Respondents by Employment Status (n=32).

Measure and variable	Frequency	Percent
Employed full time	8	25.0
Employed part time	3	9.4
Self Employed	1	3.1
Home maker	6	18.8
Unemployed	2	6.2
Retired	12	37.5

Table 7

Demographic Variable of Respondents by Income Range (n=32).

Measure and variable	Frequency	Percent
0-\$9,999.00	3	9.4
\$10,000-\$19,999	2	6.2
\$20,000-\$29,999	7	21.9
\$30,000-\$39,999	4	12.5
\$40,000-\$49,000	5	15.6
\$60,000+	10	31.2

Table 8

Demographic Variable of Respondents by Educational Attainment (n=32).

Measure and variable	Frequency	Percent
Junior high	1	3.1
High school	7	21.9
Some college	4	12.5
Certificate	1	3.1
Associates degree	2	6.2
Bachelors degree	12	37.5
Masters degree	2	6.2
Doctorate	3	9.4

Table 9

Survey question 2: How Long Have You Been Providing Care For an Adult? (n=32).

Measure and variable	Frequency	Percent
7 months to a year	2	6.2
1 to 2 years	5	15.6
2 years or more	25	78.1

Table 10

Survey Question 2: 2 Years or More (n=25).

Measure and variable	Frequency	Percent
3-5 years	9	27.9
6-9 years	3	9.3
10-15 years	11	34.1

Table 11

Survey Question 3: Do You Also Care for Children?(n=32)

Measure and variable	Frequency	Percent
Yes	3	9.3
No	26	81.2

Table 12

Survey question 4: What is Your Relationship to the Adult You Care For?(n=32)

Measure and variable	Frequency	Percent
Child	11	34.4
Parent	1	3.1
Sibling	0	0
Spouse	14	43.8
Friend	1	3.1
Other	2	6.2

Table 13

Survey Question 6: How Many Adults do You Care For?(n=32)

Measure and variable	Frequency	Percent
1	25	78.1
2	4	12.5

Table 14

Survey question 7: How Many Hours do You Provide Care Per Week? (n=32)

Measure and variable	Frequency	Percent
1-3 hours	1	3.1
4-8 hours	2	6.2
8 or more hours	26	81.2

Table 15

Survey Question 8: Do You Have Any Previous Care Giving Experience? (n=32)

Measure and variable	Frequency	Percent
Yes	14	43.8
No	16	50.0

Table 16

Survey Question 9: Please Check All the Social and Emotional Supports You Have

Available. (n=32)

Measure and variable	Frequency	Percent
Family	26	81.2
Friends	25	78.1
Spiritual	16	50.0
Medical	14	43.8
Community organizations	8	25.0
Faith Based Organizations	5	6.2
Recovery Group	4	12.5
Psychological/Psychiatric	3	9.4
Governmental	2	6.2
Occupational	1	3.1

Table 17

Survey Question 10: What Services Are You Currently Using to Provide Care? (n=32)

Measure and variable	Frequency	Percent
Adult Day Health	10	31.2
Transportation	7	21.9
In home caregivers	7	21.9
Lifeline	6	18.8
Senior meal site	5	15.6
Area Agency on Aging	5	15.6
Hospice	4	12.5
Adult Day Care	4	12.5
Respite care	3	9.4
Home Health	3	9.4
Oxygen/ Durable medical equipment	3	9.4
Meals on Wheels/ Home delivered meals	1	3.1
Physical therapy	1	3.1
Home Maker Services	1	3.1

Table 18.

Participant Ratings For Survey Questions 11-26. Please rate each service in relation to your needs.

Measure and variable	Mean	Median	Mode	(n)
Adult day care	4.8	5	5	5
Adult Day Health	4.5	5	5	15
Area Agency on Aging	5	5	5	6
Home Health	4.16	4.5	5	6
Homemaker services	4.6	5	5	3
Hospice	4.5	4.5	4	4
In home caregivers	4.25	4	4	8
Lifeline	4.6	5	5	6
Meals on Wheels/ Home delivered meals	3	3	3	1
Occupational therapy	0	0	0	0
Oxygen/ Durable medical equipment	4.3	5	5	3
Physical therapy	5	5	5	1
Respite care	4	4	3	2
Senior meal site	3	3	3	5
Speech therapy	0	0	0	0
Transportation	4.4	5	5	10
Other	0	0	0	0

Note. LIKERT Scale Rating: (1) Extremely Poor; (2) Below Average; (3) Average; (4) Above Average; (5) Excellent

Table 19

Survey Question 5: Why Did You Become a Caregiver? (n=24)

Measure and Variable	Frequency
Commitment, Responsibility, Expectation, Necessity	15
Love, Compassion, Care	7
Lack of Options	2

Table 20

Survey Question 8: Do You Have Any Previous Caregiving Experience? If so How Long and Who Have You Cared For? (n=16).

Measure and Variable	Frequency
Parents	6
Occupationally	5
Children	3
Grandparents	1
Friends	1

Table 21

Survey Question 28: What Services Have Worked Well For You In The Past? (n=18).

Measure and Variable	Frequency
Respite in Home Care	5
Hospice	4
Adult Day Health	3
Support Group	3
Home Health	3

Table 22

Survey Question 29: What Was Your Reason For Discontinuing Previous Services? (n=8).

Measure and Variable	Frequency
Got Well	2
Long Term Placement	2
Transport Dangerous	2
Death	1
Inadequate/ Unhelpful	1

Tables 21, 22 and 23 show respondents' written answers to qualitative questions about their caregiving experiences. Since this was a write-in question some respondents did not comment. The respondents that chose to answer show what services have been important and some of the reasons caregivers choose not to use available services after having accessed them.

Table 23

Survey Question 30: What Other Services Would you Find Helpful? (n=32).

Measure and Variable	Frequency
Respite	3
Group Activities for Care Recipients	2
Education	2
Online Support Group	1
Tax Relief For Caregivers	1

Discussion, Conclusions, & Recommendations

The demographics of the caregivers that responded to this survey show that these caregivers are well-educated and can generally afford the services they need to provide good care. They are better educated and have more resources than caregivers described in the literature. Most of the caregivers that responded to this survey were women over the age of 65, supporting previous research about who is providing care. This survey used a purposive convenience sample utilizing the Caregivers Support Group mailing list from Gritman Adult Day Health. These caregivers are people who have already accessed formal services to some degree and have requested ongoing educational mailings. This may indicate that caregivers with more education and resources are both more likely to seek out support and educational material and more likely to respond to research that they feel could benefit them.

Seventy eight percent of the caregivers that responded to this research have been providing care for two years or longer (Table 9). Of those providing care for two years or longer, 34% have been providing care for 10 to 15 years (Table 10). Most of these people (81.2%) did not care for children (Table 11). More of the caregivers surveyed were caring for a spouse (43.8%) than were caring for a parent (34.4%) but the difference is slim (Table 12). The majority of the caregivers were caring for only one adult (78% Table 13), but they were also providing extensive hours of care, with 81% reporting that they provided 8 or more hours of care per week (Table 14). There was a nearly even division between those that had previous care giving experience (43%) and those that did not (50%) (Table 15).

This description of caregiving dyads supports previous research that caregivers often care for a parent or a spouse, doing so over long periods of time and for many hours per week. Eighty one percent marked that they were providing care more than eight hours per week but those

caring for a spouse are often providing 24 hour a day care. Those caring for parents are also providing around the clock care when they move their parent into the home with them. This supports previous research that found caregivers providing more than 20 hours per week on average. The caregivers in this survey were less likely to be caring for more than one adult, or for children, indicating that they are more likely to be well supported.

Almost half of the caregivers in this study identified having had previous caregiving experience. Caregivers defined previous experience differently, including day care as an occupational care giving experience or caring for friends that were terminally ill. However the recurring theme identified was that caregivers caring for parents had provided care for their parents at some point in the past during a recovery period, or had cared for one parent and then the next. Further research is recommended.

Social supports can be important to reducing caregiver stress. This survey found that 81% of the caregivers had family support, 78% had friends as a source of support, 50% had spiritual support and 43.8% had medical support. Other supports were indicated but in less significant numbers. This supports the research that found many caregivers to be relying more on informal support than on formal services.

Only 6% reported having governmental sources of support (Table 16). This is of interest because earlier research has indicated that caregivers on Medicaid had less difficulty accessing services in rural areas. The difference in this study could be due to different socio-economic group surveyed. When asked what services caregivers are using to assist them in providing care, 31.2% reported using Adult Day Health, 21.9% used in home caregivers, 21.9% used transportation, 18.8% used Lifeline, 15.6% used senior meal site and 15.6% used Area Agency on Aging (Table 17). When rating these services as how well they fit their needs, caregivers

generally responded that they were adequate to excellent (Table 18). A previous study suggested caregivers had difficulty accessing in-home care and suffered stress negotiating with the in-home care provider for the kind of service they wanted. The caregivers in this study did not seem to have difficulty accessing in home care, however, as noted earlier, one respondent mentioned having difficulty getting the kind of help needed due to the limited abilities of the care provider. Further research may be indicated to evaluate what in home care agencies can do to improve the services their personnel provide. Those using in-home caregivers rated the services as above average in meeting their needs. This may simply indicate that those that have found a provider that meets their needs continue to use the service.

Respondents were also asked qualitative questions about their care giving experiences. When asked “How did you become a caregiver?” 13 respondents said their parent became ill and 13 said that their spouse had become ill, 9 respondents cited dementia and 15 said that their loved ones were no longer able to care for themselves. When asked why they became caregivers 15 said they did it out of responsibility, commitment, expectation or necessity. Seven others wrote that they provided care out of love, compassion, and care, and only two stated that they were providing care because of lack of options (Table 19). When asked if they had previous caregiving experience, six responded that they had cared for grandparents, five had done caregiving of some kind occupationally, three responded that they had cared for children, one had cared for a grandparent and one had cared for a friend (Table 20).

Caregivers wrote that respite, Hospice, Adult Day Health, Adult Day Health Caregiver’s support group and Home Health had worked well for them in the past (Table 21). One caregiver wrote, “Gritman Adult Day Health was indispensable. It provided respite care and allowed my father to stay in the home much longer.” Another wrote, “I got help from Area Agency on Aging

but it did not work out because the person they sent had a bad back and couldn't do the work.”

Agencies that are providing good service coordination and follow up are likely to be able to meet the needs of caregivers more consistently.

They responded that they had discontinued previous service because their loved one got well, went to long-term placement or the transport became dangerous. One had discontinued because of the death of the person cared for and another because the service was inadequate (Table 22). An earlier study reported that 75% of caregivers felt there were barriers to using transportation services. This study found that those that had discontinued using transportation did so because of weather or because the progression of the care recipient's illness made travel ill-advised. One of the findings of this survey is that most caregivers have discontinued services because their needs changed. This finding points to the fact that the services provided in Whitman and Latah counties are above average in meeting the needs of those caring for their loved one at home. One respondent wrote, “It is my impression that we have good care facilities in the Whitman and Latah rural and urban communities. I just don't think those in need know they are available or how or where to seek help.”

Respite care was the most mentioned service that caregivers would find helpful (Table 23). Caregivers described using the service and rated it highly in earlier parts of the survey so it is unclear what would make respite care more available to those who need it. A previous study reported that 83.6% of respondents reported barriers to accessing respite services. Previously identified barriers included availability, awareness, and affordability of services. Further research is recommended to determine what the barriers are in Whitman and Latah counties.

Group activities for persons in early stage dementia were also requested, as was more education about caring and dementia. Such services would be very beneficial for both caregivers and the

care recipient. More information is required to determine how this kind of service could be offered and what type of professionals would need to be involved in creating and maintaining such a program. One individual requested an online support group. This supports earlier research that recommended telephone support for caregivers. Another requested tax relief for caregivers. This is an important issue for caregivers and advocacy by caregivers and interested professionals is recommended.

Implications

The caregivers that this study reported on were, in many ways, better educated and better supported than caregivers in earlier research. These caregivers need services that can provide them with more information and more coordination to help them provide better care. Advocacy for tax relief for caregivers is vital. Education should be supported and expanded to reach caregivers at all socio-economic levels: not only those on Medicaid but those who are private pay clients as well. This could be supported by state and local policy makers especially focusing on the issue of making the transition from private pay to Medicaid. Education would be best focused on what services are available and how to access them.

In direct practice, this research informs social workers to be aware of the many barriers that can prevent caregivers from getting the services they need. One participant wrote that the paper work she had to deal with to access the services she needed was completely overwhelming. It may be helpful to caregivers if agencies could find ways of reducing the paper work required by their agency. One strategy could be to work on inter-agency coordination of documentation. Social Workers should understand that providing education is an important service that can help individuals improve the care they provide and reduce the stress they experience. It should be

recognized that individual caregivers at all socio-economic levels need more education about dementia and brain injuries, service availability and coping skills.

Future research can be directed at caregivers in Whitman and Latah counties that are using Medicaid or who are less connected to support services. The limitations of this study were that it did not address racial or ethnic diversity. This study did not include a representative sample of caregivers on Medicaid or caregivers of in lower socio economic status. This would be an excellent area for further research. Future research could investigate how to reduce barriers and improve service from in home care and respite agencies. Another area to study could be how to provide activities for people physical and/or psychological deficits that still live at home.

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