

The Benefits of Consumer-Directed Services for Caregivers of Persons With Alzheimer's Disease

Julie L. Masters

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ABSTRACT

Because a substantial portion of care provided to persons with Alzheimer's disease comes from families, it is beneficial to understand what services are most useful to caregivers in supporting a family member in the community. This article summarizes a project designed to explore the benefits of consumer-directed services, in which 112 caregivers were randomly assigned to a treatment or control group at intake. Results suggest that caregivers who take a consumer-directed (self-determined) path have a greater likelihood of extending their caregiving role than those who have access to traditional aging services only. Encouraging consumer-directed behavior is discussed as an avenue for social service providers to pursue when supporting caregivers and care receivers in remaining in the community.

Confronting the challenges of Alzheimer's disease requires an understanding of both the effects of the disease on the individual as well as the impact it can have on persons providing direct care. Because the majority of care provided to persons with this disease comes from family members, there is a need to understand what services they would choose on their own, and of those services, which are most useful. The purpose of this article is to address the various options available to caregivers in supporting someone with Alzheimer's disease in an effort to delay or avoid nursing home placement and in assisting the caregiver in his or her role by drawing on the theory of self-determination.

Alzheimer's disease is an irreversible and progressive brain disorder that initially affects an individual's short-term memory and then the long-term memory. Language skills, social abilities, and everyday functioning are also

affected (Alzheimer's Association, 2004). A report released by Herbert, Scherr, Bienias, Bennett, and Evans (2003) estimated that the number of people with Alzheimer's disease will increase from 4.5 million to 11.3 to 16 million by 2050. This dramatic increase can be attributed to many factors, including the expected growth in the older population as a result of the aging of the baby boomers and the declining mortality rates of people age 85 years and older. This latter point seems to be especially important given the likelihood of persons over the age 85 having a diagnosis of Alzheimer's disease or a related disorder (Herbert et al., 2003).

As the population ages, and the number of people who could potentially be diagnosed with Alzheimer's disease increases, how will all these people be cared for, as the disease robs individuals of their ability for self-care? The Alzheimer's Association (2004) estimated that of the 4.5 million people with Alzheimer's disease, 70% are cared for

in the home by family members. Family members will typically provide care until more skilled support, such as nursing home care, is required. If no cure is found for this disease and the projections by the Alzheimer's Association are accurate, we can expect that family members will continue to assume increased responsibility for supporting persons requiring greater levels of care as the disease progresses. To ensure the success of caregivers in providing care to a loved one with dementia, health care professionals and policymakers are obligated to learn ways to make this situation an achievable and manageable experience, particularly when family involvement is assumed to be the norm rather than the exception.

Programming for Caregivers

One example of an effort to find ways to support the caregiver is through Alzheimer's disease demonstration grants to states (ADDGS), from the U.S. Administration on Aging (AoA). Since its inception in 1991, most states have received funds from this federal agency to implement innovative programs to support persons with Alzheimer's disease and their families. These projects have included

creative concepts such as mobile adult day care programs and educational tools for caregivers (AoA, 2004). In 2000, the state of Nebraska applied for and received funding to create its own unique approach to meeting the needs of caregivers. The demonstration project was created to test the effectiveness of consumer-directed services in combination with case management support by exploring the differences between caregivers receiving traditional case management services and those using a consumer-directed option. The results of this demonstration project and how it further advances the theory of self-determination are the focus of this article.

Consumer-directed Services

The concept of consumer-directed services is somewhat new, having been conceived during the independent living and disability rights effort in the 1960s and 1970s (Eustis, 2000). The goal of consumer-directed services is to provide individuals with the freedom and independence to choose the person or services they feel will best meet their needs

(Doty, Kasper, & Litvak, 1996). Other examples such as the "Cash and Counseling" demonstration project have offered an expanded version of consumer-directed services in providing a monthly cash benefit to use for purchasing goods or services, as well as advice in the identification and coordination of services (Mahoney et al., 1998). While slow in supporting the geriatric market, consumer-directed services have made a significant impact in the availability and choice of services for younger, disabled persons (Kane & Kane, 2001).

Unlike the more traditional method of having an agency or health professional identify what services would be most beneficial to an older person faced with a chronic illness or condition,

it is the individual who makes this determination, in concert with a care manager who, when requested, can provide assistance; thus allowing the caregiver to maintain some degree of autonomy, or self-determination (Deci & Ryan 1985). The key to self-determination or consumer-directed behavior is the ability to choose a service or goods based on the perceived needs of the individual, rather than relying on the perception of a care provider. The flexibility of

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consumer-directed services supports the idea of the heterogeneous needs and wants of current and future caregivers that have been described by other researchers (Feinberg & Newman, 2004; Riggs, 2003–2004; Schulz et al., 2003; Hyduck, 2002).

For people opting for consumer-directed services, there is an assumption that they possess the knowledge to choose the person or services they deem to be most helpful for themselves or their loved ones. The focus of more established consumer-directed programs has been in the recruitment, hiring, and termination of personal care assistants. Other programs, like the one described here, include both the selection of persons as well as goods and services to meet caregiver and care recipient needs. In addition, when selecting personal care assistance, consumers have the ability to recruit, hire, and terminate workers. By having this level of flexibility, consumers have more control over the care delivered and make more decisions on their own. Indeed, they may also have the option of hiring a family member to perform the needed services. This is in contrast to more traditional services where

family members are generally not allowed to deliver care for a fee that is paid for by public funds (Tilly & Wiener, 2001).

Evaluations of consumer-directed care and the option of cash and counseling have generated favorable responses from participants (Doty et al., 1996; Mahoney et al., 1998). When given the opportunity to purchase personal care assistance using available state funds, Tilly and Wiener (2001) found consumer support for this option. Other researchers (Mahoney et al., 1998; Doty et al., 1996) found similar results when evaluating the benefits of consumer-directed programs, especially among younger persons. Although there is some reluctance on the part of older people, it appears to be more a consequence of their lack of familiarity with arranging for services rather than disinterest in the service (Tilly & Wiener, 2001). To illustrate, in a review of consumer-directed service use by age in California, Benjamin and Matthias (2001) found older adults willing to use services when they were made available. They simply needed to know which services were in existence.

Demonstration Grant

Because of the success of previous programs in offering consumer-directed care for older adult caregivers the partners for this grant (a state unit on aging, an area agency on aging (AAA) and the local Alzheimer's Association chapter) were interested in exploring the benefits of consumer-directed services for caregivers of persons with Alzheimer's disease. For the purposes of this demonstration grant, consumer-directed services referred to giving caregivers the flexibility to choose the person or services they believed would best meet their caregiving needs (Eustis, 2000). Services included both traditional (e.g., personal care assistance, respite, adult day care) as well as nontraditional options (e.g., furniture stores, carpet cleaning). Agency-directed services included all those traditional services found within the existing aging network (e.g., respite care, adult day care, and personal care assistance). The identification and subsequent referral to a given service or services came from a care manager employed with a local AAA when the caregiver was unable to do so independently.

Because of the exploratory nature of this study, the following research questions were raised:

1. If given the opportunity, what types of services, outside the traditional aging network, would caregivers in the treatment group select to aid them in their caregiving role?
2. Would support offered through this demonstration project extend the time caregivers spent in their caregiving role?
3. What differences, if any, existed between the treatment and control groups regarding their overall satisfaction with the project?

Methodology

Subject Recruitment

The partners for this project promoted the demonstration grant to various groups and organizations supporting caregivers and care receivers faced with an Alzheimer's diagnosis. Key targets included physician offices, adult day care centers, geriatric assessment centers, and others. In addition, the partners for this grant were in an ideal position to inform callers who would contact their respective information and referral lines of the grant and did so when appropriate.

To qualify for services, a caregiver had to be serving as the primary caregiver for a person age 60 years or older with a diagnosis of Alzheimer's disease or a related dementia. Caregivers contacted the local chapter of the Alzheimer's Association to learn of the program and to complete the intake process. Certification of a diagnosis of dementia came from the client's physician.

After receiving a referral from the chapter's intake coordinator, the care manager of the AAA contacted the caregiver and completed an intake form created by the AoA for use with this project. This form included questions related to the functional and physical health of the care recipient and the caregiver. Interestingly, gathering information about the caregiver is what Feinberg and Newman (2004) note as being an important yet often absent component to the assessment process. The authors suggest that by collecting information from both parties, a more thorough understanding of the family dynamic can be developed and addressed as part of the care plan. For this project, both the caregiver and the care receiver were of interest to the overall care plan. Every effort was made to obtain such information for this project.

Study Design

At the time of intake caregivers were randomly assigned to either a control or treatment group. Random assignment was selected by the partners at the beginning of the grant period to identify what differences, if any, would exist between the two groups. This design was useful for this study as it drew from a similar pool of caregivers supporting a family member with Alzheimer's disease while at the same time exploring both the similarities as well as differences between the treatment and control groups (Cook & Campbell, 1979). Although both groups had access to funds to pay for services received through the grant, only the treatment group could use the vouchers to purchase goods or services they felt would be of value. The control group was limited to using the vouchers to pay for traditional services such as adult day care service and home care. The voucher booklet, developed by the AAA for this project, contained 50 coupons that were provided to members of the treatment group and was used like a checkbook. Caregivers in the control group received funding for

traditional aging services (e.g., respite, adult day care) based on a sliding scale. Initially, there was no limit on how much a caregiver in the treatment group could spend for services. This decision was later amended as a result of budget constraints to a set at a limit of \$300 per month.

Caregivers in the treatment group had the flexibility of using the voucher to purchase both traditional and non-traditional services they felt would be beneficial in their caregiving role (i.e., consumer directed). In some cases, the services were suggested by the care manager; in others, the caregiver identified the service he or she needed. Persons in the treatment group were visited in their home by a care manager whose sole responsibilities were to the demonstration grant. This person would contact the family on a monthly basis. Caregivers in the control group were contacted every 6 months by the care manager dedicated to the project, as well as a care manager working for the AAA, whose role was to assist the caregiver and care receiver in applying for services that would be income based, such as adult day care and home-delivered meals.

In addition to assistance from the care manager, the caregivers in the treatment condition were provided with a three-ring binder containing educational materials to assist in the caregiving process (e.g., tips for caregivers and information about community resources). Also included in the binders were the names of vendors who agreed to accept the voucher from the AAA for payment of services. Both groups received copies of the book, *The 36-Hour Day*, by Nancy Mace and Peter Rabins (1999), from the local chapter of the Alzheimer's Association.

At the onset of the program, the AAA contacted existing vendors to learn of their interest and willingness to participate in the program. Vendors agreeing to participate were included in an initial list provided to caregivers. Over time, caregivers identified additional vendors they felt would be beneficial to themselves as well as other caregivers (e.g., furniture stores, grocery stores, etc.) suggesting a degree of self-determination among caregivers (Deci & Ryan, 1987). Before using a voucher for service or services, caregivers were instructed to contact the AAA to establish a formal relationship with the agency to accept the vouchers. An initial list was created with vendors who were willing to accept the vouchers. On a routine basis, vendors would submit a request to the AAA for payment.

Discharge of the care receiver and caregiver from the program was because of various reasons, including the declining ability of the caregiver to provide care, poor health of the caregiver, increasing safety issues with the care receiver, and death of the caregiver or the care receiver. When the functional ability of the caregiver became an issue, physicians, adult protective services, geriatric assessment centers, and others would advise the caregiver that he or she was no longer able to care for the person, and nursing home placement was necessary (C. Graham, personal communication, August 27, 2004).

Measurement of Variables

The research questions for this study were measured using caregiver self-reports to the care manager and two items from a questionnaire provided by the AoA titled the "Caregiver Support and Satisfaction Survey." The survey consisted of an assortment of questions ranging from types of services used, quality of services, and overall satisfaction with services. Two questions from this survey were selected for analysis. The first question was "Have the services you and/or the care recipient received enabled you to provide care for a longer time than would have been possible without these services?" This question tapped into whether the person felt it would extend his or her caregiving role. A 4-point scale (1–4) was used, ranging from "yes, definitely" to "no, definitely not." The second research question explored what difference, if any, existed between the two groups with respect to their satisfaction with the program. Caregivers were thus asked, "Overall, how satisfied are you with the services that (care receiver) receives?" Again, a 4-point scale (1–4) was used, ranging from "very satisfied" to "very dissatisfied." Caregivers were contacted by an employee of the AAA to participate in the survey. The employee conducted surveys in the home of the caregiver. At the conclusion of the meeting, the employee would thank the caregiver for participating in the survey and retrieve the three-ring binder containing information about vendors and caregiving issues from the caregiver.

Results

The Characteristics of Caregivers and Care Receivers

A total of 157 caregivers enrolled in the demonstration project. Caregivers participating in this program were contacted by the AAA to complete a satisfaction survey. 112 caregivers completed a face-to-face interview with a staff member of the AAA, resulting in a response rate of 71%. Reasons for caregivers not participating in the survey included poor health, death, moved away from area, and agency unable to locate caregiver. Table 1 shows a description of those caregivers and care receivers who participated in the satisfaction/exit survey process, with a breakdown of caregiver characteristics. No statistically significant differences were found between the caregivers assigned to the treatment or control groups.

Services Selected Outside Aging Network

Because of the unique nature of allowing caregivers in the treatment condition to choose the services or persons they felt would best meet their needs, additional effort was given in tracking the type of services they selected outside of the aging network. The care manager made note of any services outside of the aging network on the monthly service use form approved by AoA for this demonstration project. This information was then logged and subsequently analyzed using a Microsoft Excel database to generate descriptive statistics. In answer to the first research

TABLE 1. Care Receiver and Caregiver Characteristics (N = 112)

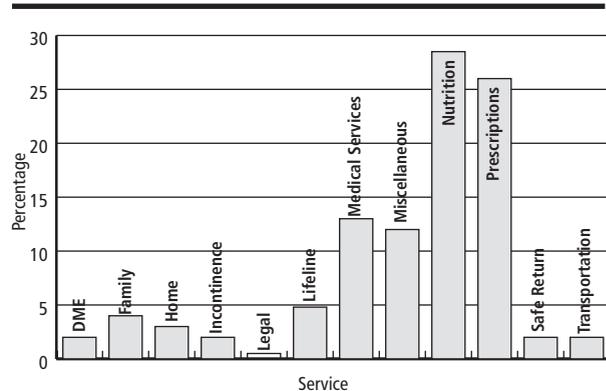
CHARACTERISTICS	TOTAL
Care Receiver Gender	
Treatment	
Male	26
Female	38
Control	
Male	24
Female	24
Caregiver Gender	
Treatment	
Male	20
Female	44
Control	
Male	14
Female	34
Care Receiver Average Age	
Treatment	80.14
Control	81.83
Caregiver Average Age	
Treatment	60.43
Control	62.97
Relationship to Care Receiver	
Spouse	42
Adult child	58
Other relative	7
Friend/neighbor	1
Relationship not reported	14
Average length of caregiving relationship (in years)	
Treatment	5.13
Control	4.69

Note: continuous variables were analyzed using a *t*-test; categorical variables were analyzed using a chi-square test. No significant differences were found between the treatment and control groups.

question, “If given the opportunity, what types of services, outside the traditional aging network, would caregivers in the treatment group select to aid them in their caregiving role?” Caregivers in the treatment group selected a myriad of services that went beyond typical aging services. Their selections were in addition to traditional services such as adult day care, in-home respite, and personal care. Figure 1 illustrates the types of services selected by caregivers in the treatment group.

Did Program Extend the Caregiving Role?

In addressing the second research question, “Did the services enable the caregiver to extend his or her caregiving role?” Both groups agreed the services did so. Interestingly, a statistically significant difference was found between the treatment and the control group ($M = 2.73$ vs. 2.45 , $t = 2.25$, $p < .05$) suggesting persons in the treatment group were more likely to extend their caregiving role than the control group.

FIGURE 1. Percentage of nontraditional services selected by caregivers.

A description of the types of nontraditional services selected by caregivers is found in the key below.

Key nontraditional services selected by caregivers

- *DME* (durable medical equipment—toilet risers, grab bars)
- *Family member paid to provide care* (preapproved through a caregiver registry)
- *Home Repair* (chimney sweeping, garage door repair/installation, plumbing, electrical repair, pest control, handyman, and modifying home to make it handicap accessible)
- *Incontinence Products* (briefs, bed protectors)
- *Legal* (obtaining assistance for advance directives and power of attorney)
- *Lifeline* (medical alert service)
- *Medical Services* (hearing aid, foot care, vision care, dental care, and physical therapy)
- *Miscellaneous* (Alzheimer's Association membership, *The 36-Hour Day*, RSVP—tax counseling, local furniture dealer—refrigerator, carpet cleaning)
- *Nutrition Services* (home-delivered meals, meal site, dietary supplement)
- *Prescriptions* (medications)
- *Safe return* (a national registry supported by the Alzheimer's Association to assist in locating a person who may have wandered off)
- *Transportation* (for adult day care—if not already provided)

Overall Satisfaction With Program

The third research question dealt with overall satisfaction. When asked about their overall satisfaction with the demonstration project, most caregivers in both groups were very satisfied with the services received. A *t*-test did not identify any statistically significant differences between the groups ($M = 1.14$ vs. 1.12 , $t = .238$, $p = .812$).

Discussion

The practitioners' sense of what services a caregiver may find useful does not always correspond to what the prospective user of this service wants (Caron & Bowers, 2003). Indeed, the caregivers in this study selected services that went above and beyond the typical services found within the context of the aging network. One such example is the use of a voucher by a caregiver for carpet-cleaning services

and incontinence products. Incontinence tends to be a deciding factor for caregivers when making the decision of placing a loved one in a nursing facility. Having access to services that reduce the negative impact of one of the many symptoms of Alzheimer's disease seemed to be of benefit to this group, based on their purchasing behavior. Similar to the findings of Caron and Bowers (2003), it is very possible that some caregivers did not perceive a need for traditional services, such as adult day care, particularly at the onset of the caregiving career. What works for one person at the onset of the illness may not necessarily be effective later in the course of the disease. Asking the caregiver what he or she wants, and allowing the person to choose the service, rather than telling the caregiver what services are most beneficial, may shed some light as to what services caregivers perceive as being of most importance. This has been supported by other researchers in their evaluation of services for caregivers (Schulz et al., 2003). It also suggests the utility of advancing the theory of self-determination in enhancing the caregiving role (Deci & Ryan, 1987) by allowing the caregiver to be the ultimate decision maker in selecting a service.

For caregivers in the treatment group, having the opportunity for consumer-directed selection of services seemed to support them in extending their caregiving role, as evidenced by the difference found between the two groups in this study. Although there was a limit of \$300 per month for caregivers to use, those in the treatment condition found they were able to do more in keeping the care receiver in the home. For policymakers at the state and federal level this suggests that even a modest amount of money can make a difference between nursing home placement and having a family member maintain a loved one at home at a significantly reduced cost. However, what is important to acknowledge is that a voucher alone is not sufficient in sustaining a caregiver, as reflected in the responses of the control group; rather, it is the ability to choose what services will best meet the needs of those directly affected that seems to make a difference in deciding to extend the length of the caregiving role.

For the person who is providing care to a family member with dementia there is an indication of a high degree of motivation to do whatever is required to make the person comfortable and well cared for in the home. The question for the health or social service professional is how conducive the environment (i.e., caregiving support) is to making this a reality. Providing caregivers with a voucher to use in their own way may contribute to a sense of self-determination and their ability to identify services not typically offered by the care manager. Being aware of one's ability to select beneficial services and being encouraged to do so by a care manager seems to reinforce the value of a supportive environment in promoting self-determination in the caregiving experience (Boehm & Staples, 2002;

Deci & Ryan, 1987). Most important, the caregivers in this demonstration project were providing care out of a sense of love and commitment to the person with Alzheimer's disease. Their motivation to stay in this role was not guided alone by the modest amount of money provided by the voucher program but in the satisfaction they derived in providing care.

Finding out why caregivers select a nontraditional service over a more traditional offering like respite or other community-based programs (Zarit, Gaugler, & Jarrott, 1999) is worthy of further inspection, particularly as more families are called on to care for an aging relative with a dementia like Alzheimer's disease. For persons in the treatment group, having the option of using available funds to purchase all or a portion of the prescribed medications was important, as these medications were used in some cases to control problem behaviors of the care receiver. Also viewed as being beneficial to the caregiver was access to nutrition services including home-delivered meals and grocery services. Finally, having the ability to purchase products that would reduce the impact of various symptoms of the disease, like incontinence, seemed to enable caregivers to keep their family member at home for a longer period of time.

In addition to tangible services, the availability of a care manager in person or by telephone was beneficial to caregivers. Both groups had someone they could talk to when the caregiving role became overwhelming. It is very possible that the presence of the care manager in offering suggested services was of greater value for some than the flexibility in choosing services. Having access to broader information is what can set the stage for more freedom and self-determination in the provision of long-term care support for older adults and their caregivers who may be unfamiliar with available services (Kane & Kane, 2001). For the care manager, allowing this shift in decision making can be initially awkward but eventually rewarding, as the caregiver learns to identify those services they think will be most beneficial (Boehm & Staples, 2002).

Although there were many benefits derived by caregivers from this project, there are also limitations to this study that need to be acknowledged. First, there was a clear ceiling effect in the measure of satisfaction used. As in previous studies of this sort (e.g., Weissert et al., 1990), the satisfaction variable was highly skewed, with most caregivers completely satisfied with the services. Because caregivers in both groups received funding for services from the project, it is difficult to know whether the availability of funds for consumer-directed services brought greater satisfaction than the use of more traditional services. In either instance, both groups indicated an overall satisfaction with the project because of the support they received. The measure used in this study was not sensitive to any differences between the two groups. A different technique using less traditional measures may have detected

a difference (Blalock, 1982). Also, the availability of a care manager to both the control and treatment groups may have impacted satisfaction scores. Second, the satisfaction surveys were administered by an employee of one of the partnering agencies, which may have contributed to the potential for response bias by caregivers (Bailey, 1994). While it would be hoped that caregivers would be honest in their appraisal of the project, it is possible some may have answered more favorably because of an ongoing need for services beyond the grant period. Finally, only those caregivers who had taken the initiative to contact the local chapter of the Alzheimer's Association participated in this project. What is not known is what benefit this project might have for caregivers less assertive in seeking support. Indeed, by their very nature, the caregivers in this study would have found benefit in any source of support.

Despite these limitations, offering consumer-directed services for people caring for family members with Alzheimer's disease is worth further study. Although not the typical approach in addressing caregiver needs, especially in those settings in which a medical model is the preferred method, empowering the caregiver and even the care receiver to consider options independently can have positive returns over the course of the caregiving lifecycle (Boehm & Staples, 2002). For the caregiver providing assistance to someone who is slowly and persistently losing his or her connection to the world, a loss of control is to be expected. In the presence of Alzheimer's disease, consumer-directed services, as a practical extension of self-determination theory, may offer a caregiver some control in a seemingly uncontrollable situation (Eustis, 2000).

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Julie L. Masters, PhD, is associate professor, University of Nebraska, Omaha, Department of Gerontology. Dr. Masters is working in collaboration with the Nebraska State Unit of Aging, the Eastern Nebraska Office of Aging, and the Midlands Chapter of the Alzheimer's Association. Correspondence regarding this article may be sent to jmasters@mail.unomaha.edu or University of Nebraska Omaha, Department of Gerontology, 310 Nebraska Hall, 901 North 17 Street, Lincoln, NE 68588-0652.

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