



## Feature Article

# Home visits by care providers – Influences on health outcomes for caregivers of homebound older adults with dementia



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## ABSTRACT

Homebound older adults benefit from provider home visits and there is an increasing need for these visits. A study was conducted to evaluate the effect of provider (MD, NP) visits on the caregivers of homebound older adults. Fifty-five caregivers were interviewed to determine any difference in health measures between those whose care recipients had access to a provider and those that did not. The participants completed the SF-36, questionnaires on demographics and access and one opened ended question. Analysis revealed statistically significant differences between the two groups of caregivers. The caregivers whose care recipients did not have access to a provider showed poorer health measures. Providers may have a positive impact on caregiver's health as well as that of the homebound. Developing new and innovative ways to support caregivers while providing care for our patients will be even more important as the population ages and the numbers of available caregivers decrease.

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## Background

Insufficient care support structures at a community level are a major barrier to providing adequate care to homebound older adults with dementia and their caregivers. At the same time, the availability of paid (formal) and unpaid (informal) caregivers are declining, and the pressure to control costs in health care has never been higher.<sup>1</sup> In the United States, there are over 5 million people living with dementia, which translates to 1 in 9 of those over 65 years of age.<sup>2–4</sup> This number is expected to grow to over 16 million by 2050, and the cost of caring for those with dementia in any setting will be significantly higher than caring for individuals without dementia.<sup>5</sup>

In addition to the rising numbers of people with dementia, the cost of their care is also increasing. In the United States, the 2013 cost of caring for those with dementia was estimated to be \$220 billion.<sup>4,5</sup> This is more than the cost of nursing home and home care combined. Insufficient care support structures at a community level are a major barrier to providing adequate care to homebound older adults with dementia and their caregivers.

At present, about one quarter of the population in the U.S. participates in some form of caregiving.<sup>6,7</sup> The caregivers of those with dementia currently number over 15 million in the U.S. and provide

on average 20 hours of care a week. This equals 17 billion hours of unpaid care each year.<sup>4</sup> While they provide an extremely valuable service, it is important to know that these caregivers have an increased risk of several significant health problems, including twice the risk of depression than age-matched non-caregivers.<sup>8</sup> They also have increased levels of anxiety, anger, compromised physical health, significant sleep disturbance, and an impaired immune response.<sup>9–11</sup> All of these problems, alone or in combination, cause increased caregiver stress. The most disturbing fact is the caregiving role itself has been shown to increase overall mortality independent of other risk factors.<sup>12,13</sup> The hefty burden of caregiving can lead to decreased levels of health for caregivers and poor outcomes for dementia patients, such as decreased quality of life and early nursing home placement.<sup>14–16</sup>

The role of an informal caregiver, however, has become indispensable as our country continues to struggle with finding cost-effective ways to provide care to older adults with dementia and support their caregivers. Since many caregiver/care recipient dyads reside in a home setting, finding ways to provide adequate and comprehensive care in this environment will be an important task for health care service researchers and practitioners. For every person living in a nursing home, there are three others living at home with similar physical needs and disease burdens.<sup>17</sup> Just like those residing in a nursing home, those cared for at home require frequent provider contact to maintain their health (9–12 visits a year).<sup>18</sup> Despite the increase in the number of

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people cared for at home, the care infrastructure of community setting that can provide house calls or home care providers remain insufficient. There are only a small percentage of providers making these types of visits, and those providing them average less than once a week.<sup>19</sup>

Moreover, current caregiving literature rarely address the caregiver's wellbeing related with the level of care support they received by the care provider for their care recipient. This study was designed to evaluate the impact of provider home visits on health-related quality of life measures between two groups of caregivers, those whose care recipients received home visits by providers (NP's, MD's) versus those who cared for individuals who did not. The specific aims of this study were: 1) investigate the differential effects of home visits by a care provider on the caregiver's perceived quality of life and other health outcomes and, 2) evaluate the presence and frequency of several well-known barriers to obtaining care and, 3) capture caregivers' thoughts about their current experience with a single open ended question.

## Methods

### Study design

We employed a mixed method design that combined quantitative and qualitative approaches. In the quantitative part of study, we used a naturally occurring comparative descriptive design to evaluate the difference in health measures for two different groups of caregivers, those that had home provider visits for the individuals they cared for and those that did not. In addition to obtaining empirical data on the topic, we also collected qualitative data provided by caregivers in response to an open-ended question regarding their overall caregiving experience. The purpose of adding an open-ended question was to examine the perceptions and experiences of informal caregivers in order to build a more in-depth understanding of issues related to the use of formal services, including care providers who can provide home visits.

The study protocol with a plan to protect study participants was reviewed and approved by the institutional review board before any study participants were contacted.

### Sample

The caregivers were recruited from several community sources including caregiver support groups from the Alzheimer's Association; caregivers for those receiving services from the local Area Agency on Aging program; and private pay home care agencies. The private pay agencies provided sitters and aids; there was no requirement for a provider visit prior to service since these services were not billed to Medicare. A total of 63 people were referred to the research team. Among those, 55 caregivers of homebound older individuals with dementia met the eligibility criteria and were enrolled to the study. One caregiver declined to participate in the study after the study process was explained by the principal researcher. After contacting key personnel at each agency, a brief explanation of the purpose and description of the study was given and contact information was left for their clients; those who were interested in participating contacted the PI via the telephone. There were two groups: one *who had utilized* a provider for their care recipient within the past 12 months ( $n = 34$ ) and one *who had not* ( $n = 21$ ). The participants were placed into groups depending on their past 12 month history of provider access. Both groups of caregivers were caring for frail homebound individuals who had difficulty leaving their homes for health care visits. Those that had not utilized a provider in the past 12 months had no contact with a physician, nurse practitioner or physician assistant, either as a

home visit or in an office setting during that time period. The participants were recruited from several different cities in south-eastern Virginia. The participants were mostly from urban or sub-urban areas; less than 10% were from rural areas. After a brief introduction and explanation of the study, only one caregiver declined to take part. Once the participants were deemed eligible, they were given informed consent; after obtaining consent, data was collected.

### Outcome measures

The descriptive survey included the MOS Short Form Health Survey (SF-36), a demographic questionnaire and five specific questions about caregiving issues with the access and utilization of care support including the home visit service. The demographic questionnaire included age, gender, and relationship to the care recipient, education, income, and ethnicity. The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) measures eight specific dimensions of health. The survey can be self-administered by the participant or completed by an interviewer over the telephone.<sup>20</sup> The SF-36 has been shown to be a reliable and valid tool for medical and psychiatric groups as well as adults across the age spectrum.<sup>21,22</sup> There are two main components, the mental health domain and the physical health domain. Both of these domain summary scores are further divided into eight more subscales: the mental health domain consists of items measure of vitality, social functioning, role limitation due to emotional problems, and overall mental health. The physical health domain consists of physical functioning, role limitation due to physical problems, bodily pain, and general health perception. These eight individual dimensions measured on the SF-36 are weighted to produce a standardized score from 0 to 100 with a median of 50 in a healthy adult population.<sup>23</sup> Each of the eight dimensions is scored separately. A greater score indicates better health measures, meaning better function and a higher level of overall health. The summary score of the mental health domain has been shown to be very useful in screening for psychiatric disorders, especially in detecting people with clinical depression or high risk people.<sup>24</sup> In addition, a brief qualitative survey was administered, consisting of five questions about specific issues involving access to care, including the cost and availability of transportation, issues with behaviors and anxiety or pain. Finally, one open question was asked to all participants; "Do you have anything else you would like to add about your caregiving experience?" These questions were selected based on literature in order to identify critical needs of the target populations.

### Data analysis

The SF-36 data were scored following recommendation from the original developer and used Quality Metric software. The psychometric analysis of the scale and descriptive analysis were conducted using SPSS. Demographic data were analyzed using descriptive statistics, including frequencies, mean, standard deviation and percentage. Chi-square, Fisher's exact tests (categorical variables), or *t*-tests (continuous variables) were used to assess differences between caregiver with provider and with no provider on demographics.

The mean comparisons were conducted by non-parametric analysis (Mann-Whitney U mean rank test) due to a small sample size. Statistical significance was considered to be a *p*-value of  $<0.05$ . Internal consistency reliability of SF scale was (Cronbach's alpha) was conducted on SF-36 scales. (Total SF-36 scores 0.924, Physical Health domain 0.873, and Mental Health domain 0.889.)

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