



Their Impact, Effectiveness and the Implications for Employers

Summary of findings from a study conducted by the National Alliance for Caregiving and Center for Productive Aging, Towson University

LifeCare[®], Inc. February 2008

Executive Summary

Providing care to an older loved one can be a complex, difficult task—one that is unpredictable, emotionally taxing and often at odds with caregivers' work schedules and other responsibilities. For the past two decades, American employers have offered programs to help their employees fulfill caregiving responsibilities while minimizing the impact to their performance at work and personal wellbeing.

This report outlines the findings of an 18-month study examining the extent to which workplace caregiving programs helped the employees who used them—specifically, whether these programs made a positive difference in their health and on-the-job performance. The study was designed and conducted by the National Alliance for Caregiving and the Center for Productive Aging, Towson University, program faculty and staff. It was funded by LifeCare[®], Inc., a privately owned specialty care services provider and longtime leader in the work/life industry.

The family caregivers who took part in the study were employed by a large managed healthcare company. They had access to two types of corporate eldercare programs: 1) a resource and referral program, and 2) a geriatric care management (GCM) program. Their feelings about and experiences with the programs were gathered via an initial written survey, follow-up telephone interviews, and a six-month follow-up survey. A total of 1,786 individuals responded to the initial survey, 36% of whom stated that they were caring for an older loved one. A sampling of employees was selected to participate in subsequent telephone interviews and follow-up survey.

Among the study's most important findings -- especially for the nation's employers -- is the fact that "presenteeism" improved over time for users of the GCM program. Essentially,

this indicates that people who used the GCM program were more focused on work after using the program than they were before using it. Additionally, GCM program users were less likely than the other groups to self-report deterioration in their health over time.

Based on these findings, employers who invest in eldercare support programs (especially those with large employee populations) could realize significant returns in productivity and lower healthcare expenses.

Demographics of study participants include:

- 84% of participants were female, with an average age of 42.6 years.
- 85% of participants were providing care to a parent or parent-in-law.
- Participants spent an average of 13.5 hours per week tending to caregiving tasks.
- 54% of participants provided some type of financial assistance to their loved ones.
- The average amount of financial assistance caregivers provided was \$300 per month.
- The average length of time caregivers had been helping their loved one was 4.9 years.
- 81% of participants reported that they had taken time during their workday to make arrangements for care or to check on their loved one.
- Nearly a quarter (24%) of caregivers reported they were helping someone with Alzheimer's disease or another form of dementia.

Background

Since 1986, American employers have offered support programs to assist their employees with caregiving responsibilities. Fashioned after child care initiatives, these programs were largely based upon a "resource and referral" model of support:

employees were given information about caregiving services in their community along with suggestions from trained professionals for managing the care needs of their loved ones.

In 2000, employers began experimenting with various models of support that focused on providing employees with decision-related support services, including access to a geriatric care manager. A geriatric care manager is a specially trained professional—usually a social worker or nurse--who delivers a greater level of service than standard resource and referral providers (e.g., personal assessments, individualized care planning and on-going follow-up services).

Most corporate eldercare studies have focused on absenteeisn and other workplace accommodations. This study looked at how presenteeism and self-reported health changed over time.

Of the 7,622 individuals surveyed at the managed healthcare firm, 1,786 responded to the online inquiry, for a 24% total response rate. More than one-third (36%) of respondents report they currently help an older loved one. The vast majority of respondents (84%) is female, with an average age of 42.6 years. The average length of time these individuals have been helping their loved one is 4.9 years.

Eighty-five percent of participants provide care to a parent or parent-in-law, and 24 percent of them are helping someone with Alzheimer's disease or another form of dementia. As has been the case in other surveys of working caregivers, most of the participants reported that they are primarily helping their loved ones with "instrumental" activities of daily living such as shopping, cooking, helping around the house, and providing transportation. Participants spend an average of 13.5 hours a week tending to their caregiving tasks.

Fifty-four percent of participants provide some type of financial assistance to their loved ones—an average of \$300 per month.

Methodology

This study was conducted in three phases:

- **Phase I:** An online survey of all employees (7,622) of a large healthcare company. The survey asked about their caregiving responsibilities, use of the caregiving programs available to them, and the effects of caregiving on their job performance and personal wellbeing.
- Phase II: Telephone interviews with three groups of caregiving employees: (1) non-users of the eldercare programs, (2) users of the resource and referral program, and (3) users of the geriatric care management program. A total of 144 employees were interviewed during this phase.
- Phase III: A six-month follow-up survey of interviewees.

 Approximately half of the respondents interviewed during Phase II completed this on-line follow-up survey.

The study was designed to compare caregiving employees who did not use corporate eldercare programs to program users on a number of dimensions, including the extent to which they needed to make changes to their normal work schedules in order to manage care, their "presenteeism" at work, their perceived level of burden related to caregiving, attitudes about support for their caregiving needs, and self-reported health effects. Employees who used the resource and referral program could elect to use the geriatric care management program if they thought it would be more appropriate to their particular care situation.

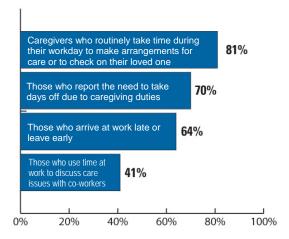
Key Findings

Among the study's most important findings, especially for the nation's employers, is the fact that "presenteeism" improved over time for users of the GCM program. Essentially, this indicates that people who used the GCM program were more focused on work after using the program than they were before using it (see pages 5 and 6).

In addition, GCM program users were less likely than the other groups to self-report deterioration in their health over time (see pages 4 and 5).

Equally important are the various negative impacts that caregiving had to the work schedules of a high percentage of caregiving employees (Figure 1):

Figure 1 Workplace Accommodations



Eighty-five percent of participants also report that their supervisors were supportive of their caregiving responsibilities.

General Perceptions of Corporate Eldercare Programs

A vast majority (90%) of employees interviewed for this study knew that there were workplace programs in place to help caregivers but many had misperceptions about the programs or the relevance of the programs to their own situations. One

employee stated: "[I would] like to take advantage of it ... I don't think anyone knows about it or how it works." Another employee, responding to a question about what would make things easier, stated: "Getting more knowledge... I don't know what kind of help is available."

There were quite a number of caregivers who felt that their situation was not yet "serious" enough to take advantage of the programs. One stated: "I don't feel that I need to use it yet ... When it's time for me to use it, I think it will be good." Many family caregivers associated the appropriate use of the program with a "crisis."

Another common explanation participants gave for not using the available programs was a lack of time to research them. One manager reports "... employees in my [supervisory] position aren't afforded the luxury of time to participate in programs or research them." Caregivers also stated that they are "too overwhelmed" to think about using the program.

Several caregivers even expressed concern about their job security if they used the program or took time off under the Family and Medical Leave Act for caregiving.

Program Non-Users

Family caregivers who elected not to use the programs available to them often spoke about their need for help and their feelings about a lack of support. These employees had expectations about support from family and friends but did not expect support from their supervisors, managers, or co-workers.

Resource and Referral Users

The majority of the resource and referral users first contacted the program after a crisis occurred in their caregiving situation, although a few had researched the program in advance of a problem arising.

Overall, users valued the program and had few complaints about their experiences. Many were clear about their primary

objective—to get information about the options available to them. The majority also expressed gratitude at receiving information and at having a "friendly voice on the other end of the phone." Several users commented specifically that it was very important to have an objective third-party to speak with about their caregiving responsibilities.

Users commonly reported that the availability of the resource and referral program, along with the support it provided, felt like a "validation" of their situation and made them feel as though they were not alone in their caregiving challenges.

Some of these caregivers also reported that they desperately needed more help and support from their family members, coworkers and supervisors.

Geriatric Care Management (GCM) Program Users

As with resource and referral users, the majority of the GCM program users turned to the program as a result of a crisis arising in their caregiving situation. Often this crisis included a serious physical or mental health emergency or diagnosis for care recipients. Crisis also was defined as the death of a parent and the realization that the surviving parent required greater attention or an altered living situation.

GCM users often reported that the availability of the program and the program's staff provided them with "validation" of their situations, their feelings, and their need to talk about caregiving challenges. As with resource and referral users, GCM users appreciated the feelings that the program inspired—feelings of being supported, of not being alone, and of having someone knowledgeable to talk with about their needs.

Even those caregivers who were grateful reported that they needed more help and often felt "overwhelmed" by their responsibilities. Many wished they had more support from their supervisors and co-

workers. Others reported that they were disappointed with their family members, concerned about conflict in the family regarding care arrangements, and needed more support from family members.

Although the majority of GCM users rated the program highly and recommended it to co-workers, they (along with the Resource and Referral users) were quick to point out its limitations: lack of follow-up, services referred were sometimes too expensive or not appropriate, displeasure with the evaluation provided, and limited help in making care arrangements.

Comparisons among Groups

All three groups (non-users of the programs, resource and referral users, and GCM users) commonly felt that using caregiving programs is something to delay until a crisis emerges and managing the situation becomes extremely difficult.

Users of the geriatric care manager program differ from resource and referral users in several ways. In their self-reported health status, GCM users are more likely than the other two groups to indicate that their health is "excellent," (Figure 2) and fewer indicate experiencing a change in their health over the study period (Figure 3).

Resource and referral users report the worst health at the beginning of the study (much worse, in fact, than the general U.S. population). Six months later nearly half said that their health had worsened.

Figure 2 How Individuals Rated Their Own Health

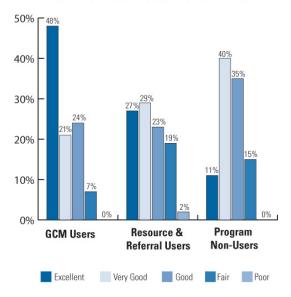
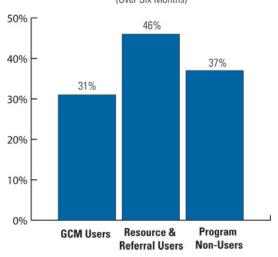


Figure 3 Reported Negative Change in Health (Over Six Months)

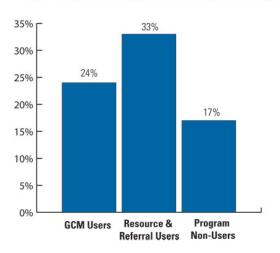


GCM users were more likely to live at a distance from the care recipient and less likely to have used paid leave. Twenty-seven percent of GCM users reported living at a distance from their loved one compared to 24% of the resource and referral users and 11% of non-users of either program.

GCM users are less likely to be involved in helping their loved one with the activities of daily living (many are long-distance caregivers) and more likely to be involved in managing services and money than the other caregivers. They also are less likely to report making work accommodations to provide care than resource and referral users.

Non-users also were less likely to be caring for someone with dementia than GCM and resource and referral users (Figure 4): only 17% of non-users reported caring for someone with dementia compared to 24% of the GCM users and 33% of the resource and referral users.

Figure 4 Reported Caring for Someone with Dementia



Levels of Burden & Presenteeism

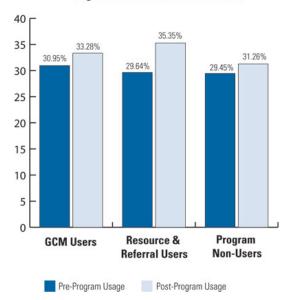
To gauge how burdened individuals felt regarding their caregiving duties and how these duties impacted their performance at work, this study utilized the Zarit Burden Inventory¹ and the Stanford Presenteeism Scale².

The Zarit Burden Inventory consists of 12 statements about caregiving. Responses to these statements indicate the caregivers' perceived levels of burden: the higher the score, the greater the perceived burden (Figure 5). This standardized scale has been used in research and clinical settings alike.

¹Medard, M. et al (2001). "The Zarit Burden Interview: A new short version and screening version." The Gerontologist, Vol. 41, No. 5, pp. 652-657.

²Koopman, Cheryl, et al (2002). "Stanford Presenteeism Scale: Health status and employee productivity." Journal of Occupational Medicine, Vol. 14, pp. 14-20.

Figure 5 Zarit Levels of Burden

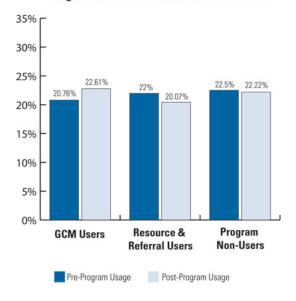


It should be noted that perceived levels of burden increased for all groups over the course of the study. For resource and referral users and for GCM users, this is due at least in part to the fact that these individuals waited until they were at a "crisis" point before engaging assistance. Perceived levels of burden often take a significantly longer period to drop. In addition, perceived levels of burden also tend to rise when individuals begin focusing more intently on their caregiving duties, as is the case when they seek out the help of a caregiving program.

The Stanford Presenteeism Scale was originally developed to assess how illness or disability affects an individual's work performance. This study used the Scale to assess the effects of caregiving on presenteeism, the extent to which workers are "on task" or focused on their work tasks (Figure 6). The Scale consists of six items, responses to which indicate the level of focus on work (also known as "presenteeism"). The higher the score, the more focused individuals are on their work tasks.

Although GCM users were less likely than the other two groups to report negative

Figure 6 Levels of Stanford Presenteeism



caregiving impacts on their work performance or health, they had slightly higher perceived levels of burden scores and lower presenteeism scores than the other two groups. Since the use of the geriatric care management program was at the discretion of the individual, it appears that GCM users appropriately linked themselves to this higher level of assistance—a level they rightly felt was needed.

Implications for Employers

By comparing users of the traditional "resource and referral" model of eldercare against those who used the GCM model and those who chose to manage caregiving on their own, this study identified several important implications for employers:

1. Employees who used the GCM program had better "presenteeism" over time than the other two groups of employees in the study.

It should be noted that the GCM user group also included more long distance caregivers and more employees who were arranging services and managing the finances of their relative than the other two groups studied. Caregiving situations involving older adults are extremely diverse and require individualized responses that often change over time. A Geriatric Care Management program is designed to address these individualized needs and the changing dynamics of a care situation. Therefore, it is often a highly effective solution—and one that benefits employers, as well. While the GCM option initially may be more costly, the improvement in presenteeism among employees suggests that it may, in fact, be more cost-effective than other less expensive options over time.

With this in mind, employers might consider being more proactive in identifying caregiving workers who are "at risk" of quitting their jobs or dropping back to parttime work. Additionally, suggesting the GCM option to employees might improve retention and presenteeism rates.

2. The majority (70%) of caregiving employees reported that their caregiving responsibilities required them to take time off from work.

While it is unlikely that employers could reduce the amount of time that caregiving employees are absent, encouraging employees to discuss their caregiving situations openly with supervisors and co-workers could allow better advance planning for absences.

Supervisors should foster a system of support that does two essential things: 1) minimizes the barriers to honest discussion about caregiving issues that might affect the work team, and 2) recognizes the importance and concerns of workers who will be called upon to take on additional work during caregiver absences.

3. Employees who did not anticipate being called upon to provide care reported higher burden levels than others. Women and those caring for a relative with dementia also had higher burden levels.

Employees must be made aware of the likelihood of becoming caregivers at some point in their lives. Educational materials, seminars and workshops are potential methods for reaching large numbers of employees on an ongoing basis.

Co-workers who currently have care responsibilities can also be instrumental in creating an environment of support and open and honest communication. By sharing their experiences and acting as mentors, they can help to smooth the transition for those taking on new caregiving roles and responsibilities.

4. Caregiving employees often reported that they waited to use workplace eldercare programs until they "needed" them (e.g., they faced a crisis, an emergency, or didn't believe they could continue to manage on their own).

Employees should be encouraged to take advantage of caregiving resources as early as possible to maximize their effectiveness.

Advance planning is essential to minimizing negative outcomes in workers' personal and professional lives.

5. In this study, all caregiving employees (even those who had not used a workplace program) felt grateful that their employer offered a program that recognized their caregiving situation—and many reported feeling "validated" by its availability.

Although utilization of workplace eldercare programs has been relatively low, this finding suggests that there are benefits to employers regardless of the number of individuals who use the program.

Positive attitudes about an employer influence both retention and productivity—two important factors in maintaining a successful business.

This study is based on a single employer. The benefits of this approach include the ability to control for culture and program differentiation. However, the results are not necessarily applicable to all workplaces. Employers are encouraged to conduct their own surveys and research to ensure that their efforts are effective and well-received.

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the wellbeing of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

About the Center for Productive Aging at Towson University

The Center for Productive Aging at Towson University is housed in the Department of Health Sciences. The Center conducts applied research on community long term care issues, workplace eldercare and working caregivers, older workers and other topics associated with our aging society.

About LifeCare®, Inc.

LifeCare's longstanding concern for working caregivers and care recipients led them to help fund this study. For more than two decades, LifeCare has provided people with customized care plans for all aspects of their personal and professional lives, including elder care and healthy aging, child care and parenting, education and personal growth, financial and legal matters, and more. LifeCare's Successful Aging SM Services help individuals resolve the full spectrum of mid-life and aging issues, including adult caregiving, cognitive health issues, legal and financial matters, and preand post retirement planning. LifeCare serves 1,500 client companies with 4.5 million individuals within corporations, health plans, government agencies and unions.