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The eXtension Employed Family Caregiver Survey: Highlights from Data Gathered from Wisconsin Employees and Employers in 2010 and 2011

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The eXtension Employed Family Caregiver Survey: Highlights from Data Gathered from Wisconsin Employees and Employers in 2010 and 2011

Abstract

Given longer life expectancy, family care of impaired adults has become increasingly common. Frequently, this care is rendered by individuals who are also employed. To collect information on employed caregiving, guided by the objective of making employers more aware of employed caregiving issues, a team of Wisconsin Extension educators developed the Employed Family Caregiver Survey available on the national eXtension website under the auspices of the Family Caregiving Community of Practice. This article reports highlights of survey data from 1,009 employees during 2010 and 2011, and describes the findings of follow-up interviews with six Wisconsin employers who were survey participants.

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Julia, age 55, works fulltime for a national non-profit organization located in a large metropolitan area. She also provides care for her 84-year-old widowed mother. A little over a year ago, Julia's mother fell, breaking her hip and fracturing a wrist. Subsequent rehabilitation was slow. The end result was that her mother will likely never regain the level of independence she had prior to the fall. Because her mother now requires more care, Julia has had a difficult time doing both her work and helping her mother. Julia reduced her hours, but that adjustment was not enough. She also finds it increasingly more difficult to stay focused on work and has often had to coordinate care management by making phone calls from her office. The gap between work and caring for her mother has widened to the point where Julia is experiencing adverse impacts on her own health and is seriously considering leaving her job to care for her mother on a full-time basis.

More than one in six Americans who work full- or part-time report assisting with the care of an elderly or disabled adult family member, relative, or friend (Cynkar & Mendes, 2011). As illustrated in the vignette above, these caregivers do not abandon their caregiving responsibilities because of work (Spillman & Black, 2005). Instead, they cope as best they can to balance what are often conflicting sets of responsibilities (Pavalko & Artis, 1997; Spiess & Schneider, 2002).

As family caregiving demands increase, however, there is a higher likelihood of adverse impacts on work performance, as well as negative effects on the well-being of the caregiver, particularly for women (National Alliance for Caregiving & the Brandeis University National Center for Women and Aging, 1999). Findings from both international and domestic studies indicate that family caregivers reduce hours of paid work more than is the case for the general population and that persons with the most intense caregiving responsibilities—mostly women—are significantly more likely to withdraw from the labor market entirely (Lilly, Laporte, & Coyte, 2007; Wakabayashi & Donato, 2005).

In July 2011, Gallup released data from 2,805 persons who self-identified as employed caregivers in the national Healthways Well-Being Index surveys conducted in 2010. The general finding is that caregiving has a significant impact on the lives of caregivers, including work (Mendes, 2011). The majority of the caregivers reported that caregiving has impacted their performance at work, a finding similar to the results of the 2009 national caregiver survey (National Alliance for Caregiving and AARP, 2009) wherein 62% of family caregivers reported making some type of workplace accommodation in order to fulfill family caregiving responsibilities.

Caregivers in the 2010 Gallup survey reported missing an average of 7 days each year due to caregiving. This magnitude of missed work translates into an estimated loss of 120 million workdays each year and the equivalent of \$25.2 billion in lost productivity (Witters, 2011). If caregivers who work part-time were to be included in this estimate, the cost of absenteeism due to caregiving responsibilities would be much higher.

In order to provide a "national one-stop site" for Extension's educational resources aimed at benefiting caregivers, the Family Caregiving Community of Practice (FC/CoP) was formed under the auspices of eXtension, an Internet-based collaborative environment where land-grant university content providers exchange objective, research-based knowledge (Sellers, Crocker, Nichols, Kirby, & Brintnall-Peterson, 2009). Guided by the philosophy that Web-based information and programming would be an effective means of addressing the educational needs of caregivers and those working with and on behalf of caregivers (including employers), several members of the FC/CoP developed an online Employed Family Caregiver Survey for use by employers. Pilot testing of the survey was conducted using county employees in selected areas of Wisconsin (Spaulding, Brintnall-Peterson, Malek, Miller, Nordgren, Weber, & Zuege-Halvorsen, 2009).

The Employed Family Caregiver Survey was designed to serve as an effective means of helping employers and Extension educators collect data on (a) the extent to which employees are involved in caregiving, (b) the impact(s) that caregiving has on workplace performance, and (c) the educational/informational needs of caregivers. Extension educators routinely assess needs and design educational interventions to address the problems/concerns of families in local communities, and it was felt that an online survey would provide useful assessment information. It was also hoped that

the survey's results would make employers more aware of employed caregiving issues and encourage the development, adoption, and implementation of workplace supports that would accommodate the needs of employed caregivers.

Methods

The Employed Family Caregiver Survey is available on the FC/CoP eXtension website: <http://www.extension.org/pages/27975/employed-family-caregiver-survey>. When an employer wishes to access the online survey, a workplace representative or a "Survey Coordinator" (often an Extension educator working in collaboration with the workplace representative) completes an online registration form. Once a completed registration form is submitted and processed, an Instant Survey template is used to create a survey expressly for use by employees at a given workplace, company, or organization, such as a local hospital, school district, or non-profit organization. A unique weblink (URL) for accessing the survey is generated and sent via email to a contact person or employer representative who subsequently arranges to have the survey's weblink shared with employees. Within a given timeframe, employees access and anonymously complete the survey. Frequency data for responses to survey items are generated by Instant Survey and subsequently sent to the contact person together with a spreadsheet template for creating reports of the results.

The online Employed Family Caregiver Survey is organized into five sections. The first solicits information regarding whether the employee has—within the past 6 months—performed each of 11 caregiving tasks related to activities of daily living. If the employee indicates that they have NOT performed one or more of these tasks, they are directed to the fifth and concluding section of the survey.

Employees who have helped with one or more of the 11 tasks are identified as "family caregivers" and are directed to the second section wherein they are asked to provide information about the number of adults for whom care is rendered, their relationship to the care recipient(s), time spent in caregiving (e.g. hours of care per week, years in the caregiving role), whether they are the "primary" caregiver, whether the care recipient has a dementia such as Alzheimer's disease, and whether the care recipient co-resides with them.

The third section of the survey solicits information regarding the extent to which shouldering caregiving responsibilities for an elderly or disabled adult family member has impacted the employee's work (e.g., arrived late for work, turned down a promotion, missed days of work, etc.). Section four collects information on educational topics on which the caregiving employee would like to learn more (e.g., learning about benefits offered by the employer that are designed to help employees engaged in family caregiving) and the format(s) the employee would prefer to use in learning more about topics of interest to caregivers (e.g., lunchtime seminars, employee newsletters, fact sheets, etc.). The fifth and final section solicits information on the employee's gender, age, race/ethnicity, and years with the current employer.

The Employed Family Caregiver Survey was posted on the national eXtension website in 2010. As of November 2011, a total of 2,167 employees representing 20 different employers in Wisconsin had accessed the Survey, 1,588 of whom completed the survey (a 73% completion rate). This article focuses on a sub-set of those who completed the survey and were also identified as family

caregivers. Included, too, are findings from follow-up interviews conducted with six Wisconsin employers whose employees participated in the Survey.

Results

Employed Family Caregivers

To be categorized as a "family caregiver," an employee needs to meet the criterion of having helped—within the last 6 months—an adult family member with one or more of 11 tasks related to activities of daily living, such as driving to doctor appointments, arranging for or preparing meals, grocery shopping, home maintenance/repairs/yard work, and paying bills. Admittedly, this is a "generous" criterion, but the intent of the survey is to collect data from any employee who is shouldering caregiving responsibilities. Approximately seven in 10 respondents had provided help with six or fewer tasks. Only 8% reported providing help for all or almost all of the 11 tasks listed.

Using this criterion, 1,009 (64%) of the 1,588 employees who completed the online survey from October 2009 through November 2011 were identified as family caregivers. Table 1 displays the frequency and percentage distributions for selected caregiver characteristics. The modal profile of a respondent identified as a caregiver was that of a daughter between the age of 46 and 65 who had been providing care to one parent (or parent-in-law) for 1-5 years.

Table 1.

Selected Characteristics of Employees Categorized as Family Caregivers (n = 1,009)

Characteristic	Number	%
Gender		
Female	760	75.3
Male	198	19.6
No response	51	5.1
Age		
45 or younger	326	32.3
46-65	623	61.8
66 or older	21	2.1
No response	39	3.9
Race/Ethnicity		
White	944	93.6
Other	20	1.9
No response	45	4.5

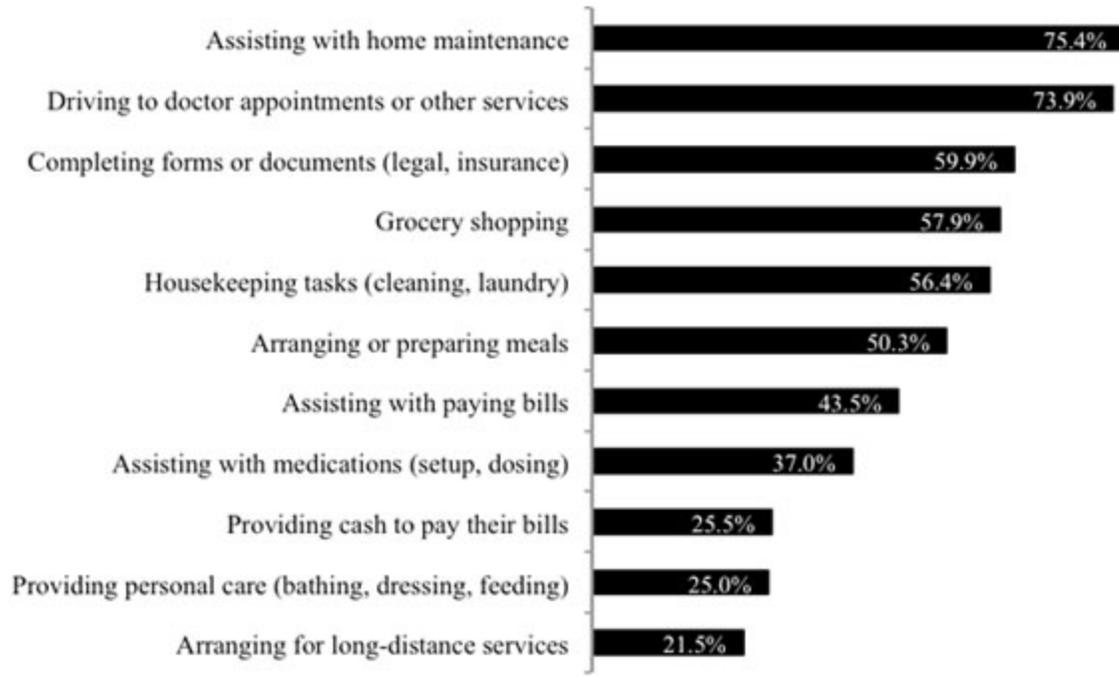
Number of adults for whom employee renders care		
One	669	66.2
Two	280	27.8
Three or more	60	6.0
Number of caregiving tasks (out of 11 listed) performed within the past 6 months		
Fewer than 3	257	25.5
Between 3 and 6	439	43.5
Between 7 and 9	229	22.6
More than 9	84	8.4
Person for whom employee is providing the most care		
Parent or parent-in-law	708	70.2
Brother or sister	26	2.6
Spouse	37	3.7
Adult child	36	3.6
Grandparent	73	7.2
Other relative	41	4.1
Friend or neighbor	64	6.4
No response	24	2.4
Is the employee the "primary" caregiver?		
No	702	69.6
Yes	307	30.4
Living arrangement of care recipient		
With employee	96	9.5
In their own residence	714	70.8
Other (e.g. nursing home, assisted living facility)	199	19.7
Does the person from whom the employee provides the most care have dementia?		
No	792	78.5
Yes	217	21.5

In a typical week, how many hours does the employee spend providing care?		
0-7 hours	830	82.3
8-14 hours	118	11.7
15-21 hours	28	2.8
22 hours or more	33	3.3
Years the employee has been caring for this individual		
Less than one year	225	22.3
1-5 years	574	56.9
6-10 years	132	13.1
11-15 years	36	3.6
16 years or more	42	4.2
Number of Years Employed by Organization/Company		
10 years or less	401	39.7
11-20 years	288	28.6
More than 20 years	270	26.7
Prefer not to answer	50	5.0

Level of Caregiving Involvement

The bar graph in Figure 1 lists the 11 caregiving tasks related to activities of daily living, together with the number and percentage of the 1,009 family caregiving employees who reported that they had been engaged in each task (in helping an older family member) during the 6-month period of time prior to the time the Survey was completed. About three in four employed family caregivers reported assisting with home maintenance (e.g., repairs, yard work) and driving the care recipient to doctor's appointments and/or other services. Nearly six in 10 reported helping with legal and financial forms (e.g., insurance), grocery shopping, and housekeeping. Half assisted with meal preparation. Providing personal care (e.g., bathing and dressing) and arranging for long-distance services were the least reported caregiving tasks, involving about one in five employed caregivers.

Figure 1.
 Percentage of Respondents Performing Caregiving Tasks (n = 1,009)



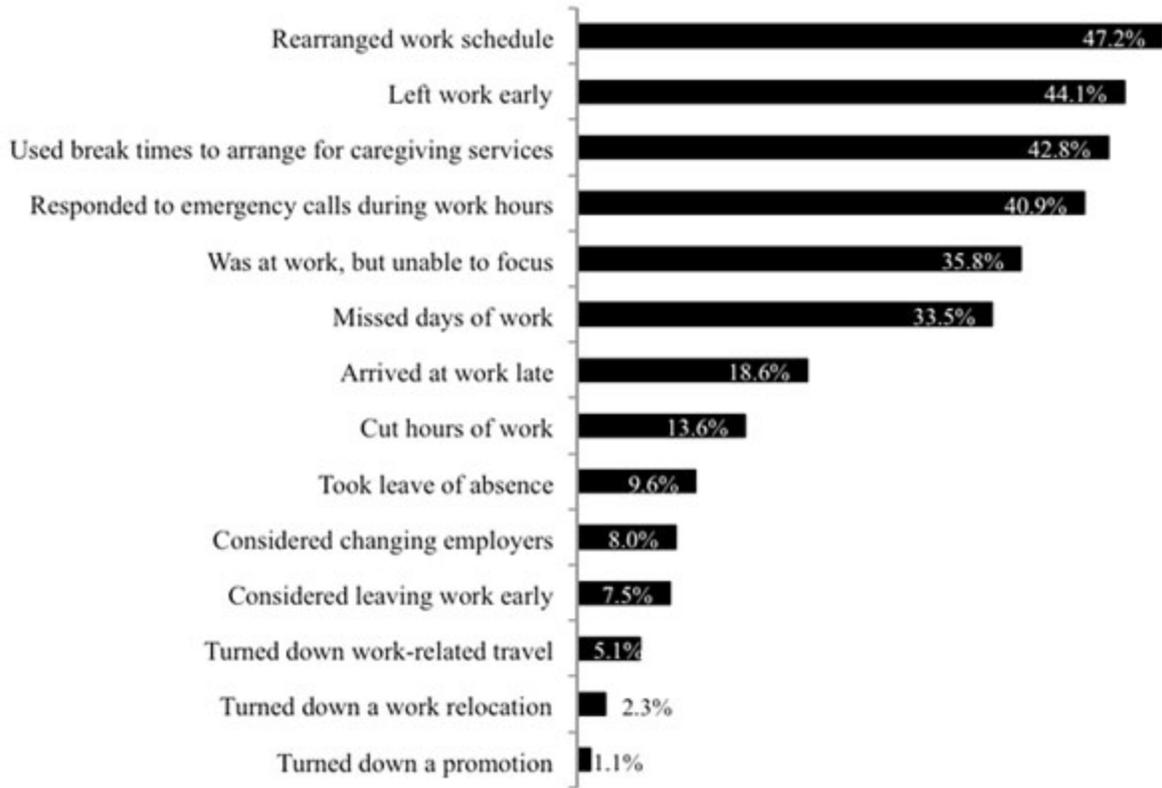
In general, the employees categorized as family caregivers in the study were not deeply enmeshed in the caregiver role at the time they completed the survey. Only one in five caregivers rendered more than 7 hours of care per week to the care recipient, and three in 10 viewed themselves as the primary caregiver. More than six in 10 had been able to take a vacation in the last 6 months in order to take time away from caregiving responsibilities, and a similar proportion said that they could continue providing care for as long as necessary with the level of help they are currently receiving. Only 21.5% of the caregiving respondents in the survey indicated that they were caring for someone afflicted with memory impairment, such as Alzheimer's disease or a related dementia.

Reported Impact(s) of Caregiving on Work

Despite the comparatively low level of caregiving involvement among survey respondents, the impact of caregiving on work was still evident. Almost half (47.2%) indicated that they had to rearrange work schedules to accommodate caregiving responsibilities, and about four in 10 reported that caregiving has resulted in leaving work early, using break times to arrange for care, and responding to emergency calls (related to caregiving) during work hours. Thirty-five percent indicated that caregiving responsibilities had made it difficult for them to focus on their work, and one-third had missed days of work as a result of caregiving. The bar graph in Figure 2 shows the percentage distribution of responses to the question, "In the past year, have your caregiving responsibilities caused you to....?"

Figure 2.

Percentage of Respondents Indicating That Caring for a Dependent, Adult Family Member Had Impacted Work (n = 1,009)



Because the caregivers responding to the survey were not as deeply enmeshed in the caregiver role as would be individuals who are primary caregivers of family members afflicted with a dementia such as Alzheimer's disease, it was not surprising to find that only one in 10 reported using a leave of absence to provide care and that an even smaller percentage reported turning down a promotion. When asked if providing or arranging care had made current employment more difficult, only 16.2% responded in the affirmative.

Still, the fact that caregiving impacted work should not be minimized. Even though one in four caregivers did not check any of the 14 work impact items listed in the survey, more than a third (35.7%) indicated that caregiving had impacted work in one-three of the listed areas, and nearly 40% reported that their work had been impacted in four or more of the areas listed.

Topics of Informational Interest to Family Caregivers

Table 2 presents the percentage distribution of responses to the survey items wherein caregivers were asked to indicate the topics for which they would like to acquire more information. Topics that garnered the most interest for caregivers included learning more about (a) caregiving benefits offered by the employer, (b) legal and financial aspects of caregiving (e.g., powers of attorney), and (c) community resources to assist with caregiving.

Table 2.
Frequency and Percentage of Caregivers Expressing Interest in Learning More About Information Topics Related to Caregiving (n = 1,009)

Topic (respondents could select more than one)	Number	%
Caregiving benefits offered through your employer	339	48.8
Legal, financial and/or health care planning (powers of attorney for health care and finances, guardianship, estate planning, etc.)	313	45.1
Community resources to assist with caregiving tasks and responsibilities (in-home assistance, educational classes, support groups, etc.)	293	42.2
Strategies to approach difficult decisions such as taking away driver's license, needing paid help, moving to care facility, etc.	253	36.5
Communicating with health care professionals	225	32.4
Communicating with family members	220	31.7
Understanding how your relationships change throughout the caregiver journey	201	29.0
Juggling work and caregiving	178	25.6
Long term care insurance	162	23.3
Exploring residential long-term care options (nursing home, assisted living facilities and other housing options)	145	20.9
Dealing with problem behaviors (wandering, asking same question, etc.)	137	19.7
Finding and hiring paid help	127	18.3
Dealing with loss and grief	120	17.3
Communicating with your supervisor and work colleagues about your family caregiving situation	103	14.8
Personal care skills such as bathing, transferring, and feeding	63	9.1

Respondents were also asked to identify the preferred workplace format for receiving caregiving information of interest to them. The percentage distributions of caregivers' responses appear in Table 3. The majority of the caregiving respondents indicated employee newsletters and fact sheets.

Table 3.

Frequency and Percentage Distribution of Caregivers Indicating the Format in Which They Would Prefer to Receive More Information on Caregiving Topics
(N = 1,009)

Preferred Educational Formal	Number	%
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Employee newsletters	494	63.0
Fact sheets	483	61.6
E-mail	338	43.1
Lunchtime seminars	243	31.0
Printed directory of caregiver services	242	30.9
Online	232	29.6
Before or after work seminars	117	14.9
Individual meetings with someone to help you problem solve	109	13.9
On-site support groups	71	9.1
Other (please specify)	16	2.0

Responses from Employers

Two to 5 months after employees had completed the survey and the data had been compiled in summary reports and shared with employers, a follow-up interview was conducted with a person representing the employer. Generally, the person interviewed was the one with whom the Extension educator coordinator had worked in the survey registration process. The interview consisted of eight questions concerning employer reactions to the survey results, what workplace supports are currently available for employees who are caregivers, and what the employer might do in the future to provide information for their employees.

Six employers were interviewed over the telephone or in person by the Survey Coordinator 2 to 5 months after the survey was completed. Employers A, B, C, D, E, F were interviewed to determine the employers reactions to the survey results and what, if any, work place supports for caregivers were being adopted by the employer.

Half of the six employers interviewed were surprised about the number of caregivers among their employees. Employer A was "shocked" at the higher number of employees who identified themselves as caregivers. Two employers were aware of caregivers in the workplace because of conversations with employees, noticing employees changing jobs or changing shifts, going from full to part-time, and increase in requests for family and medical leave in the past 3 to 5 years.

All six employers interviewed stated they already offered their employees support with flexible work hours, unpaid leave to care for family member, personal time off, or other paid leave to care for an elderly family member, family health insurance, pension /retirement plan, employee assistance program (EAP), and seminars on balancing work and family issues. Not all the employees were likely to use these supports frequently, however, except the more common benefits such as health insurance, retirement plan, and EAP.

The survey indicated employees were most interested in knowing more about caregiving benefits

offered through the employer (49%); legal, financial, and/or health care planning (45%); and community resources to assist with caregiving tasks and responsibilities (42%). All employers thought they did a good job informing their employees about their benefits and were concerned when benefits that could be used for caregiving was what the employees wanted to know about the most. The survey data and the employers interview findings appear to indicate a "disconnect" between employees knowing about employee benefits and how they might be utilized.

Employees indicated on the survey that they were most interested in receiving information by newsletters and fact sheets. Employer A would like help identifying appropriate information for employees. Employer B was surprised that lunch time learning sessions weren't chosen more frequently but noted many employees said they used breaks and lunch time for taking care of individual caregiving issues.

As a result of this employee survey, each employer had begun plans to help their caregiving employees.

1. Employer A was planning a caregiving fair at the work place for the fall 2011.
2. Employer B already has an employee newsletter but would like to offer on-site lunch time learning sessions. They are also currently working on a comprehensive plan related to caregiving and felt the survey provided them with a snapshot of employed caregivers and what their needs are so they will be able to make an informed comprehensive plan.
3. Employer C stated that the support offered in the future will be very much due to the survey. They will provide training for supervisors on the impact of family caregiving on the workplace and how to identify the stressed employee in order to determine individual caregiving issues. This employer will also provide face-to-face programs for employees to help them pre-plan for a "caregiving crisis," which the employer believes will reduce lost time and productivity.
4. Employer D is thinking about marketing their benefits to potential employees more often because they have an 8% turnover rate at this time and plan to do a better job of informing current employees how to utilize benefits for family caregiving issues. This employer is also looking for information and speakers on caregiving topics to be a part of a wellness fair in 2012.
5. Employer E had planned some face-to-face sessions but had to cancel due to low registration. A series of fact sheets related to caregiving issues was sent to interested employees during National Caregiver's Month.
6. Employer F has set up an internal website for employees with financial information relating to caregiving.

Summary and Implications for Extension

The Employed Family Caregiver Survey described in this article is an effective tool for helping employers collect data on (a) the extent to which employees are simultaneously involved in caregiving, (b) the impacts of caregiving on workplace performance, and (c) informational needs

related to caregiving. With regard to the first two points, we note that the majority of the 1,009 employees in Wisconsin whose responses are profiled in this article were in the early stages of their caregiving responsibilities, providing 7 or fewer hours of caregiving weekly. Still, the impact of caregiving on work was evidenced by the reported need to leave work early, using break times to arrange for care, responding to emergency calls during work hours, and missing days of work due to caregiving responsibilities.

Parenthetically, employers outside of Wisconsin are registering for the survey. Once sufficient data have been collected from employees nationally, the intent of the authors is to re-analyze survey data for the purpose of investigating state and regional differences.

In terms of employees' informational needs, a key finding for Extension educators was that more than 60% of the employees surveyed desired to receive information on caregiving topics via newsletters and/or fact sheets. Importantly, content for such newsletters and fact sheets can be gleaned from information posted on the website sponsored and maintained by the eXtension Family Caregiving Community of Practice (<http://www.extension.org/pages/9262/family-caregiving-community-page>).

Follow-up interviews with a sample of participating employers in Wisconsin revealed they were surprised by the prevalence of employed caregivers, by the impacts on work, and by the frequency with which employee benefit information was requested. As a result of having participated in the survey, all employers interviewed expressed an interest in initiating follow-up work with their employed caregivers.

We note, too, that five of six employers interviewed became involved in the survey as a result of coordinating efforts of University of Wisconsin Extension Family Living educators, who subsequently prepared and presented survey results to employers. They also provided direction for additional education on topics of interest to employed caregivers. The point to be emphasized here is that employers increasingly recognize that Extension educators are skilled in adult education methods and have the ability to effectively deliver the needed practical, reliable, and researched-based information.

Although it was not highlighted as a finding in the body of this article, we note that the Employed Family Caregiver Survey affords employees the opportunity to "self-identify" as caregivers. This is not inconsequential. As Suzanne Mintz, President/CEO of the National Family Caregivers Association, has observed: "By giving a name to our situation we validate our experiences, and all of our feelings. We say to the world: Here I am! Acknowledge me! Help me!" (Mintz, 2011). Being identified as a caregiver places individuals in a group with common issues and increases the likelihood of accessing supports that help with balancing family, work, and caregiving roles.

Last, the Extension educators involved in the study reported here feel that a cross-programming model could be used to more effectively market the survey. For example, Extension colleagues could collaborate on company identification and recruitment, interpreting demographic data, and program delivery. Bringing together the expertise of Extension colleagues from different program areas (e.g., Community and Economic Development) may strengthen Extension's community connections.

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