Health Profile of Aging Family Caregivers Supporting Adults With Intellectual and Developmental Disabilities at Home

Kiyoshi Yamaki, Kelly Hsieh, and Tamar Heller

Abstract

The health status of 206 female caregivers supporting adults with intellectual and developmental disabilities at home was investigated using objective (i.e., presence of chronic health conditions and activity limitations) and subjective (i.e., self-perceived health status) health measures compared with those of women in the general population in 2 age groups: middle age (Ages 40–59 years) and older ages (≥60 years). Prevalence of arthritis, high blood pressure, obesity, and activity limitations for the caregivers in both age groups was significantly higher than that for women in the general population. Middle-age caregivers reported a higher prevalence of diabetes and high blood cholesterol than their age peers from the general population. Despite the potential health challenges, the caregivers generally perceived their health better than that of women in the general population. Older caregivers' perceptions on their psychological well being, however, appeared to an exception. Implications regarding potential health risks for caregivers and residential services for persons with intellectual and developmental disabilities are discussed.

DOI: 10.1352/1934-9556-47.6.425

Family caregivers are the backbone of residential support for individuals with intellectual and developmental disabilities in the United States. Although the capacity of publicly funded residential service programs has shown steady growth over the past decades (Lakin, Prouty, & Coucouvanis, 2004), these out-of-home placements support only a fraction of the population with intellectual and developmental disabilities (Fujiura, 1998). In fact, family caregivers support 60% of the population in their own homes (Braddock, Hemp, & Rizzolo, 2008). Older age (Ages 60 years or older) caregivers constitute 25% of these family caregivers; another 35% are considered middle ages (Ages 41–59). Combined, 1.7 million adults with intellectual and developmental disabilities are supported by older and middle-age family caregivers (Braddock et al., 2008). Because the current state service systems cannot meet the demand of individuals with intellectual and developmental disabilities and their families for residential services (Alba, Prouty, & Lakin, 2007), it is likely that these older and middle-age family caregivers will continue to be the largest providers of residential support to this population in the foreseeable future.

Individuals in the middle- and older age groups are frequently confronted with challenges of maintaining their own health. Common chronic conditions among adults in these age cohorts include, but are not limited to, arthritis, heart disease, stroke, diabetes, hypertension, and hearing impairment (Hootman, Bolen, Helmick, & Langmaid, 2006; Neyer et al., 2007; Schoenborn, Vickerie, & Powell-Griner, 2006). The high prevalence of these conditions is the most likely cause for a significant proportion of these adults reporting difficulties in their daily activities, such as walking a quarter mile (23.8%), pushing and pulling large objects (20.5%), and shopping (12.4%; Schoenborn et al., 2006). Furthermore, across the two cohorts, the burden of chronic disease and health conditions and related activity limitations is much higher for older adults than for middle-aged adults (Hootman et al., 2006; Steinmetz, 2006; Wan, Sengupta, Velkoff, & DeBarros, 2005).

The purpose of the present study was to better understand the health status of middle- and older age female family caregivers supporting adults with intellectual and developmental disabilities at home. Despite concerns about the needs of aging family caregivers who support adults with intellectual and developmental disabilities (Heller, Caldwell, & Factor, 2007; Seltzer & Krauss, 1989) and the health status of individuals in mid- and later life (He & Baker, 2004; Pope, Sowers, Welch, & Albrecht, 2001; Schoenborn et al., 2006; U.S. Centers for Disease Control and Prevention and the Merck Company Foundation, 2007; Willcox et al., 2006), present knowledge about the health of these family caregivers is limited (Chen, 2001; Magana & Smith, 2006; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Seltzer & Krauss, 1989). The health status of these caregivers could have a direct impact on their current and future capacity in supporting their family members with intellectual and developmental disabilities (Essex, Seltzer, & Krauss, 1997). To address the multidimensional aspects of health (Idler & Benyamini, 1997), we used both objective (i.e., presence of chronic health conditions and activity limitations) and subjective (i.e., self-perceived health status) measures to assess the health of caregivers. Results were compared with available population data to examine whether there were any health disparities for these caregivers versus the general population of middle- to older age women living in the same state.

Method

Procedure

The health status data used in the present study were obtained from a convenience sample of 206 female caregivers, Ages 40 years and above, who resided with their adult family member with intellectual and developmental disabilities in Illinois. Data were collected as part of a statewide health survey of adults with intellectual and developmental disabilities living with their family members and their primary family caregivers. During the period between August 2005 and November 2006, research staff asked 53 community agencies across the state to send a recruitment flyer to 3,200 family caregivers. Of those, 321 caregivers contacted the research staff by telephone and postcard to express their interest in participating in the mail survey. All of these caregivers, except 2 who failed to provide their addresses, received the survey questionnaire by mail and were instructed to respond to questions on self-rated health status, access and use of health services, chronic disease and related health conditions, medication, and health-related behaviors for themselves as well as on behalf of their family members with intellectual and developmental disabilities. Completed questionnaires were returned to the research staff by caregivers using an enclosed, self-addressed, stamped envelope. Four to 8 weeks after the initial mailing of the questionnaire, the second mailing to nonrespondents was conducted. A total of 241 surveys were returned (7.5% response rate). Responses from 29 male caregivers and 6 caregivers who did not report age were excluded from the present analysis. The protocol was reviewed and approved by the Institutional Review Board of the University of Illinois at Chicago.

Measures

The health status of the caregivers was examined using both objective and subjective measures. The former included 10 variables on the presence of common chronic diseases and health conditions and a variable on activity limitation. The latter consisted of 5 variables on caregivers' perception of their own well being.

Objective measures. Caregivers were asked if they had ever been told by a health professional that they had any of the following 9 chronic health conditions: arthritis, asthma, diabetes, angina or coronary heart disease, heart attack, stroke, high blood pressure, high blood cholesterol, and/or osteoporosis. Obesity, the 10th variable, was defined as the Body Mass Index (BMI) equal to or higher than 30.0 based on a caregiver's self-reported weight and height information (National Institutes of Health, 1998). Caregivers who reported difficulty in any of the following three daily activities were labeled as having an *activity limitation*: "lifting or carrying something more than 10 lbs, such as a full bag of groceries," "climbing a flight of stairs without resting," and "walking far distances, such as three blocks."

Subjective measures. We adopted the following five indicators of the health-related quality of life (HRQOL), developed by the U.S. Centers for Disease Control and Prevention (Moriarty, Kobau, Zack, & Zahran, 2005), to assess caregivers' perception of their own health status. First,

caregivers were asked to rate their general health status using the following five categories: *excellent, very good, good, fair,* and *poor*. Caregivers were then asked to report the number of unhealthy days in the past 30 days when their (a) physical health was not good because of physical illness or injury; (b) mental health was not good because of stress, depression, and other emotional problems; and (c) poor physical or mental health prevented them from doing regular activities, such as self-care, work, or recreation. We tabulated the fifth variable, healthy days (i.e., days without any physical symptoms and mental distress), using the suggested formula (U.S. Centers for Disease Control and Prevention, 2000).

Population data. To compare the health profile of female caregivers in the study to women in the state, data from the 2005 and 2006 Illinois Behavioral Risk Factor Surveillance System (ILBRFSS) were used. The ILBRFSS is an annual state-level, random-digit telephone survey on the health and health-risk behaviors of adult residents that is conducted by the Illinois Department of Public Health. Households in the state were selected randomly using their telephone number. At each sampled household, a telephone interview, approximately 10 min, was conducted with a randomly selected adult, ages 18 and above. For the 2005 survey, 67.6% of the selected adults completed the interview. The rate was 66.2% for the 2006 survey (U.S. Centers for Disease Control and Prevention, 2006, 2007). The majority of the data for Illinois women were extracted from the 2006 ILBRFSS, which included 1,324 middle-age and 1,121 older age women. Arthritis, high blood pressure, high blood cholesterol, and osteoporosis prevalence for Illinois women was based on 1,249 middle-age and 1,066 older age women extracted from the 2005 ILBRFSS.

Analysis

Respondents were divided into two age groups: middle age (40–59 years) and older age (60 years and above). Chi square or Fisher's exact tests were used to compare the proportions across caregivers in the two age groups. For continuous variables (i.e., number of unhealthy–healthy days), t tests were used to examine if the group means differed across the two age groups. The level of significance was set at .05. These analyses were conducted using SPSS 16 (SPSS Inc., 2008). In analyzing the ILBRFSS data, SPSS 16 Complex Samples add-on was used to produce a statistically weighted population-level estimate and associated 95% confidence interval. The difference between the female caregivers and women in the general population was tested using the 95% confidence interval. If the rate for the caregiver did not fall within the range of 95% confidence interval of the population estimate, it was considered to be a statistically significant difference between the two groups. Note that the high blood cholesterol prevalence for Illinois women was based on those who ever had blood cholesterol checked (approximately 90% of all women in the two age groups); prevalence for the female caregivers was based on all caregivers who answered the question. To compare the presence of activity limitation between the two groups, the rate of caregivers who reported an activity limitation was compared to the rate of Illinois women who reported a limitation "in any way in any activities because of physical, mental, or emotional problems" (Illinois Department of Public Health, n.d., p. 5).

Results

The majority (86.3%) of 206 study caregivers were mothers of a family member with intellectual and developmental disabilities. Most of the remaining caregivers (10.8%) were sisters. A few were aunts, nieces, or grandmothers. The mean age of the caregivers was 58.3 years ($SD = 9.8$). Middle-age caregivers constituted 63.1% of the study caregivers ($n = 130$). The older age group included 8 women (10.5%) in their 80s. Analysis of the 2006 ILBRFSS data showed that there were approximately 3 million middle- and older age women in Illinois in 2006. The general population's mean age was 58.2 years ($SD = 0.3$); 60.3% ($SD = 1.1$) of the women were in the middle-age group, and 20.8 % ($SD = 1.3$) of the older age women were Ages 80 or above.

Shown in Table 1 are demographic characteristics of the study caregivers and Illinois women across the two age groups. The middle- and older age caregivers were similar when broken down by race and residence. Older age caregivers were more likely to be widowed, $\chi^2(3, N = 202) = 26.12$, $p = .000$; had limited incomes, $\chi^2(2, N = 184) = 17.77$, $p = .000$; and had lower educational achievement, $\chi^2(2, N = 203) = 9.45$, $p = .009$, compared with middle-aged caregivers. Compared with women in the general population, the caregivers were signif-

icantly more likely to be White and residents of Chicago metropolitan area across the two age groups. They were less likely to be residents of urban areas. Although the marital status of middle-age caregivers generally did not differ from that of middle-age women in general population, older caregivers were significantly more likely to be married and less likely to be widowed than their age counterparts in the general population. Both income and educational achievement of the caregivers appeared to be skewed toward the higher end compared with their age counterparts in the general population.

Prevalence of chronic conditions and activity limitations for the study caregivers and their age peers in the general population, across the two age groups, are summarized in Table 2. The prevalence of these conditions and limitations for older age caregivers were generally higher than that for their middle-age counterparts. Arthritis prevalence for older age caregivers, for example, was twice that for middle-age caregivers, 73.0% versus 36.9%, $\chi^2(1, N = 204) = 24.51$, $p = .000$. Similarly, rates for high blood pressure and osteoporosis for older age caregivers were 1.8 times and 3.5 times, respectively, higher than for the middle-age caregivers: 66.7% versus 35.7%, $\chi^2(1, N = 204) = 18.30$, $p = .000$, and 27.8% versus 7.9%, $\chi^2(1, N = 199) = 14.22$, $p = .000$. Older age caregivers also reported 2.5 times higher rate of activity limitations than middle-age caregivers: 56.0% versus 22.5%, $\chi^2(1, N = 204) = 23.48$, $p = .000$. Although older caregivers reported a higher prevalence of cardiovascular diseases (i.e., coronary heart disease, heart attack, and stroke) than middle-age caregivers, a statistically significant difference was found only for coronary heart disease (Fisher's exact test, $p = .019$). Differences in asthma, diabetes, and obesity prevalence across the two cohorts were not significant.

Compared with women in the general population, study caregivers reported a significantly higher prevalence of arthritis, high blood pressure, obesity, and activity limitations across the two age groups. The proportion of obese caregivers, for example, was 39.0% for the middle-age group and 39.4% for older age group compared with 28.5% (95% CI = 25.7–31.5) and 25.3% (95% CI = 22.4–28.4), respectively, for women in the general population. Prevalence of activity limitations reported by older age caregivers (56.0%) was 1.8 times higher than the rate reported by older women in the general population (30.2%; 95% CI = 27.2–33.3). Middle-age caregivers reported 1.7 times higher prevalence of diabetes (12.4%) and 1.2 times higher prevalence of high blood cholesterol (40.3%) than middle-age Illinois women (7.0%, 95% CI = 5.6–8.7; and 32.9%, 95% CI = 29.8–36.1, respectively). In the older age group, however, the rate was similar. Prevalence of asthma and cardiovascular diseases for the caregivers was generally comparable with that of Illinois women with one exception. A proportion of older age caregivers who had heart attacks (8.0%) were significantly lower than their age peers in the general population (11.2%, 95% CI = 9.1–13.7).

Table 3 summarizes the subjective measures of health by the caregivers and Illinois women across the two age cohorts. Note that results of the self-rated health status were aggregated to the three categories representing favorable (i.e., *excellent, very good*), neutral (*good*), and unfavorable (i.e., *fair, poor*) ratings of the respondent's own health status. There was no significant difference between the middle- and older age caregivers for all subjective measures except the number of physically unhealthy days. Older caregivers reported significantly more days in which their physical health was not good than their younger counterparts: 4.31 days versus 2.18 days, respectively, $t(190) = -2.11$, $p = .036$. For Illinois women, in contrast, older women generally perceived their health more unfavorably than their middle-age counterparts. Comparison of the self-rated health status between the two groups showed that the study caregivers generally rated their health status more favorably than Illinois women across the two age groups. Analyses of the four healthy-days measures showed the similar results. That is, the caregivers reported fewer physically unhealthy days and days with poor health than Illinois women across the two age groups and more healthy days in the middle-age group. Older caregivers' perceptions on their psychological well being, however, appeared to be an exception. Mentally unhealthy days reported by older age caregivers (4.65 days) was twice as many as the number reported by their age peers in the general population (2.3 days, 95% CI = 1.90–2.74).

In summary, a considerable proportion of middle-age and older age female caregivers in the present study reported arthritis, high blood pressure, high blood cholesterol, obesity, and activity limitation. The prevalence of these and other conditions was often higher for the older age group. Compared with women in the general population,

Table 1 Demographics of Female Caregivers and Illinois Women Across Two Age Cohorts

	Female caregivers			IL women[a]	
Demographic	Middle age (40–59 yr.)	Older age (≥60 yr.)	χ^2	Middle age (40–59 yr.)	Older age (≥60 yr.)
n	130	76		1,324 (1,814,000[b])	1,121 (1,194,000[b])
M age (*SD*)	52.7 (4.5)	68.9 (7.2)		49.0 (0.18)	72.2 (0.27)
Race (%)					
White[c]	80.0	84.0	0.91	72.3 (69.1–75.3)	80.2 (76.7–83.3)
Black	13.8	9.3[c]		15.5 (13.1–18.2)	12.5 (10.2–15.3)
Hispanic	3.1[c]	4.0		8.2 (6.3–10.6)	5.1 (3.3–7.8)
Other	3.1	2.6		4.0 (2.8–5.8)	2.1[d] (—)
Residence (%)					
Chicago metro[c]	68.9	65.7	0.21	59.0 (56.0–61.9)	51.1 (47.8–54.4)
Urban[c]	9.8	10.4		20.0 (17.7–22.5)	22.0 (19.5–24.8)
Rural	21.3	23.9[†]		21.1 (18.9–23.5)	26.9 (24.2–29.7)
Marital status (%)					
Married[e]	73.6	52.1[c]	26.12**	71.2 (68.4–73.9)	42.5 (39.2–45.9)
Widowed	3.9	28.8[c]		3.2 (2.2–4.5)	39.1 (36.0–42.4)
Divorced/Separated	14.7	13.7		15.6 (13.5–17.9)	13.9 (11.7–16.4)
Never married	7.8[†]	5.5		10.1 (8.4–12.1)	4.5 (3.5–5.8)
Household income (%)					
<$15K	8.2	24.2	17.77**	8.9 (6.9–11.7)	20.7 (17.5–24.4)
$15K to <$50K[c]	36.1	50.0		42.7 (39.1–46.4)	67.2 (63.3–71.0)
$50K or above[c]	55.7	25.8		48.3 (44.7–52.0)	12.0 (9.7–14.8)
Education status (%)					
Some HS or less	3.8[c]	13.7	9.45*	5.6 (4.1–7.7)	15.6 (13.1–18.5)
HS graduate[c]	22.3	30.1		25.8 (23.2–28.6)	39.9 (36.7–43.2)
College or above[c]	73.8	56.2		68.6 (65.5–71.4)	44.5 (41.2–47.8)

Note. IL = Illinois; HS = high school. For race, residence, marital status, household income, and education status variables for women in the general IL population, ranges in parentheses represent 95% confidence interval percentages.

[a]Estimates based on the 2006 Illinois Behavioral Risk Factor Surveillance System (ILBRFSS) data. [b]Statistically weighted state-level population estimate. [c]Difference between caregivers and their age counterparts in Illinois women is significant using 95% confidence interval. [d]Estimate is not statistically stable (i.e., standard error exceeds 30% of the estimate). [e]Estimates for Illinois women include "unmarried couples."

*$p < .01$. **$p < .001$.

female caregivers reported higher rates of arthritis, high blood pressure, obesity, and activity limitations across the two age cohorts. The rate of older caregivers who reported activity limitations was close to twice that of older women in the general population. The prevalence of diabetes and high blood cholesterol for female caregivers was higher for the middle-age group only. Low prevalence of heart attack among the older age caregivers was the only finding in which the caregivers reported better objective health than their peers. Nonetheless, the study caregivers perceived their health as generally good. There was no detectable discrepancy in their self-rated health status between the two age groups of caregivers; a notable contrast with the general population in which older women often reported

Table 2 Objective Measures of Health Status Between Female Caregivers and Women in the General Population in IL by Age Group

	Female caregivers (%)			IL women (%)	
Objective measures	Middle age	Older age	χ^2 or Fisher's Exact Test	Middle age	Older age
Arthritis [a]	36.9	73.0	24.51**	31.6 (28.7–34.7)	57.8 (54.3–61.2)
Asthma	13.2	14.9	0.11	14.8 (12.7–17.2)	13.0 (10.9–15.5)
Diabetes	12.4[a]	18.7	1.48	7.0 (5.6–8.7)	17.9 (15.5–20.6)
Coronary heart disease	2.3	11.0	0.019[b*]	2.5 (1.7–3.6)	10.0 (8.1–12.2)
Heart attack	2.3	8.0[a]	0.079[b]	2.1 (1.3–3.5)	11.2 (9.1–13.7)
Stroke	1.5	6.8	0.101[b]	1.2 (0.7–1.9)	7.4 (5.9–9.2)
High blood pressure [a]	35.7	66.7	18.30**	26.3 (23.6–29.2)	58.8 (55.5–62.1)
High blood cholesterol[c]	40.3[a]	56.3	4.66*	32.9 (29.8–36.1)	55.4 (51.7–58.9)
Obesity (BMI $\geq$ 30)[a]	39.0	39.4	0.003	28.5 (25.7–31.5)	25.3 (22.4–28.4)
Osteoporosis[c]	7.9	27.8	14.22**	6.3 (4.3–9.1)	25.3 (20.9–30.2)
Activity limitations[a]	22.5	56.0	23.48**	19.5 (17.1–22.1)	30.2 (27.3–33.3)

Note. IL = Illinois; BMI = Body Mass Index. For all measures for the IL women, ranges in parentheses represent 95% confidence interval percentages. Estimates for arthritis, high blood pressure, and high blood cholesterol for IL women are based on the 2005 Illinois Behavioral Risk Factor Surveillance System (ILBRFSS) data. All other estimates are from the 2006 IBRFSS data.
[a]Prevalence for female caregivers significantly differs from Illinois women in the same age group using 95% confidence interval. [b]*p* value derived from Fisher's Exact Test. [c]Estimate for IL women is based on those who ever had blood cholesterol checked.
*$p < .05$. **$p < .001$.

diminished self-rated health status than their middle-age counterparts. Study caregivers' perception on their own health was generally better than that of their counterparts in the general population with the exception of mental health for older caregivers.

Discussion

In the present study, we investigated the objective and subjective health status of middle- and older age female caregivers supporting adults with intellectual and developmental disabilities at home compared with those of women in the same state. Results of our analyses were generally consistent with previous findings in which chronic health conditions were common among female caregivers, particularly among those who were older (Chen, 2001; Magana & Smith, 2006). The increased prevalence of chronic conditions in later life has been listed at the top of the national health agenda (U.S. Department of Health and Human Services, 2000). In fact, about 80% of older persons are estimated to have at least one chronic health condition, and 50% are estimated to have at least two (Wan et al., 2005). Our findings underscore that aging female caregivers supporting adults with intellectual and developmental disabilities are no exception to this national trend and that they are providing care to their family member with intellectual and developmental disabilities while dealing with their own age-related health challenges.

Consistent with the previous study on minority female caregivers (Magana & Smith, 2006), we found that the prevalence of arthritis among our mostly White caregivers was disproportionately higher than for their counterparts in the general population. Magana and Smith speculated that stress from caregiving, physical inactivity, and depression could have been potential causes for their finding. Another explanation could be a higher rate of obesity found among female caregivers in the present study because obesity is an independent risk factor for arthritis (Busija, Hollingsworth, Buchbinder, & Osborne, 2007; Gross,

Table 3 Subjective Measures of the Health Status Between Female Caregivers and IL Women by Age Group

	Female caregivers (% or frequency)			IL Women (% or frequency; 95% CI)	
Subjective measure	Middle age	Older age	χ^2 or t	Middle age	Older age
Self-rated health status					
Excellent/very good	48.5[a]	34.2	5.70	54.8 (51.7–57.9)	36.4 (33.3–39.6)
Good[a]	37.7	40.8		28.4 (25.7–31.3)	33.7 (30.6–36.9)
Fair/poor[a]	13.8	25.0		16.8 (14.4–19.4)	30.0 (26.9–33.2)
Number of ...					
Physically unhealthy days[a]	2.18	4.31	−2.11*	3.45 (2.95–3.95)	5.80 (5.12–6.48)
Mentally unhealthy days	3.49	4.65[a]	−0.963	3.93 (3.42–4.45)	2.32 (1.90–2.74)
Poor health days[a]	1.68	1.52	0.211	3.72 (3.03–4.41)	5.59 (4.71–6.46)
Healthy days	24.76[a]	22.92	1.24	23.48 (22.86–24.11)	22.69 (21.94–23.43)

Note. IL = Illinois; CI = confidence interval. Estimates for IL women are based on the 2006 Illinois Behavioral Risk Factor Surveillance System (ILBRFSS) data.

*Significant difference between middle-age and older age female caregivers using t test ($p < .05$).

[a]Significant difference between female caregivers and Illinois women in the same age group using 95% confidence interval.

Fickert, & Gunther, 2005; Symmons et al., 1997; Voigt, Koepsell, Nelson, Dugowson, & Daling, 1994). Arthritis is also a leading cause of activity limitation in the nation (McNeil & Binett, 2001). Perhaps, the higher prevalence of activity limitations found among older female caregivers in the present study may be attributable, at least partially, to the relatively higher rate of arthritis for this group.

The elevated prevalence of high blood cholesterol, high blood pressure, and obesity among female caregivers suggests that they might be at a higher risk for cardiovascular disease. High blood pressure and high blood cholesterol are notable risk factors for heart disease and stroke, the leading and third leading cause of death in the United States, respectively (Hahn, Heath, & Chang, 1998; Minino, Heron, Murphy, & Kochanek, 2007). Obesity, which is often comorbid with high blood pressure and high blood cholesterol, is a rapidly increasing actual cause of death, second to tobacco, in the United States (Mokdad, Marks, Stroup, & Gerberding, 2004; Rao, Donahue, Pi-Sunyer, & Fuster, 2001). Although we did not find any difference in the prevalence of cardiovascular disease between female caregivers and women in the general population, the higher prevalence of these risk factors found among female caregivers underscores that efforts to reduce these risks may be critical to their health.

Findings on caregivers' perception of their own health suggested that their health-related quality of life might be as good as or better than that of women in the general population. These findings were consistent with previous studies reporting that caregivers' self-rated physical and mental health were similar to or better than that of their counterparts in the general population (Chen, 2001; Seltzer et al., 2001). Researchers have speculated that female caregivers often have made a lifestyle change in response to the needs of their family members with intellectual and developmental disabilities and that the positive perception on their health would be one of the outcomes of such adaptation (Seltzer et al., 2001; Seltzer & Krauss, 1989). An act of caregiving could be another explanation of their favorable perception on their health. Family caregivers often felt rewarded psychologically by their family member with intellectual and developmental disabilities living at home (Heller, Miller, & Factor, 1997). These positive experiences associated with caregiving might lead them to have positive perception on their own health. By reporting more mentally unhealthy days than their age counterparts, however, the self-rated mental health status of older

caregivers in the present study diverged from the pattern. This finding could be associated with their declining physical health status, as evidenced in the present study, coupled with their concerns for the future of their family member with intellectual and developmental disabilities as they are entering their own later life stage (Heller & Caldwell, 2006).

Interpretation of the present findings is subject to the following four methodological limitations. First, the extent to which our findings represent the health status of female caregivers supporting an adult family member with intellectual and developmental disabilities in general is unknown. Although we relied on developmental disability service agencies to recruit caregivers, many aging family caregivers do not use such services (Heller & Caldwell, 2006). Health status of these family caregivers who do not access formal services remains unknown. Second, the use of convenience samples and a low response rate might have resulted in biased samples of female caregivers who are well connected to the developmental disability service agencies and more concerned about their own and their family member's health. Third, because all information provided by the study caregivers was self-reported, our findings, particularly findings based on reporting by older caregivers, were subject to reporting error, memory retention, and recall bias. Fourth, the presence of activity limitations reported by the study caregivers could be attributable to factors not addressed in the present study, such as, for example, the presence of other health conditions, duration and symptoms of the each condition, success of medical treatment, and availability of an assistive device. A relationship between the study caregivers' activity limitations and the presence of the specific chronic conditions investigated in the present study is, thus, unknown.

Nonetheless, there are several reasons to believe that present findings might underreport the true health status of aging caregivers supporting adults with intellectual and developmental disabilities at home and that health disparities between the caregivers and the general population could be even wider. First, because they reported a better income and educational status than their counterparts in the general population, the socioeconomic status (SES) of the study caregivers appears to have been better than that of typical families supporting a family member with intellectual and developmental disabilities, as previously reported (Fujiura, 1998). Because individuals with a lower SES are more likely to report higher prevalence of chronic conditions (Illinois Department of Public Health, 2007a, 2007b; Schoenborn et al., 2006) and a more unfavorable self-rating of their own health status (Bhandari, 2006; U.S. Centers for Disease Control and Prevention, 2008) than those with a higher SES, health status of caregivers who were not included in the present study could be poorer than our findings. Second, among family caregivers who accessed formal services, those with poor health might have already placed their family member with intellectual and developmental disabilities out of home (Magana & Smith, 2006). Thus, the present findings likely represent the health status of a relatively healthier subset of the group. Third, the true prevalence of activity limitations among study caregivers may be higher than the rate reported in the present study, because our operational definition of activity limitations did not include a limitation likely to be associated with sensory impairment, a common cause of age-related activity limitations (Schoenborn et al., 2006).

Findings from the present study draw attention to the impact of caregivers' health status on their capacity to support their family members with intellectual and developmental disabilities. The presence of chronic health conditions can certainly limit caregivers' capacity in performing daily chores and, in turn, affect their ability to provide care (Evercare & National Alliance for Caregiving, 2006). When their health begins to interfere with their ability to care, family caregivers often have few other family members to whom they can shift their caring responsibility (Heller et al., 2007). Despite their health problems, their caregiving responsibilities do not subside, and out-of-home residential placement is often difficult to obtain (Essex et al., 1997). Although the majority of individuals with intellectual and developmental disabilities are cared by families, only 4% of developmental disability service expenditures are allocated in supporting families (Parish, Pomeranz-Essley, & Braddock, 2003). Because there are already long waiting lists for publicly funded residential services across states (Alba et al., 2007), the health status of caregivers and its implications to their caregiving activities should be a concern for policy planners and service providers in the field of intellectual and developmental disabilities.

Chronic disease prevention and management programs targeting family caregivers should be in

place to promote their health. Even though these diseases and conditions are among the most prevalent and costly health problems, they are also among the most preventable and manageable. For example, periodic monitoring of blood pressure and blood cholesterol is effective in preventing and managing cardiovascular diseases (U.S. Department of Health and Human Services, 2000). As another example, individuals with a chronic disease can learn self-management skills by participating in health promotion workshops (Lorig & Fries, 2006; Lorig et al., 1999). Family support programs may want to seek collaboration with aging and public health organizations to include family caregivers in their ongoing health promotion programs. Because family caregivers tend to neglect their own health needs in light of the care demanded by their family members (Evercare & National Alliance for Caregiving, 2006), they may have difficulty in motivating and accessing these programs. In addition, since their family members with intellectual and developmental disabilities tend to have a higher need for health promotion programs (Rimmer, Braddock, & Fujiura, 1994; Rimmer & Yamaki, 2006; Yamaki, 2005), a health promotion intervention that targets both caregivers and care receivers with intellectual and developmental disabilities simultaneously, as a family unit, may be a program option.

Heller et al. (2007) pointed out that one of the factors contributing to the growing number of aging family caregivers who support adults with intellectual and developmental disabilities is the extended longevity of the U.S. population and the population of adults with intellectual and developmental disabilities. In fact, the number of family caregivers 80 years and older supporting their adult family member with intellectual and developmental disabilities is expected to increase over the next 30 years, and most of them are likely to keep their sons and daughters in their home as long as possible due to choice or the lack of satisfactory residential alternatives (Factor, 2005). A national health promotion agenda of "achieving a longer and healthier life" (U.S. Department of Health and Human Services, 2000, p. 10) appears to be a relevant and important health message to an increasing number of aging family caregivers who wish to continue providing support to their family members with intellectual and developmental disabilities at home.

References

Alba, K., Prouty, R. W., & Lakin, K. C. (2007). Services provided by state and nonstate agencies in 2006. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006* (pp. 71–78). Minneapolis: Research and Training Center on Community Living, Institute on Community Integration/ UCEDD, College of Education and Human Development, University of Minnesota.

Bhandari, S. (2006). Health status, health insurance, and health services utilization: 2001. In *Current population reports* (P70-106). Washington, DC: U.S. Census Bureau.

Braddock, D., Hemp, R., & Rizzolo, M. (2008). *The state of the states in developmental disabilities*. Boulder: Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.

Busija, L., Hollingsworth, B., Buchbinder, R., & Osborne, R. H. (2007). Role of age, sex, and obesity in the higher prevalence of arthritis among lower socioeconomic groups: A population-based survey. *Arthritis Care Research*, *57*, 553–561.

Chen, S. C., Ryan-Henry, S., Heller, T., & Chen, E. H. (2001). Health status of mothers of adults with intellectual disability. *Journal of Intellectual Disability Research*, *45*, 439–449.

Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1997). Residential transitions of adults with mental retardation: Predictors of waiting list use and placement. *American Journal on Mental Retardation*, *101*, 613–629.

Evercare & National Alliance for Caregiving. (2006). *Evercare study of caregivers in decline: Finding from a national survey*. Minnetonka, MN: Author.

Factor, A. (2005, December 8). *Aging with a developmental disability*. Paper presented at the 2005 White House Conference on Aging, Chicago, IL.

Fujiura, G. T. (1998). Demography of family households. *American Journal on Mental Retardation*, *103*, 225–235.

Gross, A. F., Fickert, S., & Gunther, K. P. (2005). Obesity and arthritis. *Orthopade*, *34*, 638–644.

Hahn, R. A., Heath, G. W., & Chang, M. H. (1998). Cardiovascular disease risk factors and preventive practices among adults, United

States, 1994. *Morbidity & Mortality Weekly Report, Surveillance Summaries*, *47*(SS-5), 35–69.

He, X. Z., & Baker, D. W. (2004). Body mass index, physical activity, and the risk of decline in overall health and physical functioning in late middle age. *American Journal of Public Health*, *94*, 1567–1573.

Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, *44*, 189–202.

Heller, T., Caldwell, J., & Factor, A. (2007). Aging family caregivers: policies and practices. *Mental Retardation and Developmental Disability Research Reviews*, *13*, 136–142.

Heller, T., Miller, A. B., & Factor, A. (1997). Adults with mental retardation as support to their parents: Effects on parental caregiving appraisal. *Mental Retardation*, *35*, 338–346.

Hootman, J., Bolen, J., Helmick, C., & Langmaid, G. (2006). Prevalence of doctor-diagnosed arthritis and arthritis-attributable activity limitation: United States, 2003-2005. *Morbidity and Mortality Weekly Report*, *55*, 1089–1092.

Idler, E. L., & Benyamini, Y. (1997). Self-rated health and mortality: a review of twenty-seven community studies. *Journal of Health and Social Behavior*, *38*, 21–37.

Illinois Department of Public Health. (n.d.). 2006 Illinois Behavioral Risk Factor Surveillance System Questionnaire. Available from http://app.idph.state.il.us/brfss/ques/2006BRFSSqnaire.pdf

Illinois Department of Public Health. (2007a). *Burden of heart disease and stroke in Illinois: Mortality, morbidity and risk factors*. Springfield: Illinois Department of Public Health.

Illinois Department of Public Health. (2007b). *Illinois Arthritis Data Report: The burden of arthritis in Illinois in 2005*. Springfield: Illinois Department of Public Health.

Lakin, K. C., Prouty, R., & Coucouvanis, K. (2004). U.S. residential support recipients with ID/DD now exceed 400,000 after 30% increase in past decade: Increases evident in all states. *Mental Retardation*, *42*, 490–493.

Lorig, K. R., & Fries, J. F. (2006). *The arthritis helpbook* (6th ed.). Cambridge, MA: Da Copo.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Jr., Bandura, A., Ritter, P., et al. (1999). (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Medical Care*, *37*, 5-14.

Magana, S., & Smith, M. J. (2006). Health outcomes of middle and older Latina and Black American mothers of children with developmental disabilities. *Mental Retardation*, *44*, 224–234.

McNeil, J. M., & Binett, J. (2001). Prevalence of disabilities and associated health conditions among adults, United States, 1999. *Morbidity & Mortality Weekly Report*, *50*, 120–125.

Minino, A. M., Heron, M. P., Murphy, S. L., & Kochanek, K. D. (2007). Deaths: Final data for 2004. *National Vital Statistics Report*, *55*(19).

Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of death in the United States, 2000. *Journal of the American Medical Association*, *291*, 1238–1245.

Moriarty, D. G., Kobau, R., Zack, M. M., & Zahran, H. S. (2005). Tracking healthy days—A window on the health of older adults. *Prevention of Chronic Disease*, *2*(3), A16.

National Institutes of Health. (1998). *Clinical guidelines on the identification, evaluation, and treatment of overweight and obesity: The Evidence Report* (Publication No. 98-4083). Bethesda, MD: National Institutes of Health.

Neyer, J. R., Greenlund, K. J., Denny, C. H., Keenan, N. L., Casper, M., Labarthe, D. R., & Croft, J. B. (2007). Prevalence of Stroke, United States, 2005. *Morbidity and Mortality Weekly Reports*, *56*, 469–474.

Parish, S. L., Pomeranz-Essley, A., & Braddock, D. (2003). Family support in the United States: Financing trends and emerging initiatives. *Mental Retardation*, *41*, 174–187.

Pope, S. K., Sowers, M. F., Welch, G. W., & Albrecht, G. (2001). Functional limitations in women at midlife: The role of health conditions, behavioral and environmental factors. *Women's Health Issues*, *11*, 494-502.

Rao, S. V., Donahue, M., Pi-Sunyer, F. X., & Fuster, V. (2001). Obesity as a risk factor in coronary artery disease. *American Heart Journal*, *142*, 1102–1107.

Rimmer, J. H., Braddock, D., & Fujiura, G. (1994). Cardiovascular risk factor levels in adults with mental retardation. *American Journal on Mental Retardation*, *98*, 510–518.

Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and*

Developmental Disabilities Research Reviews, *12*, 22–27.

Schoenborn, C. A., Vickerie, J. L., & Powell-Griner, E. (2006). *Health characteristics of adults 55 years of age and over: United States, 2000-2003* (Advance Data No. 370). Hyattsville, MD: National Center for Health Statistics.

Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, *106*, 265–286.

Seltzer, M. M., & Krauss, M. W. (1989). Aging parents with adult mentally retarded children: Family risk factors and sources of support. *American Journal on Mental Retardation*, *94*, 303–312.

SPSS. (2008). *SPSS 16.0 user's guide*. Chicago, IL: Author.

Steinmetz, E. (2006). Americans with disabilities: 2002. *Current Population Reports* (P70-107). Washington, DC: U.S. Census Bureau.

Symmons, D. P., Bankhead, C. R., Harrison, B. J., Brennan, P., Barrett, E. M., Scott, D. G., et al. (1997). (1997). Blood transfusion, smoking, and obesity as risk factors for the development of rheumatoid arthritis: Results from a primary care-based incident case-control study in Norfolk, England. *Arthritis Rheumatology*, *40*, 1955–1961.

U.S. Centers for Disease Control and Prevention. (2000). *Measuring healthy days*. Atlanta, GA: Author.

U.S. Centers for Disease Control and Prevention. (2006). *2005 behavioral risk factor surveillance system summary data quality report*. Atlanta, GA: Author.

U.S. Centers for Disease Control and Prevention. (2007). *2006 behavioral risk factor surveillance system summary data quality report*. Atlanta, GA: Author.

U.S. Centers for Disease Control and Prevention. (2008). Health status among persons aged >25 years, by education level—National Health Interview Survey, United States, 2007. *Morbidity and Mortality Weekly Reports*, *57*, 1282.

U.S. Centers for Disease Control and Prevention and the Merck Company Foundation. (2007). *The state of aging and health in America 2007*. Whitehouse Station, NJ: Merck Company Foundation.

U.S. Department of Health and Human Services. (2000). *Healthy People 2010* (2nd ed.). Washington: DC: U.S. Government Printing Office.

Voigt, L. F., Koepsell, T. D., Nelson, J. L., Dugowson, C. E., & Daling, J. R. (1994). Smoking, obesity, alcohol consumption, and the risk of rheumatoid arthritis. *Epidemiology*, *5*, 525–532.

Wan, H., Sengupta, M., Velkoff, V. A., & DeBarros, K. A. (2005). *65+ in the United States: 2005* (No. P23-209). Washington, DC: U.S. Census Bureau.

Willcox, B. J., He, Q., Chen, R., Yano, K., Masaki, K. H., Grove, J. S., et al. (2006). (2006). Midlife risk factors and healthy survival in men. *Journal of the American Medical Association*, *296*, 2343–2350.

Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Mental Retardation*, *43*, 1–10.

Received 6/9/08, first decision 11/6/08, accepted 2/22/09.

Editor-in-Charge: Dianne Ferguson

Preparation of this manuscript was supported in part by Grant H133B031134 from the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, through the U.S. Department of Education, National Institute on Disability and Rehabilitation Research, and by Grant U59/DD000271-01 from the National Center on Birth Defects and Developmental Disabilities, U.S. Centers for Disease Control and Prevention. We thank participating family members for their contribution; community agencies for their assistance in recruitment; Center for Health Statistics, Illinois Department of Public Health for preparation of the ILBRFSS data; and Violet Rutkowski-Kmitta, Department of Disability and Human Development, University of Illinois at Chicago, for her editorial assistance on the earlier draft of this article.

Authors:
Kiyoshi Yamaki, PhD (E-mail: kiyoshiy@uic.edu), Research Assistant Professor, Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Rd., Chicago, IL 60608. **Kelly Hsieh, PhD,** Research Assistant Professor, Department of Disability and Human Development, University of Illinois at Chicago. **Tamar Heller, PhD,** Head, Department of Disability and Human Development, University of Illinois at Chicago.

