

The effect of caregiving on preventive care for people with disabilities

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Abstract

Background: Overall, disparities exist in preventive health care services for people with disabilities compared with other Americans. Little is known about the effects of caregiving on preventive services use. This study examines caregiver characteristics and influence on the use of preventive services for people with disabilities.

Methods: The 2000-2001 Behavioral Risk Factor Surveillance System of 25 states included 5486 self-reported respondents with disabilities who were surveyed for preventive care use. Multivariate logistic regression adjusted for demographic and functional status of these respondents.

Results: Among the subset of the respondents with caregivers, those with paid caregivers were significantly more likely to receive an influenza vaccination (adjusted odds ratio [OR], 1.49; 95% confidence interval [CI], 1.08-1.93). Among those with a caregiver, those with a spouse/partner caregiver were also significantly more likely to receive an influenza vaccination (adjusted OR, 1.33; 95% CI, 1.05-1.69) or PPV (adjusted OR, 1.59; 95% CI, 1.41-2.38) compared with those with “other” as their caregiver. Women with disabilities with a spouse/partner caregiver were significantly more likely to have ever had a Pap test (adjusted OR, 3.13; 95% CI, 1.41-6.67) or mammogram (adjusted OR, 1.85; 95% CI, 1.23-2.70) than those with “other” relative caregiver. Those respondents who reported “rarely adequate” caregiver satisfaction were significantly more likely to have self-reported ever having colon cancer screening compared with those with a usually adequate caregiver. The majority of results did not show consistent evidence of caregiver benefit, and a fair number of the associations were not statistically significant.

Conclusion: The findings suggest that having a caregiver is not consistently associated with self-report of ever using preventive services. However, this study suggests that caregiver characteristics are associated with preventive care for people with disabilities. For influenza vaccination, our results showed that paid caregivers were more likely to provide preventive care to individuals with disability than a spouse or partner, which were more likely to provide more preventive care than those with “other” caregiver. Given the number of comparisons, we consider these results to be preliminary and require more confirmation in other population data. © 2008 Elsevier Inc. All rights reserved.

Keywords: Access to care; Caregiving; Disability; Preventive care; Screening

Access to health care for people with disabilities is both necessary and complex. An estimated 54 million Americans, nearly one of every five, currently live with some form of disability [1]. Disabilities are acquired at any point throughout one's life, but especially as one ages. With an aging population of “baby boomers,” the numbers of people with disabilities in the United States and countries with similar social, economic, and age structures are expected to climb dramatically. Adding to the problem are the growing numbers of disabling chronic conditions like obesity, asthma, and diabetes in younger populations [2]. Also, people with

disabilities are experiencing more problems with safety and quality of health care than are people without disabilities [2]. Despite potential vulnerability to disparate and potentially harmful health care experiences, most people with disabilities can expect to live a normal life span [3]. Therefore, people with disabilities demonstrate a need for regular, routine preventive health care, such as cancer screening and adult immunizations. Routine preventive health care is an important health issue for comprehensive medical care [4].

One environmental component who has received some national exposure is the caregiver [5]. Caregivers of people with disabilities may influence their behavior to seek preventive health care services. For example, caregivers may assist with personal and/or routine care needs, coordinate and manage the health care for their care recipients, and ensure that treatments prescribed by providers are not in

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conflict. The manner in which caregivers influence the care recipient to use preventive services is not quite understood.

Environmental factors can both facilitate and impede access to preventive care for people with disabilities. Preventive care for people with disabilities becomes compromised due to a variety of environmental factors such as poorly trained staff and physicians, inadequate medical equipment (e.g., adjustable mammography tables), constrained and limited physician-patient visits due, in part, to reimbursement-based protocols, and inaccessible medical care sites [4,6–10]. Access to adequate medical equipment or knowledgeable providers who are aware of the needs for people with disabilities can mean the difference in having preventive care. Because the vast majority of patient provider time is consumed with underlying primary acute and chronic medical needs of the person with the disability, preventive care often gets missed [6,7]. People with disabilities typically receive less screening [4,11] and may be susceptible to iatrogenic illnesses or secondary conditions due to inappropriate health services they may receive [8,9].

Based on the reported underutilization of screening in people with disabilities [4,11] and the potential impact of caregivers to serve as facilitators and coordinators of care for people with disabilities [5,12], we pose two main questions. First, does having a caregiver increase the use of health services by people with disabilities? Then, among those people with disabilities with a caregiver, what caregiver characteristics impact screening?

Methods

Population and setting

The present study analyzed data from the 2000 and 2001 national Behavioral Risk Factor Surveillance System (BRFSS) [13]. The BRFSS is a state-based, nationwide telephone (random-digit-dialed) health survey of the noninstitutionalized U.S. population aged 18 years and older [14,15]. This survey provides annual population-based cross-sectional data that provide self-reported risks and health conditions. The BRFSS is composed of national “core” questions and modules and state-added modules on special topics of interest to each state.

In 2000 and 2001, a Quality of Life and Caregiving module was added to the BRFSS in 25 states. A total of 107,135 adults were surveyed in these states, providing a diverse, nationally representative population. In 2000, 60,395 respondents were from a total of 19 states, while in 2001, 46,740 respondents were from a total of 13 states. Seven states included the module in both 2000 and 2001.

We limited our sample to respondents with a disability, defined by self-reported activity limitations ($N = 18,370$, or 17.1%). Of these respondents, 30.6% ($n = 5533$) reported they needed assistance with instrumental activities of daily living (IADLs) and/or activities of daily living (ADLs). Of the respondents reporting needing assistance,

95.7% ($n = 5297$) reported having a caregiver, 3.4% ($n = 189$) reported not having a caregiver, and 0.3% ($n = 47$) either did not know or refused to answer who helps with either their ADL or IADL care and were not included in the working sample. Therefore, the 5486 respondents with care assistance needs form the study sample for our analysis of the effects of caregiving on the use of health services. Among the 5297 respondents who reported having a caregiver, we also analyzed the characteristics of caregiving that may impact the use of health services.

Variables

The 2000 and 2001 BRFSS included several standard sections asking about preventive services that formed our outcomes of interest. We used eight preventive health services in our analysis: influenza and pneumococcal vaccination, colon cancer screening via sigmoidoscopy or colonoscopy, breast cancer screening via mammography and clinical breast exam, cervical cancer screening (Pap test), and prostate cancer screening via digital rectal exam (DRE) and prostate-specific antigen (PSA) testing. All BRFSS questions were classified as the respondent having “ever” had the screening test/exam. The working sample for each outcome was restricted to those with relevant age and gender based on recommendations by the 2006 American Cancer Society (ACS) guidelines for cancer screening [16] and the Centers for Disease Control and Prevention (CDC) adult immunization schedule [17] for influenza and pneumococcal vaccination. Influenza guidelines from the CDC recommend annual influenza vaccinations beginning at age 50; therefore, our influenza analysis was restricted to persons aged 50 or older. Also, the CDC recommends annual pneumococcal vaccinations starting at age 65, and only persons aged 65 and older were analyzed for that outcome. Colon cancer screening includes colonoscopy, sigmoidoscopy, and/or fecal occult blood test, and the ACS guidelines recommend initiating screening at age 50, and for our analysis persons aged 50 and older were included. For breast cancer screening, the ACS guidelines recommend women start clinical breast exams annually after 20 years of age and begin mammography regularly at age 40. Based on ACS breast cancer guidelines for clinical breast exam, our sample was restricted to women at least 21 years or older. Similarly, our sample for mammography was limited to women at least 40 years or older. ACS guidelines recommend beginning cervical screening no later than 21 years of age. Pap tests become optional after a woman reaches age 70 and has had 3 normal Pap tests in the last 10 years or if a woman has had a complete hysterectomy. Based on the data available in the BRFSS, we analyzed Pap test compliance for women between ages 21 and 69. The ACS recommends that all men start prostate cancer screening at age 50, which consists of the DRE and PSA testing; therefore, we included only men of these ages in our analysis of both outcomes.

From the 2000 and 2001 BRFSS Caregiving and Quality of Life Module, people with disabilities were asked two questions about whether they needed help with ADL (personal care) or IADL (routine care) needs. We excluded persons who reported they did not need assistance. For people with disabilities who responded “yes” to one of the care need questions, they were asked who provides assistance with their ADL and/or IADL care needs. If a person with a disability answered having someone assist with either ADL or IADL care when such a need exists, they were defined as having a caregiver. People with disabilities were classified as not having a caregiver if they reported there was no one to assist them with ADLs or IADLs. Our primary exposure of interest for this study, caregiver status, was dichotomized into people with disabilities with and people with disabilities without caregivers.

For the second phase of our analysis assessing caregiver characteristics, only people with disabilities with caregivers were included. Because there were two separate questions that we asked about who helps with either ADL or IADL care needs, it was possible to have two different caregivers. Approximately 80% of respondents with both ADL and IADL needs have the same caregiver for both. Because there was discordance (13.4%) among respondents reporting different ADL and IADL caregivers, we selected a single primary caregiver. The relationship between the caregiver and care recipient predicts responsibility of care, so we chose the primary caregiver based on closeness of relationship instead of the type of care provided (i.e., not selecting ADL caregiver over the caregiver providing IADL care).

Additionally, two questions asked people with disabilities whether the assistance received met care needs (care satisfaction), for ADL or IADL assistance. A single satisfaction with care variable was constructed by selecting ADL adequacy of care to supersede IADL adequacy of care when responses were discordant for people with disabilities having both adequacy needs. The primary satisfaction with care variable included 3 levels (usual, somewhat, and rarely adequate).

Because type of care provided (ADLs or IADLs) is associated with caregiver burden, we created a caregiving need variable. ADL care reflects assistance with personal care needs like bathing, eating, and dressing, so we compared respondents with ADL care needs with or without IADL care needs with those with only the IADL needs.

Covariates investigated as possible confounding variables included age, gender, race/ethnicity (white non-Hispanic, African American non-Hispanic, Hispanic, and other non-Hispanic groups), current employment status (employed or not employed), education (less than high school graduate versus high school graduate/college), marital status (married, separated/divorced, widowed, never been married), body mass index (BMI normal, low, overweight, and obese), current smoking status, and annual income (<\$10,000, \$10,000–\$14,999, \$15,000–\$24,999, \geq \$25,000, and those with income missing included as a separate dummy category).

Descriptive analyses compared characteristics of the respondent group based on needing assistance and having a caregiver. Multiple logistic regression models were constructed for each of the 8 preventive services using odds ratios (OR) and 95% confidence intervals (95% CI) to compare people with and without a caregiver. Models were constructed by forced entry of caregiver status (yes or no) into the models and including additional variables as confounders if they had a meaningful effect on the OR for the caregiver (\geq 10% change in adjusted OR) or if the variable itself was a significant predictor of the preventive outcome of interest. The models for caregiver relationship and adequacy were constructed using the same method. The analyses were performed with SPSS [18]. The University of Florida Institutional Review Board (IRB) approved the study protocol.

Results

The differences between people with disabilities with a caregiver and people with disabilities without a caregiver are depicted in [Table 1](#). Those respondents without a caregiver ($n = 189$) were more likely to be older, unmarried/not coupled, Hispanic, underweight, and a smoker and to have health insurance, compared with people with disabilities with a caregiver. The use of preventive services showed some variation. For example, men without a caregiver seem to use more prostate screening services than were those with a caregiver. However, women with caregivers were more likely to receive breast cancer screening.

The final models are provided in [Table 2](#). While the majority of our associations were found to be not statistically significant, there were some main findings. In general, people who required more caregiving need (needing ADLs) received less preventive care service than other people with disability. Among the subset of respondents with caregivers, those with paid caregivers were significantly more likely to receive an influenza vaccination (adjusted OR, 1.49; 95% CI, 1.08–1.93). In addition to an influenza vaccination, having paid caregivers was associated with higher point estimates for prevalence of vaccination (influenza: adjusted OR, 1.49; pneumonia: adjusted OR, 1.19), colon cancer screening (adjusted OR, 1.08), and PSAT (adjusted OR, 1.18) compared with spouse/partner caregivers. Additionally, among those people with disabilities with a caregiver, those with a spouse/partner caregiver were also significantly more likely to receive an influenza vaccination compared with those with “other” as their caregiver (adjusted OR, 1.33; 95% CI, 1.05–1.69). Those with a spouse/partner caregiver were also significantly more likely to receive PPV (adjusted OR, 1.59; 95% CI, 1.41–2.38) than those with “other” as their caregiver. People with disabilities who have a spouse/partner caregiver were also significantly more likely to have ever had a Pap test (adjusted OR, 3.13; 95% CI, 1.41–6.67) or mammogram (adjusted OR, 1.85; 95% CI, 1.23–2.70) than were those with those with “other” as their caregiver. Those respondents

Table 1
Sample Characteristics of Persons with Self-reported Activity Limitation and Assistance Needs & the Presence of a Caregiver from the 2000-2001 BRFSS

Variables		Caregiver Status		
		All N=5,486	No N=189	Yes N=5,297
Age: (N=5,445)	Mean age (\pm sd)	54.9 (17.0)	55.5 (18.6)	54.9 (16.9)
Age groups:	18-20	0.8%	0.2%	0.8%
	21-39	18.9%	24.1%	18.8%
	40-49	20.6%	9.2%	21.0%
	50-64	30.5%	32.7%	30.4%
	\geq 65	29.2%	33.8%	29.0%
	Women	68.3%	62.3%	68.5%
	Married or coupled	51.9%	33.1%	52.6%
	Never been married	10.3%	22.2%	9.9%
	High school graduate or higher	46.5%	51.7%	46.5%
	White, non-Hispanic	74.3%	64.6%	74.6%
Hispanic	7.9%	21.1%	7.4%	
Black, non-Hispanic	12.5%	11.8%	12.5%	
Others	5.3%	2.5%	5.4%	
Mean body mass index (\pm sd)	Mean body mass index (\pm sd)	28.3 (7.3)	27.6 (7.9)	28.4 (7.2)
	Underweight (<18.5)	3.8%	9.7%	3.6%
	Normal (18.5-24.9)	31.2%	34.8%	31.1%
	Overweight (25.0-29.9)	31.4%	21.5%	31.8%
	Obese (\geq 30.0)	33.6%	34.0%	33.5%
High cholesterol [◆] : (n=2,296)		45.7%	51.6%	45.6%
Hypertension [⊥] : (n=2,558)		47.2%	56.9%	46.9%
Current smoker: (n=5,457)		27.7%	41.9%	27.2%
Caregiving need:	ADL +/- IADL	31.4%	33.7%	31.3%
	IADL ONLY	68.6%	66.3%	68.7%
Income (n=5486):	<\$10,000	13.5%	22.4%	13.1%
	\$10,000-14,999	10.9%	17.7%	10.7%
	\$15,000-24,999	22.1%	26.0%	21.9%
	\geq \$25,000	37.2%	21.4%	37.8%
	No information (n=970)	16.3%	12.6%	16.4%
Employed (n=5,477)		22.7%	32.6%	22.3%
Have health insurance: (n=5,472)		89.8%	95.8%	89.6%
Caregiver adequacy: (n=5,223)	Usually adequate			76.7%
	Sometimes adequate			17.6%
	Rarely adequate			5.7%
	Spouse/partner			41.6%
Caregiver relationship: (n= 5297)	Parent/child/in-law			25.2%
	Paid			9.1%
	Others			24.1%
Preventive services use:	Ever have flu vaccine (ages 50+)(n=2517)	57.3%	57.6%	57.3%
	Ever have pneumococcal vaccine (ages 65+, n=1276)	69.4%	60.9%	54.0%
	Ever have colonoscopy/sigmoidoscopy (ages 50+, n=1432) [†]	54.6%	69.7%	69.7%
Women:	Ever have clinical breast exam (ages 21+, n=2923) [‡]	89.7%	84.1%	89.9%
	Ever have Pap test (ages 21-69, n=2147) [‡]	97.5%	97.6%	97.6%
	Had Pap test within a year (n=2058) [‡]	69.1%	72.5%	69.0%
	Ever mammogram (ages 40+, n=2439) [‡]	90.8%	84.1%	89.9%
Men:	Ever prostate-specific antigen test (ages 50+, n=330) [‡]	72.4%	86.0%	71.9%
	Ever digital rectal exam (ages 50+, n=351) [‡]	87.0%	89.1%	86.9%

* Weighted data; ADL=Activities of Daily Living; IADL=Instrumental Activities of Daily Living; sd = standard deviation.

◆ Cholesterol awareness was a module in 2000 (IA, OK, TN, VA) and core in 2001.

⊥ Hypertension awareness was a module in 2000 (IA, TN, VA) and core in 2001.

‡ Women's health was core in 2000 and a module in 2001 (AZ, GA, NJ, TN).

‡ Prostate cancer screening was core in 2001, and not asked in 2000.

† Colon cancer screening was a module in 2000 (OH and MA) and core in 2001.

Table 2

Adjusted Odds Ratios (95% Confidence Intervals) for Preventive Services according to Caregiver Presence and Relationship for People with Disabilities

Explanatory Variables	Flu Vaccine [†]	PPV [†]	Colon Screening [‡]	Clinical Breast [‡]
	Ages 50+ N=2486	Ages 65+ N=1185	Ages 50+ N=1303	Ages 21+ N=2645
Does having a caregiver increase preventive care?*				
Caregiver: Yes v. no	0.83 (0.54, 1.29)	1.65 (0.91, 3.02)	0.94 (0.50, 1.78)	1.19 (0.62, 2.26)
Caregiving need: ADL ± IADL v. IADL only	0.87 (0.72, 1.05)	0.86 (0.65, 1.15)	0.87 (0.68, 1.12)	0.73 (0.56, 0.97)
Age: Age per year	1.05 (1.04, 1.06)		1.02 (1.00, 1.03)	
Age groups: 21-39				1.00
40-49				1.23 (0.74, 2.05)
50-64	1.00			0.88 (0.56, 1.39)
≥65	2.09 (1.60, 2.74)			0.43 (0.27, 0.68)
Among those with caregivers, what characteristics increase preventive care? [‡]				
Caregiver relationship: Parent/son/daughter/in-law v. spouse/partner	0.82 (0.65, 1.03)	0.74 (0.50, 1.09)	0.81 (0.60, 1.10)	0.75 (0.47, 1.22)
Paid v. spouse/partner	1.49 (1.08, 1.93)	1.19 (0.78, 1.83)	1.08 (0.74, 1.57)	0.91 (0.52, 1.57)
Others v. spouse/partner	0.75 (0.59, 0.95)	0.63 (0.42, 0.94)	1.08 (0.78, 1.48)	0.95 (0.57, 1.58)
Caregiver satisfaction: Somewhat v. usually adequate	0.94 (0.75, 1.20)	0.91 (0.63, 1.34)	1.21 (0.89, 1.65)	0.95 (0.66, 1.36)
Rarely v. usually adequate	0.80 (0.53, 1.23)	1.44 (0.72, 2.89)	1.90 (1.07, 3.35)	0.78 (0.45, 1.35)
Assistance need: ADL ± IADL v. IADL only	0.80 (0.66, 0.97)	0.85 (0.64, 1.14)	0.87 (0.68, 1.12)	0.71 (0.53, 0.94)
Explanatory Variables	Mammogram [‡]	Pap Test [‡]	Digital Rectal [‡]	PSA [‡]
	Ages 40+ N=2420	Ages 21-69 N=1931	Ages 50+ N=335	Ages 50+ N=321
Does having a caregiver increase preventive care?*				
Caregiver: Yes v. no	1.11 (0.59, 2.08)	1.62 (0.47, 5.60)	2.22 (0.54, 9.09)	0.96 (0.21, 4.35)
Caregiving need: ADL ± IADL v. IADL only	0.78 (0.59, 1.03)	0.49 (0.28, 0.85)	1.26 (0.63, 2.50)	0.65 (0.38, 1.12)
Age groups: 21-39	1.00			
40-49	0.96 (0.42, 2.20)			
50-64	2.45 (1.73, 3.48)	0.64 (0.30, 1.37)	1.00	1.00
≥65	1.68 (1.16, 2.45)	0.40 (0.15, 1.08)	1.52 (0.72, 3.24)	1.32 (0.70, 2.49)
Among those with caregivers, what characteristics increase preventive care? [‡]				
Caregiver relationship: Parent/son/daughter/in-law v. spouse/partner	0.44 (0.31, 0.63)	0.47 (0.21, 1.05)	0.69 (0.22, 2.19)	0.89 (0.33, 2.37)
Paid v. spouse/partner	0.79 (0.49, 1.26)	0.32 (0.12, 0.82)	0.88 (0.21, 3.73)	1.18 (0.37, 3.76)
Others v. spouse/partner	0.54 (0.37, 0.81)	0.32 (0.15, 0.71)	0.47 (0.15, 1.48)	0.57 (0.22, 1.48)
Caregiver satisfaction: Somewhat v. usually adequate	1.32 (0.90, 1.92)	1.07 (0.51, 2.28)	1.13 (0.39, 3.26)	1.82 (0.72, 4.61)
Rarely v. usually adequate	0.87 (0.50, 1.50)	0.51 (0.20, 1.26)	2.17 (0.15, 31.54)	0.33 (0.06, 1.87)
Assistance need: ADL ± IADL v. IADL only	0.77 (0.57, 1.02)	0.43 (0.24, 0.75)	1.18 (0.57, 2.46)	0.54 (0.31, 0.96)

Each odds ratio was adjusted for other additional explanatory variables in the models. Flu vaccine adjusted by gender, race, and income; PPV adjusted by gender, race, and body mass index; Colon screening adjusted by gender, race, income, body mass index, smoking status, and marital status; Clinical Breast Exam adjusted by race and marital status; Mammogram adjusted by race, marital status, and income; Pap test was adjusted by race, marital status, and body mass index; Digital Rectal Exam adjusted by race, marital status, and body mass index; PSA adjusted by race, education, income, smoking, and marital status.

PPV=pneumococcal polysaccharide vaccine, colon screening=colonoscopy or sigmoidoscopy, IADL=Instrumental Activities of Daily Living; ADL=Activities of Daily Living, BRFSS=Behavioral Risk Factor Surveillance System.

* Data are unweighted from 2000 & 2001 BRFSS.

† Ages for Flu and PPV recommendations based on the Centers for Disease Control & Prevention.

‡ Ages based on recommendations from the American Cancer Society.

‡ Caregiver characteristics model adjustment for: Flu adjusted by age and race; Pneumococcal adjusted by age, gender, race/ethnicity, and income; Colonoscopy adjusted by age group, gender, race/ethnicity, and income; Clinical breast exam, adjusted by age group, race/ethnicity, education, body mass index, and marital status; Mammography, adjusted by age group and race; Pap test, adjusted by age group, race/ethnicity, marital status, and body mass index; DRE adjusted by age group, race/ethnicity, body mass index, and marital status; Prostate-specific antigen test, adjusted by age group, race/ethnicity, marital status, and body mass index.

who have “rarely adequate” caregiver satisfaction were significantly more likely to have self-reported ever having colon cancer screening compared with those with “usually adequate” caregiver satisfaction.

Discussion

The results did not show consistent evidence of caregiver benefit for all preventive services, and most of the

associations were not statistically significant. The caregiver role in influenza vaccination, for example, suggests a protective effect for people with disabilities who have paid caregivers, followed by spousal/partner caregivers, followed by “other” caregivers. The presence of a caregiver demonstrated weak positive influence on preventive care services of some types. Additionally, the caregiver relationship, nature of care, and satisfaction with care received showed inconsistent influences on preventive service use.

The trend that people with higher levels of disability (ADLs) had less preventive care despite a caregiver is troubling. In another report of disability and use of preventive services, Iezzoni and her colleagues showed that reduced use of these services was present only for those with the highest levels of impairment, but that study did not include the possible impact of environmental components such as caregiver [4]. Health promotion for people with disabilities is highlighted as a critical objective outlined in *Healthy People 2010* (Disability, Chapter 6) [19]. Understanding more detailed caregiver effects will help pinpoint public health interventions and clinical opportunities for improving care for people with disabilities. Despite our mixed findings, caregiving still remains an important emerging public health issue. More research is needed to further understand the conceptualization of caregivers and care recipients [20]. Caregivers have been conceptualized within the environmental domain of the *International Classification of Functioning, Disability and Health* [21]. Theoretically, they provide a facilitating role—our results suggest that this is not as strong as theory would indicate.

Family caregivers provide an estimated \$257 billion per year in uncompensated, informal services [22]. Economic burdens associated with caregiving can lead families to make choices about financing medical care priorities, like choosing between preventive care versus assistive technology. About 61% of the estimated 2.5 million Americans who need assistive technology cannot afford it [23]. Perhaps, care not related to the primary disability, such as preventive health care, is seen as unimportant. In addition, two of five primary care physicians do not believe that they have enough time with patients, and people with disabilities often require more time from their physicians [10,24]. Because physicians are not spending enough time with patients with disabilities, preventive care can suffer [4].

Our findings are subject to some limitations. First, the BRFSS sampling frame excludes institutionalized adults, eliminating individuals with severe disabilities who may report different preventive care services. The BRFSS telephone survey methodology excludes people with hearing deficits as well as those people with significant disabilities who are unable to answer the telephone [25]. In addition, BRFSS response has continued to decline in tandem with secular trends of research (see http://www.cdc.gov/brfss/technical_infodata/quality.htm). Also, “disability” status was determined by self-reported activity limitation, which may include a number of people with temporary limitations or limitations not linked to a disability identity. Finally, the BRFSS is cross-sectional; while it is unlikely that having a caregiver has a reversed temporal trend to use of preventive services, cross-sectional surveys have some limitations for causal inference. While the outcomes ask about “ever” using a preventive service, the respondent may not have used the preventive service as described by the ACS/CDC guidelines, possibly diluting the effect because of misclassification of “appropriately” timed preventive services.

The BRFSS also has a number of strengths, including the population-based sampling methodology, which increases the generalizability of the findings. An additional strength is that respondents from 25 states were included, representing all regions of the United States. The substantial sample size of the dataset provides the ability to examine caregiving within a broadly defined disability population.

Conclusion

These findings suggest that having a caregiver is not consistently associated with self-report of ever using preventive services. With some services, such as influenza vaccination, we see certain patterns emerging, whereas other preventive care remains inconsistent. Given the number of comparisons, we consider these results to be preliminary and require confirmation from other population data sources. Because caregiver influence on preventive care for people with disabilities yielded insignificant findings, more research is needed for consistency. Nevertheless, at present, these findings contribute to a better understanding of the effect of caregiving on preventive care, which can have significant public health implications for people with disabilities through the use of a large, representative national sample and reliance on the widely recognized BRFSS survey.

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