



## Original Article

# Caregiving in the shadows: National analysis of health outcomes and intensity and duration of care among those who care for people with mental illness and for people with developmental disabilities

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## ABSTRACT

**Background:** The health impacts of caring for people with mental illness (MI) and developmental disabilities (DD) are not well understood.

**Objective:** The present study explored whether health outcomes differed between MI and DD caregivers, and if intensity and duration of care moderated health outcomes.

**Methods:** Nationally representative 2016 Behavioral Risk Factor Surveillance System survey data were used to explore how caring for people with MI ( $n = 1071$ ) and DD ( $n = 888$ ) impacted general health status and physical and mental health days, and whether intensity and duration of care moderated health outcomes. Logistic regression models and cumulative logistic regression models were used to model health outcomes.

**Results:** Caregivers had worse health ( $p = 0.0001$ ) and more poor physical ( $p < 0.0001$ ) and mental health days ( $p < 0.0001$ ) than non-caregivers. Relative to DD caregivers, MI caregivers had worse health status ( $p = 0.02$ ) and more poor physical ( $p = 0.02$ ) and mental ( $p = 0.003$ ) health days. As intensity of care increased, MI caregivers had more poor physical health days ( $p = 0.04$ ) than DD caregivers and as duration of care increased, MI caregivers had worse health status ( $p = 0.03$ ) than DD caregivers.

**Conclusions:** Although the care provided to adults with DD was more intense and for a longer duration, MI caregivers had poorer health outcomes and were more impacted by intensity and duration of care. Implications for supporting MI and DD caregivers are discussed.

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## Introduction

An estimated 39.8 million Americans, or 16.6% of the U.S. population report serving in a caregiving role to an adult.<sup>1</sup> This caregiving population is estimated to grow due, in part, to population aging.<sup>1</sup> While some aspects of caregiving have been shown to positively influence caregiver health,<sup>2</sup> other research has shown that caregiving negatively influences caregivers' perceived burden,<sup>3</sup> physical and mental health,<sup>4–9</sup> financial security,<sup>10,11</sup> and overall quality of life.<sup>12</sup> Much of the caregiving research has focused on the health of caregivers of adults with certain conditions such as cancer

and dementia. Caring for adults with developmental disabilities (DD) and for adults with mental illness (MI) has been described as intense, prolonged,<sup>13,14</sup> and lacking services to support the caregiving role.<sup>13–16</sup> Despite these risk factors, the health of these caregivers has received little research attention.

The impact of caregiving on the caregiver's health and wellbeing depends on many factors, including intensity (hours of care provided per week) and duration (length of time providing care).<sup>17–19</sup> As intensity and duration increase, caregiver health worsens.<sup>17–19</sup> A report on caregiving in the U.S. (2015) found that, on average, caregivers provided care for nearly 25 hours per week and for an average duration of four years. Nearly one fourth of caregivers provided care for five years or longer. This same report found that over 50% of caregivers were employed full-time in addition to their caregiving role.<sup>1</sup> The authors concluded that the intensity and duration of caregiving contributed to high emotional stress, poor

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physical and mental health, and financial insecurity among caregivers.<sup>1</sup> Because developmental disabilities are lifelong conditions that first occur during the developmental period and mental illness often manifests during adolescence or early adulthood,<sup>20</sup> the caregiving needs for these two populations can be intense and prolonged.

In a national study of unpaid caregiving, approximately 33% of caregivers reported having been asked by health care providers about what was needed to provide quality care to their care recipient, and that 16% of health care providers asked caregivers what resources they need to care for their own health and quality of life. Providing more intense care for a longer time was negatively associated with these information needs: as care intensity per week increased, caregivers reported fewer conversations with health care providers regarding both the care of their recipient and self-care.<sup>1</sup> Caregivers reported needing more information on how to be a caregiver (84%), how to keep care recipients safe and in the home (42%), and how to manage stress (42%).<sup>1</sup> Managing stress was mentioned more often among caregivers who provided more intense hours of care (51%).<sup>1</sup> This study builds upon previous research by exploring the degree to which caregiving affects health and how intensity and duration of care provided by MI and DD caregivers moderated health outcomes.

#### *Caring for people with developmental disabilities and mental illness*

Anderson and colleagues (2017) examined caregiving in a national sample of over three thousand individuals who provided care for people with intellectual and developmental disabilities (IDD). In this study, a third of IDD caregivers had provided care for more than 25 years, which is more than six times longer than the national average duration of four years.<sup>1</sup> On average, IDD caregivers provided 57.4 hours per week of caregiving, more than twice the national average 24.4 hours per week.<sup>1</sup> Approximately 90% of IDD caregivers reported being stressed, with 45% of them being very or extremely stressed.<sup>13</sup> Several negative economic consequences related to increased intensity and duration of caregiving—exceeding caregiver national averages—were observed such as needing to quit work or reducing work hours at jobs outside of their caregiving role and declining job-related opportunities, such as promotions, to fulfill caregiving responsibilities.<sup>13</sup> Taken together, IDD caregivers appear to work more hours and for substantially longer duration than the national caregiving average. Furthermore, IDD caregivers face high stress levels and negative economic consequences related to the caregiving experience.

Another national report of over one thousand caregivers of people with MI was released by the National Alliance for Caregiving (2016). On average, MI caregivers provided approximately 32 hours per week of care for nine years, which is longer and more intense than the national caregiving average.<sup>1</sup> According to this study, approximately 62% of participants caring for adults with MI reported that caregiving had negatively impacted their own health.<sup>14</sup> Almost half (48%) of MI caregivers reported difficulty talking with others about their loved one's mental health condition(s), highlighting the stigma around mental health conditions, poor social support, and potential gaps in available resources to support MI caregivers.<sup>14</sup> Over half (63%) of MI caregivers reported feeling isolated and that they had little or no time to focus on themselves as a consequence of providing care. Nearly 75% of MI caregivers reported high emotional stress and were less likely (33% versus 48%) to report very good or excellent health compared to caregivers nationally.<sup>1</sup> The stigma and isolation associated with providing care for someone with MI may have contributed to high levels of stress and poor health outcomes in this population.<sup>14</sup> Indeed, nearly 50% of MI caregivers reported difficulties talking to others about their

loved one's MI, which was linked to feeling isolated, difficulties accessing resources to promote care, and poor support to better manage their role as a caregiver.<sup>14</sup> Taken together, MI caregivers provided more intense care for a longer duration compared to national averages. They reported that providing care adversely impacted their health, was associated with high stress, and to feeling socially isolated due to the perceived stigma of the mental health condition of the person for whom they provided care.

#### *The present study*

The present study had several aims. First, we explored differences in health outcomes between caregivers and non-caregivers. Given the literature on the negative effects of caregiving on health outcomes,<sup>4–9</sup> we predicted that caregivers would be more likely to report fair/poor health status and to report more poor physical and mental health days than non-caregivers. Next, we investigated whether health outcomes differed between MI and DD caregivers, and whether intensity and duration of care moderated these health outcomes. Our goal was to extend previous research on the health of MI and DD caregivers<sup>13,14</sup> and to explore the association between intensity and duration of care and the physical and mental health of these caregivers.

## **Methods**

#### *Data source*

Data were analyzed from the 2016 Behavioral Risk Factor Surveillance System (BRFSS).<sup>21</sup> BRFSS was established by the Center for Disease Control and Prevention to collect information on health-related risk behaviors, chronic health conditions, access to preventative healthcare, and health status. BRFSS uses landline and cellular telephone surveys to collect data from adult, non-incarcerated, United States residents in all 50 states, the District of Columbia, and three U.S. territories. Data are collected via a survey consisting of core components, state-specific questions, and optional modules containing questions related to specific topics (e.g., caregiving). Survey weights are provided to enable population-level estimates.

Data analyzed were limited to the 19 states and territories that collected data on the optional caregiver module in 2016. The following states and territories are represented in these data: Arizona, Arkansas, California, Colorado, Connecticut, Georgia, Minnesota, Missouri, Montana, Nevada, New Jersey, New York, North Dakota, Ohio, Oregon, South Dakota, Tennessee, Texas, Utah, the District of Columbia, and Puerto Rico. The caregiver module consists of nine questions, including whether the participant is a caregiver, the nature of the relationship between caregiver and recipient, intensity and duration of care, and the main health problem or disability of the care recipient.

#### *Analytic sample*

A total of 486,303 people participated in the BRFSS survey in 2016, 134,701 of whom participated in the nine states that used the caregiver module that year. Approximately 10% of participants were excluded ( $n = 13,957$ ) because they did not respond to the question about whether they were a caregiver or not. The final sample was 120,744, comprised of 24,152 (20%) caregivers (answered yes to the initial caregiver question) and a comparison group of 96,592 respondents who reported they were not caregivers. The caregiving group was further divided according to the disabling condition impacting the person for whom they provided care. A total of 1079 provided care to someone with MI and 888 respondents provided

care to someone with DD. For the analyses comparing DD to MI caregivers, 23,961 respondents were excluded because they did not provide care to someone with DD or MI.

### Measures

Three questions were used to measure health outcomes. Responses to the first question, "Would you say that in general your health is very good, good, fair, or poor?", were grouped into two categories for analysis: good or very good and fair or poor. The second health outcome question was "how many days in the past 30 days was your physical health not good." The third question was "how many days in the past 30 days was your mental health not good". For the second and third questions, respondents could answer with any number between 0 and 30 days. In addition to the actual number of days, the BRFSS public use data provides three categories: "no poor physical/mental health days", "1 to 13 poor physical/mental health days", and "14 or more poor physical/mental health days". We chose to use this categorized variable due to the highly skewed nature of responses (more than 50% of respondents reported zero days) and to facilitate comparison to other BRFSS research using these items.

Five questions from the caregiver module were used in the analyses. The first question asked if the person had provided care to a "person with a health problem or disability in the past 30 days". The second question asked about intensity of care, with four answer options: up to 8 h per week, 9–19 h per week, 20–39 h per week, and 40 h or more. The third question asked about duration of care with response options of less than 30 days, 1 month to less than 6 months, 6 months to less than 2 years, 2 years to less than 5 years, and more than 5 years.

The fourth question asked, "What is the main health problem, long-term illness, or disability that the person you care for has?". Respondents were instructed to provide only one condition, selecting the "major problem" if more than one condition was present. Per BRFSS grouping, responses were put into the following fifteen categories: arthritis/rheumatism; asthma; cancer; chronic respiratory conditions such as emphysema or COPD; dementia or other neurocognitive disorders; developmental disabilities such as Down syndrome, autism, and spina bifida; diabetes; heart disease, hypertension, or stroke; HIV; mental illnesses such as anxiety, depression, or schizophrenia; organ failure or diseases; substance abuse or addiction; injuries including broken bones; old age, infirmity, or frailty; and other. For this study, we were interested in caregivers of people with MI, "mental illnesses such as anxiety, depression, or schizophrenia" and caregivers of people with DD, "such as Down syndrome, autism, and spina bifida". The final question asked respondents to select from a list of five support services the one service they need that they are not currently receiving, with an option to select "[I] don't need any of these support services." These five support services were: classes about giving care, such as giving meds; help in getting access to services; support groups; individual counseling to help cope with giving care; and respite care.

### Data analysis

Frequency tables for demographic characteristics and health outcomes were created using survey weights and survey design information (i.e., strata) to produce population-level estimates. Rao-Scott design-adjusted chi-square tests were used to determine whether select demographics were statistically significantly different across groups (caregivers vs. non-caregivers; MI vs. DD caregivers) in order to identify potential confounders. Logistic regression models and cumulative logistic regression models

(adjusted for survey design) were used to model health outcomes. This allowed for a comparison of outcomes across groups while controlling for potential confounders in adjusted models. Confounders were chosen that significantly differed across groups (caregivers vs. non-caregivers; MI vs. DD caregivers). SAS version 9.4 (Cary, NC) was used for data analysis.

### Results

Demographic characteristics for caregivers ( $n = 24,152$ ) and non-caregivers ( $96,592$ ) are presented in Table 1. There were significant differences between groups in terms of sex ( $p < 0.0001$ ), race ( $p < 0.0001$ ), marital status ( $p = 0.0001$ ), age ( $p < 0.0001$ ), and level of education ( $p < 0.0001$ ) (see Table 1). Caregivers were more likely to be female, white, older, and have attended college than non-caregivers. The difference in marital status was significant ( $p = 0.0001$ ) though small in magnitude, with caregivers slightly less likely to be widows.

We then compared health outcomes between caregivers and non-caregivers (Table 2). A significantly larger proportion of caregivers had fair or poor health (19.8%, CI: 18.3–21.2%) compared to non-caregivers (17.8%, CI: 17.1–18.4%), corresponding to an odds ratio of 1.14 ( $p = 0.01$ ). This effect was stronger in the adjusted model that controlled for age, sex, race, marital status, and education level (OR = 1.24,  $p = 0.0001$ ). In terms of physical and mental health, caregivers reported more poor physical and mental health days (Table 2). A larger proportion of caregivers reported 14 + days (15.0%) and 1–13 days (26.8%) of poor physical health compared to non-caregivers (11.9% and 22.6%, respectively). This effect remained significant in the adjusted model, with caregivers having 1.34 times the odds of having more poor physical health days than non-caregivers ( $p < 0.0001$ ). Similarly, larger proportions of caregivers reported 14 + days (17.5%) and 1–13 days (26.2%) of poor mental health days than non-caregivers (10.1% and 21.6%, respectively), with caregivers having 1.70 times the odds of having poor mental health days than non-caregivers in the adjusted model ( $p < 0.0001$ ). Therefore, caregivers had worse health outcomes in all areas.

Demographic and health outcomes for MI ( $n = 1079$ ) and DD ( $n = 888$ ) caregivers were then examined. There was a significant difference in sex across the groups ( $p = 0.002$ ); 67.1% of DD caregivers were female, compared 48.1% of MI caregivers. No other demographic characteristics differed between these two groups (Table 3). There was, however, a significant difference in intensity of care across caregiver groups ( $p = 0.02$ ). The proportion of DD caregivers who provided 40 or more hours a week of care (42.5%) was nearly double that of MI caregivers (22.1%). Similarly, there was a large difference in duration of care reported by caregiver groups ( $p = 0.0004$ ), with DD caregivers being much more likely to have provided care for more than 5 years (68.4%) compared to MI caregivers (47.5%). Differences in the main support service that the caregiver needed, but was not currently receiving, were not statistically significant ( $p = 0.052$ ).

Health outcomes and odds ratios comparing MI and DD caregivers for general health status, number of poor physical health days, and number of poor mental health days are shown in Table 4. In the adjusted models, all three health outcomes were significantly different between the two types of caregivers. MI caregivers had higher odds of having fair/poor health (OR = 2.11,  $p = 0.02$ ), poorer physical health (OR = 1.79,  $p = 0.02$ ), and poorer mental health (OR = 1.97,  $p = 0.003$ ) compared to DD caregivers.

Finally, since both intensity and duration of care significantly differed between the two types of caregivers, we investigated whether either of these factors moderated differences in health outcomes across the two caregiver groups (Table 5) by including an

**Table 1**  
Comparison of demographic characteristics for caregivers versus non-caregivers.

	Caregivers				Non-Caregivers				P-value
	N	Wtd. N	%	95% CI	N	Wtd. N	%	95% CI	
<b>Sex</b>									<0.0001
Male	8766	9,322,345	41.6	39.6–43.6	43,109	46,477,767	50.4	49.5–51.4	
Female	15,380	13,112,076	58.4	56.4–60.4	53,468	45,684,931	49.6	48.6–50.5	
Unknown/Missing	6	5237			15	8094			
<b>Race</b>									<0.0001
Non-Hispanic White	18,236	13,900,620	63.1	61.0–65.2	72,230	51,051,431	56.5	55.5–57.4	
Non-Hispanic Black	1923	2,448,009	11.1	9.8–12.4	6460	8,899,563	9.8	9.3–10.4	
Non-Hispanic Other/Multiracial	1463	1,498,487	6.8	5.8–7.8	5064	8,762,691	9.7	8.9–10.5	
Hispanic	2125	4,185,672	19.0	17.1–20.9	11,319	21,719,400	24.0	23.1–25.0	
Unknown/Missing	405	406,869			1519	1,737,708			
<b>Age</b>									<0.0001
18–24	918	2,432,072	10.8	8.9–12.7	5098	11,811,609	12.8	12.0–13.6	
25–34	1832	3,446,400	15.4	13.8–16.9	9342	16,310,410	17.7	16.9–18.5	
35–44	2595	3,187,220	14.2	12.8–15.6	11,044	15,827,193	17.2	16.4–18.0	
45–54	4563	4,870,392	21.7	20.0–23.4	14,597	14,990,213	16.3	15.6–17.0	
55–64	6585	4,384,169	19.5	18.3–20.8	20,363	14,734,098	16.0	15.3–16.7	
65 or older	7659	4,119,405	18.4	17.1–19.6	36,148	18,497,269	20.1	19.5–20.7	
<b>Marital Status</b>									0.0001
Married/Unmarried Couple	14,740	12,769,035	57.3	55.3–59.4	52,364	50,960,406	55.7	54.7–56.6	
Divorced/Separated	3826	3,288,004	14.8	13.5–16.1	14,945	11,924,802	13.0	12.4–13.6	
Widowed	2035	1,088,542	4.9	4.3–5.5	13,577	6,317,260	6.9	6.6–7.2	
Never Married	3401	5,128,260	23.0	21.0–25.0	15,112	22,353,467	24.4	23.5–25.3	
Unknown/Missing	150	165,816			594	614,858			
<b>Income</b>									0.49
<\$15000	2038	2,364,394	12.1	10.5–13.7	8986	9,708,987	12.3	11.7–13.0	
\$15000-24999	3557	3,397,194	17.4	15.9–18.8	13,549	13,265,192	16.9	16.0–17.7	
\$25000-34999	2296	1,951,714	10.0	8.9–11.1	8660	8,144,504	10.3	9.7–11.0	
\$35000-49999	3155	2,754,317	14.1	12.4–15.8	11,261	10,022,147	12.7	12.0–13.4	
\$50000 or more	9857	9,090,338	46.5	44.3–48.6	38,815	37,565,746	47.7	46.7–48.8	
Unknown/Missing	3249	2,881,700			15,321	13,464,216			
<b>Education Status</b>									<0.0001
Did not graduate high school	1427	2,496,046	11.1	9.8–12.4	8039	14,643,198	15.9	15.1–16.8	
Graduated high school	6229	5,744,978	25.6	24.0–27.3	26,686	24,563,484	26.7	25.9–27.6	
Attended college/technical school	7452	8,335,206	37.2	35.1–39.3	26,230	27,429,619	29.9	28.9–30.8	
Graduated from college/tech school	9001	5,846,749	26.1	24.5–27.6	35,347	25,238,422	27.5	26.7–28.3	
Unknown/Missing	43	16,679			290	296,070			
<b>Insurance Status</b>									0.52
Has healthcare plan	22,546	19,597,435	87.6	86.1–89.2	90,129	80,755,281	88.2	87.5–88.9	
Does not have healthcare plan	1552	2,770,665	12.4	10.8–13.9	6100	10,838,758	11.8	11.1–12.5	
Unknown/Missing	54	71,558			363	576,754			

P-values comparing caregivers to non-caregivers from survey design-adjusted chi-square tests (unadjusted for any covariates).

interaction between each variable and caregiver type. For these analyses, days of poor physical health and days of poor mental health were collapsed into “one or more days” versus “no days” due to small sample sizes for this exploratory interaction analysis. For

MI caregivers, a higher intensity of care was associated with poorer physical health (interaction  $p = 0.04$ ). This association was not observed among DD caregivers. As a result, there was little difference in the proportion of MI and DD caregivers with one or more

**Table 2**  
Comparison of health outcomes for caregivers versus non-caregivers.

	Caregivers				Non-Caregivers				Unadjusted P-value	Adjusted Odds Ratio <sup>a</sup>	95% CI	P-value
	N	Wtd. N	%	95% CI	N	Wtd. N	%	95% CI				
<b>General Health Status</b>									0.01	1.24	1.11–1.38	0.0001
Excellent/Very Good/Good	19,276	17,964,508	80.2	78.8–81.7	77,756	75,550,705	82.2	81.6–82.9				
Fair/Poor	4818	4,421,559	19.8	18.3–21.2	18,571	16,336,318	17.8	17.1–18.4				
Unknown/Missing	58	53,590			265	283,770						
<b>Poor physical health days, past month</b>									<.0001	1.34	1.23–1.47	<.0001
0 days	13,914	12,838,637	58.2	56.2–60.2	61,182	59,284,163	65.6	64.6–66.5				
1–13 days	6183	5,916,384	26.8	25.0–28.6	20,542	20,404,598	22.6	21.7–23.4				
14 + days	3651	3,312,959	15.0	13.6–16.4	12,817	10,737,133	11.9	11.3–12.5				
Unknown/Missing	404	371,677			2051	1,744,899						
<b>Poor mental health days, past month</b>									<.0001	1.70	1.54–1.87	<.0001
0 days	14,425	12,517,477	56.4	54.3–58.4	68,322	62,046,030	68.4	67.5–69.3				
1–13 days	5849	5,809,070	26.2	24.3–28.0	18,022	19,558,111	21.6	20.7–22.4				
14 + days	3525	3,886,131	17.5	15.9–19.1	8701	9,145,464	10.1	9.5–10.7				
Unknown/Missing	353	226,979			1547	1,421,187						

Unadjusted p-values comparing caregivers to non-caregivers from survey design-adjusted chi-square tests; Adjusted p-values comparing caregivers to non-caregivers from logistic regression models.

<sup>a</sup> From (cumulative) logistic regression models controlling for age, sex, race, marital status, and education status.

**Table 3**

Comparison of demographic characteristics and intensity and duration of care for caregivers of people with developmental disabilities (DD) versus caregivers of people with mental illness (MI).

	DD Caregivers				MI Caregivers				P-value
	N	Wtd. N	%	95% CI	N	Wtd. N	%	95% CI	
Sex									0.002
Male	270	304,819	32.9	24.5–41.2	400	663,092	51.9	42.8–61.1	
Female	618	622,489	67.1	58.8–75.5	679	613,997	48.1	38.9–57.2	
Race									0.51
Non-Hispanic White	671	545,829	60.3	51.6–69.1	793	803,556	63.4	53.8–73.0	
Non-Hispanic Black	67	117,038	12.9	6.5–19.4	100	90,448	7.1	4.0–10.3	
Non-Hispanic Other/Multiracial	58	64,139	7.1	1.0–13.2	72	80,012	6.3	1.5–11.1	
Hispanic	81	177,758	19.6	13.2–26.1	106	293,503	23.2	13.5–32.8	
Missing/Unknown	11	22,545			8	9571			
Age									0.63
18–24	46	112,324	12.1	4.7–19.6	72	248,142	19.4	8.9–29.9	
25–34	107	156,287	16.9	10.7–23.1	123	168,134	13.2	7.9–18.4	
35–44	150	188,543	20.3	14.6–26.1	155	232,831	18.2	11.9–24.5	
45–54	211	227,966	24.6	17.2–32.0	194	258,536	20.2	13.1–27.4	
55–64	193	136,986	14.8	8.2–21.4	264	217,065	17.0	11.1–22.9	
65 or older	181	105,202	11.3	6.2–16.5	271	152,381	11.9	8.1–15.8	
Marital Status									0.31
Married/Unmarried Couple	554	504,478	54.5	45.5–63.5	544	535,582	42.3	33.5–51.0	
Divorced/Separated	135	135,514	14.6	8.7–20.6	214	231,896	18.3	11.5–25.1	
Widowed	66	47,311	5.1	0.3–9.9	97	68,608	5.4	3.0–7.9	
Never Married	128	237,719	25.7	16.4–35.0	218	431,040	34.0	23.8–44.3	
Missing/Unknown	5	2286			6	9963			
Income									0.97
<\$15000	64	90,795	11.6	3.8–19.4	136	135,751	12.1	7.7–16.5	
\$15000–24999	135	163,575	20.8	12.8–28.8	201	219,715	19.6	13.4–25.9	
\$25000–34999	87	82,305	10.5	6.4–14.5	95	90,261	8.1	3.2–13.0	
\$35000–49999	124	82,125	10.5	6.6–14.3	141	125,280	11.2	5.9–16.5	
\$50000 or more	379	366,250	46.7	37.7–55.6	388	548,239	49.0	38.9–59.1	
Missing/Unknown	99	142,259			118	157,843			
Education Status									0.44
Did not graduate high school	66	169,229	18.3	11.2–25.3	74	162,667	12.7	7.1–18.4	
Graduated high school	223	221,356	23.9	16.5–31.2	274	262,209	20.5	14.6–26.5	
Attended college/technical school	270	332,186	35.8	27.0–44.7	337	548,793	43.0	33.2–52.8	
Graduated from college/tech school	328	204,507	22.1	16.6–27.6	393	302,954	23.7	17.0–30.5	
Missing/Unknown	1	30			1	467			
Insurance Status									0.89
Has healthcare plan	828	786,911	85.2	77.9–92.5	991	1,055,780	84.3	75.0–93.7	
Does not have healthcare plan	57	137,201	14.8	7.5–22.1	82	196,442	15.7	6.3–25.0	
Missing/Unknown	3	3195			6	24,867			
Intensity of Care									0.02
Less than 8 h	291	317,410	35.4	26.1–44.7	559	579,220	48.5	38.9–58.2	
8–19 h	65	100,733	11.2	4.0–18.5	132	173,794	14.6	8.8–20.3	
20–39 h	98	98,058	10.9	6.5–15.4	87	176,584	14.8	5.9–23.7	
40 or more hours	392	381,063	42.5	34.2–50.7	241	264,287	22.1	15.5–28.7	
Missing/Unknown	42	30,044			60	83,204			
Duration of Care									0.0004
Less than 30 days	77	79,188	8.9	4.0–13.9	125	124,696	10.0	6.0–14.0	
30 days – less than 6 mo.	28	15,530	1.8	0.7–2.8	106	165,347	13.3	5.0–21.6	
6 mo – less than 2 yrs.	74	92,182	10.4	4.3–16.5	164	206,127	16.6	7.7–25.4	
2 yr – less than 5 yrs.	96	92,795	10.5	5.4–15.6	173	155,983	12.5	8.3–16.8	
More than 5 yrs.	602	605,531	68.4	60.2–76.6	496	591,208	47.5	38.2–56.9	
Missing/Unknown	11	42,082			15	33,729			
Support services needed (not currently receiving)									0.052
Classes about giving care, such as giving meds	6	12,514	1.4	0.0–3.9	17	73,463	6.0	0.3–11.6	
Help in getting access to services	91	124,781	13.7	7.3–20.2	121	141,793	11.5	6.4–16.7	
Support groups	40	27,540	3.0	1.3–4.8	56	57,812	4.7	0.9–8.5	
Individual counseling to help cope with giving care	36	89,906	9.9	2.1–17.7	52	67,232	5.5	1.6–9.3	
Respite care	85	73,038	8.0	4.4–11.7	40	24,059	2.0	0.0–3.9	
You don't need any of these support services	609	580,449	63.9	54.9–72.9	751	864,726	70.4	61.9–78.8	
Missing/Unknown	21	19,079			42	48,004			

P-values comparing caregivers of DD to caregivers of MI from survey design-adjusted chi-square tests (unadjusted for any covariates).

days of poor physical health at the lowest level of caregiving intensity (38.4% vs. 39.5%, respectively), but there was a large difference at the highest level of intensity (65.5% vs. 38.2%, respectively). Longer duration of care was associated with poorer general health status for MI caregivers but not for DD caregivers (interaction  $p = 0.03$ ). However, for shorter duration of care, there was a larger proportion of DD caregivers with fair/poor health

(19.7%) compared to MI caregivers (6.4%), and this pattern was reversed at the longest duration of care (DD caregivers: 18.5%; MI caregivers: 35.0%).

## Discussion

This study adds to existing research on the adverse effects of

**Table 4**  
Comparison of health outcomes for caregivers of people with developmental disabilities (DD) and caregivers of people with mental illness (MI).

	DD Caregivers				MI Caregivers				Unadjusted P-value	Adjusted Odds Ratio <sup>a</sup>	95% CI	P-value
	N	Wtd. N	%	95% CI	N	Wtd. N	%	95% CI				
<b>General Health Status</b>									0.50	2.11	1.15–3.88	0.02
Excellent/Very Good/Good	713	753,598	81.3	75.0–87.5	839	995,040	78.0	70.7–85.3				
Fair/Poor	174	173,652	18.7	12.5–25.0	237	280,609	22.0	14.7–29.3				
Unknown/Missing	1	58			3	1441						
<b>Poor physical health days, past month</b>									0.56	1.79	1.10–2.94	0.02
0 days	517	544,034	60.9	52.7–69.0	556	709,943	56.1	47.1–65.0				
1–13 days	251	228,931	25.6	18.6–32.6	298	326,193	25.8	18.7–32.8				
14 + days	112	120,808	13.5	7.4–19.6	205	230,488	18.2	11.5–24.8				
Unknown/Missing	8	33,535			20	10,466						
<b>Poor mental health days, past month</b>									0.04	1.97	1.26–3.08	0.003
0 days	513	551,498	59.7	51.3–68.2	513	561,999	44.2	34.9–53.6				
1–13 days	244	237,953	25.8	18.3–33.2	326	416,861	32.8	23.9–41.7				
14 + days	121	133,652	14.5	8.6–20.3	225	291,692	23.0	15.5–30.4				
Unknown/Missing	10	4205			15	6537						

Unadjusted p-values comparing caregivers of DD to caregivers of MI from survey design-adjusted chi-square tests; Adjusted p-values comparing caregivers of DD to caregivers of MI from logistic regression models.

<sup>a</sup> From (cumulative) logistic regression models controlling for sex, intensity of care, and duration of care.

**Table 5**  
Comparison of the effect of caregiving intensity and caregiving duration on health outcomes for caregivers of people with developmental disabilities (DD) versus caregivers of people with mental illness (MI).

Outcome	Predictor	DD Caregivers			MI Caregivers			Interaction P-value <sup>b</sup>
		N <sup>a</sup>	Wtd. %	95% CI	N	Wtd. %	95% CI	
Fair/poor health	Intensity of Care							
	Up to 8 h per week	52/291	10.7	4.3–17.2	98/559	9.4	5.6–13.1	0.20
	9–39 h per week	34/163	27.9	8.3–47.4	48/218	27.4	10.1–44.7	
	40 h or more	80/391	21.3	12.8–29.7	78/241	38.9	23.2–54.5	
	Duration of Care							
	<30 days	16/77	19.7	1.2–38.3	18/124	6.4	0.0–12.9	0.03
1 + days poor physical health	1 month to <2 years	20/102	11.2	1.8–20.5	53/270	10.2	3.7–16.6	
	2 years–5 years	17/96	12.7	1.5–23.8	30/172	14.7	5.9–23.4	
	>5 years	119/601	18.5	11.9–25.0	129/495	35.0	22.3–47.6	
1 + days poor mental health	Intensity of Care							
	Up to 8 h per week	118/289	39.5	23.3–55.8	259/554	38.4	26.2–50.6	0.04
	9–39 h per week	73/162	43.2	22.8–63.6	88/213	36.8	18.6–55.0	
	40 h or more	158/390	38.2	28.3–48.1	130/236	65.5	53.0–78.1	
	Duration of Care							
	<30 days	32/77	59.5	34.1–84.9	64/124	51.2	31.6–70.8	0.05
1 + days poor mental health	1 month to <2 years	42/102	31.3	10.1–52.5	121/267	32.6	16.2–49.1	
	2 years–5 years	39/94	63.7	42.9–84.6	78/168	44.9	28.9–60.8	
	>5 years	248/597	32.8	24.6–40.9	229/486	50.3	37.8–62.7	
	Intensity of Care							
	Up to 8 h per week	113/288	39.2	22.4–56.1	283/552	47.3	33.4–61.2	0.81
1 + days poor mental health	9–39 h per week	78/160	47.5	26.8–68.2	121/217	63.3	46.4–80.2	
	40 h or more	161/389	39.1	29.1–49.1	118/238	57.7	42.9–72.4	
	Duration of Care							
	<30 days	31/75	60.0	33.7–86.2	64/121	70.1	55.1–85.1	0.09
	1 month to <2 years	38/100	23.1	8.3–38.0	149/269	58.5	35.1–81.9	
1 + days poor mental health	2 years–5 years	45/96	49.6	24.0–75.2	86/167	42.9	27.1–58.7	
	>5 years	248/596	38.3	28.8–47.9	243/493	52.7	40.4–65.0	

<sup>a</sup> N presented as number with the outcome (e.g., fair/poor health) over the total number in the category. For example, 52/291 means that there were 291 DD caregivers who reported up to 8 h/week of care, and of these, 52 reported fair/poor health. The denominators may not exactly match those in Table 3 due to missing data on the health outcomes.

<sup>b</sup> Interaction p-values (caregiver type x intensity; caregiver type x duration) from logistic regression models adjusted for sex.

caregiving on caregiver health and advances our understanding of two underexplored populations: caregivers of people with MI and caregivers of people with DD. In a large national sample, we found

that caregivers had poorer general health and more poor physical and mental health days compared to non-caregivers. Caregiving was associated with poor general health and more poor physical

and mental health days when controlling for age, sex, race, marital status, and education level. This study extends previous research on caregiver health outcomes<sup>4–9,12</sup> by providing a representative national snapshot of caregiver health.

Two caregiver subgroups were compared in this study: caregivers of people with MI and caregivers of people with DD. Compared to MI caregivers, DD caregivers were more likely to be female, which is consistent with previous research.<sup>13</sup> DD caregivers were more likely to provide care for 40 or more hours per week and for five or more years than MI caregivers, which is also consistent with recent findings.<sup>1,13</sup> Compared to DD caregivers, MI caregivers reported poorer overall health and more days of poor mental and physical health. Although DD caregivers reported higher intensity and longer duration of care, MI caregivers were more likely to report negative health impacts as a function of intensity and duration of care. As intensity of care increased (e.g., 40 or more hours per week), MI caregivers reported more poor physical health days compared to DD caregivers. As duration of care increased (e.g., five years or more), MI caregivers had poorer general health status compared to DD caregivers.

These findings should be interpreted with caution. Although the health of MI caregivers was worse and more sensitive to intensity and duration of care compared to DD caregivers, it is important to note that caregivers experienced significantly poorer health status and more poor physical and mental health days compared to non-caregivers. Caregivers who provide intense, long-term care can often experience chronic stress, which may contribute to poor health conditions, including anxiety, muscle pain, high blood pressure, and a weakened immune system.<sup>22</sup> Chronic stress among caregivers has been shown to impact caregiver health as well as the quality of care provided.<sup>23,24</sup> These findings extend previous research on the relationship between caregiving and health outcomes.

Poor MI caregiver health outcomes compared to DD caregivers may reflect differences in available resources to support MI and DD caregivers.<sup>13,15,25–28</sup> Although marginally significant, our data show a surprising trend toward MI caregivers being more likely than DD caregivers to report *not* requiring any additional support services. This finding may reflect caregivers' uncertainty about what resources could help in their caregiving role. Previous research found that some MI caregivers assumed the complete burden of care because they believed other sources of assistance were not adequately prepared or trained to help with their loved one with MI.<sup>15,25,29</sup> Related research has identified that MI caregivers feel isolated as a result of providing care for a person with MI.<sup>30</sup> These findings highlight important differences between MI and DD caregiving and help explain differences in health outcomes. The experience of caring for a person with MI may be different than caring for a person with DD and *not merely* as a function of intensity and duration of care. The differences in health outcomes among caregivers of MI and caregivers of DD could be partially attributed to the increased stigma around mental illness, lack of resources to support care, and poor social support among MI caregivers.<sup>25,31–33</sup> Future research is needed to understand and improve caregiver health.

#### Limitations and future directions

Several limitations and future directions for research should be considered when interpreting these findings. First, the cross-sectional nature of the present study prevents attributions of causality between caregiving and health outcomes; however, our large national sample is representative of the US population. Second, the relatively small sample sizes of MI and DD caregivers limited our ability to analyze caregiver-specific variables such as the relationship to the care recipient. Future research should investigate

whether formal (e.g., paid caregiver) or informal (e.g., family member) caregiving uniquely influences MI and DD caregivers' health. Third, we were not able to analyze specific conditions within the MI and DD categories, as well as other disabilities in which caregiving may be needed (e.g., intellectual disability). Future research is needed to investigate whether specific health conditions (e.g., autism spectrum disorder, schizophrenia) uniquely interact with intensity and duration of care to impact caregiver health. Fourth, BRFSS is self-reported via telephone interview and data were not independently verified. Fifth, our conceptualization of intensity of care, while supported by previous research,<sup>18</sup> was limited to the number of self-reported hours worked per week by caregivers. Future research should expand on this conceptualization to include type of help that was required to support the person receiving care (e.g., physical lifting or crisis management).<sup>34</sup> Finally, our MI caregiving sample included the full spectrum of MI. If our MI sample had been limited to those caring for more severe forms of MI such as people with schizophrenia, for example, we may have found their intensity and duration of care to be similar to that of DD caregivers. Future research is needed to disentangle environmental and social determinants of health from genetic determinants for family caregivers. Notwithstanding these limitations, the finding that MI caregivers, on average, provided less intense care for shorter durations, and experienced worse health outcomes compared to DD caregivers, is concerning and warrants further study. Future research is needed to better understand the impact of variables such as intensity and duration of care, as well as how relationship to care recipient influences caregiver health outcomes. Moreover, future research should further explore how variables such as perceived stigma, social support, and availability of resources impact health of MI and DD caregivers. Finally, research is needed to evaluate caregiver support programs and services in terms of mitigating the health impacts of caregiving.

#### Conclusions

The negative effects associated with caregiving on caregiver health, coupled with increased need for caregivers, make the health of this population a major public health concern.<sup>35,36</sup> Caring for people with the most intense and persistent support needs, such as people with MI and DD, is likely associated with the most profound adverse health impacts. As health and social service systems increasingly rely on "natural supports", research is needed to protect the health and well-being of caregivers.<sup>36</sup> Consistent with previous research, we found that caregivers had worse health outcomes than non-caregivers. Compared to DD caregivers, MI caregivers, on average, reported providing lower intensity and duration of care, but reported worse health outcomes. Finally, intensity and duration of care moderated health outcomes among MI caregivers but not DD caregivers. These findings provide service providers, policy-makers, and researchers with actionable information to develop and evaluate programs to improve the health of the most vulnerable caregivers and improve their provision of care.

#### Declaration of interest

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## Prior Presentation

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