

Understanding the Impact of Patients' Disease Types on Caregiving Time and Caregiver Burden: An Analysis of the Health Information National Trends Survey

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Abstract

Background: Patients with different medical conditions often have distinctive caregiving needs that could result in varying levels of caregiver burden. However, despite empirical advances in this area, little is known about how patients' disease types interact with caregiving time and caregiver burden. To bridge this gap, we examined the impact of patients' disease types on caregiving time and burden.

Methods: Data were analyzed from the 2018 Health Information National Trends Survey 5 Cycle 2. Only participants self-identified as caregivers were included in the final analysis. Data on patients' disease types, caregiving time (i.e., caregiving duration and caregiving hours spent per week), and caregiver burden (i.e., caregivers' self-rated health, body mass index, and psychological distress) were examined using logistic regression analysis.

Results: Patients' disease types impacted caregiving time and burden. Caregivers of patients with neurological disease spent the greatest amount of time. For caregiver burden, caregivers of patients with cancer or aging related disease experienced worst self-rated health, caregivers of patients with orthopedic disease have the greatest likelihood to be overweight or obese, while cancer caregivers experienced greatest levels of psychological distress.

Conclusions: Patients' disease types had highly varied effects on caregiving time and burden. This study underscores the need for healthcare researchers to adopt a nuanced approach in acknowledging and addressing the burden of care experienced by caregivers, such as tailoring interventions based on both patients and caregivers' characteristics and preferences.

Introduction

Caregiving is a challenging experience that often results in physical and psychological burden on informal caregivers [1–3]. An informal caregiver is a person who offers unpaid or ill-compensated care to a family member, friend, or partner due to illness-related reasons or old age. Results indicate that informal caregivers often experience substantial physical and psychological health consequences as a result of caregiving, such as fatigue [4, 5], loss of sleep [6, 7], perceived stigma [8, 9], anxiety symptoms [10, 11], depression disorders [12, 13], worsened subjective wellbeing [14, 15], and compromised quality of life [16, 17]. Evidence further shows that informal caregivers' self-rated health has been in decline for the past five years, further widening the gap between caregivers and the general population' health status [18]. As more than one in five Americans (~ 53 million) is an informal caregiver [18], research is needed to better understand factors that influence caregiver burden so that more effective health solutions could be developed to alleviate resultant health disparities.

Across disease contexts, factors that may impact caregiver burden have been examined, including caregivers' sociodemographic characteristics (e.g., gender) [19], caregiver self-care abilities (e.g., self-efficacy) [20], social support factors (e.g., caregiving unmet needs) [21], and patient-related factors (e.g., time spent on caregiving) [22]. While less studied, many thanks to the increasing recognition of the interactive nature of caregiving, research on patient-related factors' impact on caregiver burden is gaining momentum [23, 24]. A growing body of evidence suggests that patients' disease types could have a considerable impact on caregiving time and caregiver burden [25–29]. Comparing caregivers of patients face renal transplantation and caregivers of patients undergo hemodialysis, researchers found that caregivers of patients receive hemodialysis had significantly higher levels of caregiver burden [26]. Findings further indicate that caregivers of frontotemporal lobar degeneration and caregivers of dementia with Lewy bodies patients experienced significantly more burden than caregivers of people with Alzheimer's [28].

Conflicting findings are also present in the literature [24, 30]. In a comparative study, researchers found no significant difference in levels of burden reported by leukemia caregivers and cerebral palsy caregivers [24]. Comparing the impact of Alzheimer’s disease and frontotemporal dementia on caregiver burden, study also indicates that there are no significant differences in levels of burden experienced in these two groups of caregivers [31]. Though evidence is needed to clarify mixed findings in the literature, research is scarce. Overall, only a handful of studies have investigated the impact of patients’ disease types on caregiving consequences such as caregiving time and caregiver burden [26, 28, 29, 31, 32]. Furthermore, considering that most of the available studies are either conducted in the cognitive impairment disease context (e.g., comparing different types of dementia conditions) [28, 29] or only examined two to three types of distinctive medical conditions’ in the analysis [26, 31, 32], these studies are limited in the diversity of insights they can offer. To bridge this gap, we aim to examine the impact of patient’s disease types on caregiving time (i.e., caregiving duration and caregiving hours spent per week) and caregiver burden (i.e., caregivers’ self-rated health, body mass index or BMI, and psychological distress), using data that examined a comprehensive list of patients’ disease types (see Table 1).

Table 1
List of patient’s disease types

Disease type	Example
Cancer	Skin cancer, breast cancer, lung cancer, etc.
Alzheimer’s or related issues	Alzheimer’s, confusion, dementia (e.g., frontotemporal dementia), forgetfulness.
Orthopedic or related issues	Back problems, broken bones, arthritis, mobility problems, can’t get around, feeble, unsteady, falling).
Mental health or related issues	Mental illness, emotional problems, depression, anxiety, and substance/drug/alcohol abuse.
Chronic conditions	High blood pressure/hypertension, diabetes, heart disease, heart attack, lung disease, emphysema, Chronic Obstructive Pulmonary Disease (COPD), Parkinson’s
Neurological or related issues	Brain damage or injury, developmental or intellectual disorder, mental retardation, Down syndrome, and stroke.
Acute conditions	Health conditions that are severe and sudden in onset, such as a broken bone or an asthma attack.
Aging or related issues	Aging and related health issues not listed in the other categories above.
Multiple disease conditions	We coded this variable to represent patients with multiple health conditions mentioned above or different patients caregivers that have two or more distinctive conditions.
Other conditions	Medical conditions that are not listed above.
Unknown conditions	Conditions that are unknown to the caregiver and/or patients.

Methods

Study Design and Participants

This is a cross-sectional study using data from the Health Information National Trends Survey (HINTS, 2018) Version 5, Cycle 2, a nationally representative survey of U.S. adults aged ≥ 18 years (civilian and non-institutionalized) [33]. The survey is first conducted by the National Cancer Institute (NCI) in 2003, aiming to gauge how Americans seek, share, and use cancer-related health information in their daily interactions [34]. The HINTS 5 (Cycle 2) survey used in this study was administered from January 26 to May 2, 2018. We utilized data from the 2018 HINTS survey because, by far, caregiver burden related variables were only included in this particular HINTS survey. Of all the 14,585 surveys mailed, 3,527 participants returned their questionnaires (response rate: 24.2%) [34]. As this study mainly focuses on the caregiver population, we used “Are you currently caring for or making health care decisions for someone with a medical, behavioral, disability, or other condition?” as the screening question to identify caregivers. A total of 458 (13.0%) participants who self-identified as caregivers (i.e., replied “yes” to the question) were included in the final data analysis.

Measures

To adequately gauge the impact of patients’ disease types on caregiving consequences, both direct and indirect consequences were evaluated in this study. Based on insights gained from the literature [35–38], direct consequence of caregiving is measured by caregiving time, in terms of caregiving duration and caregiving hours spent per week, while indirect consequences of caregiving are measured by caregiver burden in terms of caregivers’ self-rated health, BMI, and psychological distress. Details of all measures used in this study are reported by the National Cancer Institute and available online [34].

Caregiving time

We adopted two measures to gauge caregivers’ time spent on providing care to patients: caregiving duration and caregiving hours spent per week [34].

Caregiving duration. Participants were directed to “Think about the individual for whom you are currently providing the most care. About how long have you been providing care for this person?” and asked to choose one response from the 5 available choices (i.e., “Less than 30 days”=1, “1 to 6 months” = 2, “7 months to 2 years” = 3, “3 to 5 years” = 4, “More than 5 years”=5).

Caregiving hours spent per week. Participants were asked to “Think about the individual for whom you are currently providing the most care. About how many hours per week do you spend in an average week providing care?” and indicate hours they spent per week on offering care to the patients.

Caregiver burden

In line with the literature [35–38], caregiver burden was gauged using three variables: Self-rated health, BMI, and psychological distress.

Self-rated health. To assess respondents’ self-rated health status, participants’ were asked to respond to the question “In general, would you say your health is. . .” on a five-point scale (“excellent” = 1, “very good” = 2, “good” = 3, “fair” = 4, “poor” = 5).

BMI. Participants’ BMI levels were calculated using information on participants’ self-rated weight and height (formula: weight (kg) / [height (m)]²). Based on Centers for Disease Control and Prevention’s guidelines, BMI was subsequently coded into three categories: underweight or normal (< 25), overweight (25–29.9), and obese (≥ 30) [39].

Psychological distress. Participants' psychological distress was measured with the four-item Patient Health Questionnaire (PHQ-4) [34, 40]. Participants completed four items in response to "Over the past 2 weeks, how often have you been bothered by any of the following problems?": (a) Little Interest, (b) hopeless, (c) nervous, (d) worrying on scales from 0 (Not at all) to 3 (nearly every day). Based on available guidelines, the four items were subsequently summed [34, 40]. The summed scores ranged from 0 to 12, with a higher score indicating a higher level of psychological distress [40].

Caregiver Characteristics

Demographic factors included were gender ("male" = 0 vs. "female" = 1), race/ethnicity ("non-Hispanic White" = 1, "other" = 0), and marital status ("married" or "living as married" = 1 vs. "divorced," "widowed," "separated," or "single, never been married" = 0). Other covariates examined were household income ("US\$50,000 or more" = 1, or "less than US\$50,000/year" = 0), education (coded into four categories: less than high school, high school graduate, some college, and college graduate or more), and employment status ("employed" = 1 vs. "unemployed," "homemaker," "student," "retired," "disabled," or "other" = 0). A 9-point rural urban continuum code was used to classify participants as residing either in metropolitan (codes 1–3) or nonmetropolitan (codes 4–9) areas [41]. Smoking status (categorized as current smoker, former smoker, or never smoker). Drinking status ("having at least one drink of any alcoholic beverage more than 1 day per week" = 1, "none" = 0). We reclassified the response options into a single dichotomous outcome variable for physical activity, that is, whether the subject (1) met physical activity recommendations (≥ 150 minutes per week) or did not meet the physical activity recommendations (< 150 minutes per week). Having health insurance ("yes" = 1, "not" = 0).

Data Analyses

First, the characteristics of the participants were described using descriptive statistics (means accompanied with SDs or frequencies, as appropriate). Second, to explore the relationship between health outcome and independent variables, we used multivariate logistic regression method for analyzing the self-rated health variable and ordered logistic regressions for the BMI and psychological distress variables. In order to test the potential interaction, we generated several interaction terms by multiplying the categorical variables. Third, we calculated the mean scores of health indicators and caregiving burden of caregivers. In order to adjust for HINTS' multistage probability sampling design, a set of 50 jackknife replicate weights was applied to all analyses, estimating the model parameters for the U.S. population as a whole. Finally, to explore the association between caregiver burden, caregiver health outcomes, and independent variables, we used ordered logistic regression for analyzing self-rated health, BMI, psychological distress and applied linear regression analyses to examine caregiving duration and caregiving hours spent per week to answer the research question.

Odds ratios (ORs) or regression coefficients with CI were employed to depict the relationships between caregiver burden, caregiver health outcomes, and independent variables while controlling for covariates. Listwise deletion of each subjects were used for participants who provided invalid or missing responses for the dependent variables; sample sizes for each regression analysis are noted in Table 3 ranging from 3,256 to 3,264. All covariates with missing data were multiple imputed. All analyses were performed using Stata 14 [42].

Results

The characteristics of participants who completed the HINTS questionnaire were illustrated in Table 3. Analyses show that compared to non-caregivers, caregivers experienced higher BMI (OR = 1.42, 95% CI = 1.18–1.71) and greater levels of psychological distress (OR = 1.44, 95% CI = 1.21–1.73). This association was statistically significant

even after controlling for the interaction between caregiver and gender (OR = 1.96, 95% CI = 1.45–2.65) and the interaction between caregiver and employment status (OR = 1.89, 95% CI = 1.45–2.47).

Table 2
 Characteristics of participants (N = 3504)

Variables	Freq.	Percent	Variables	Freq.	Percent
Age			Employment status		
~ 45	843	24.06	Unemployed	1,761	50.84
45~	1,396	39.84	Employed	1,703	49.16
65~	1,265	36.1	Smoking		
Sex			Current	460	13.13
Male	1,416	40.41	Former	880	25.11
Female	2,088	59.59	Never	2,164	61.76
Race			Drinking		
Others	1,328	37.9	Not	2,086	59.53
Non-Hispanic White	2,176	62.1	Yes	1,418	40.47
Residence			Recommended PA*		
Non-metropolitan	489	13.96	Not	2,323	66.3
Metropolitan	3,015	86.04	Yes	1,181	33.7
Marital status			Having Health Insurance		
Unmarried	1,737	49.57	Not	248	7.08
Married	1,767	50.43	Yes	3,256	92.92
Educational level			Emotional Support		
Less than HS [#]	281	8.02	Never	140	4.00
HS Grad	643	18.35	Rarely	194	5.54
Some College	1,050	29.97	Sometimes	483	13.78
College Graduate	1,530	43.66	Often	554	15.81
Income Ranges			Always	2,133	60.87
\$0 to \$9,999	245	7.00	Self-care Efficacy		
\$10,000 to \$14,999	212	6.05	Completely confident	33	0.95
\$15,000 to \$19,999	198	5.65	Very confident	110	3.17
\$20,000 to \$34,999	484	13.81	Somewhat confident	834	24.03
\$35,000 to \$49,999	458	13.07	A little confident	1,618	46.61
\$50,000 to \$74,999	631	18.01	Not confident at all	876	25.24
\$75,000 to \$99,999	412	11.76	Caregiver		

Variables	Freq.	Percent	Variables	Freq.	Percent
\$100,000 to \$19,999	635	18.12	Not	2,918	85.77
\$200,000 or more	229	6.54	Yes	484	14.23
Freq.=frequency; *PA = physical activity; #HS = high school					

Table 3
Factors associated with general health, BMI, and psychological distress

Variables	General Health	BMI3	Psychological Distress		
	(1)	(2)	(3)	(4)	(5)
Caregiver (Ref: Not)	1.22	1.42***	1.44***	1.96***	1.89***
	(0.89–1.66)	(1.18–1.71)	(1.21–1.73)	(1.45–2.65)	(1.45–2.47)
Self-care efficacy	0.22***	0.72***	0.51***	0.51***	0.51***
	(0.18 – 0.26)	(0.66–0.79)	(0.47–0.56)	(0.47–0.56)	(0.47–0.56)
Metropolitan (Ref: Non-metropolitan)	0.78	0.83	1.00	1.01	1.01
	(0.58–1.05)	(0.68–1.01)	(0.82–1.22)	(0.83–1.23)	(0.83–1.23)
Age	1.02***	1.01*	0.98***	0.98***	0.98***
	(1.01–1.03)	(1.00–1.01)	(0.97–0.98)	(0.97–0.98)	(0.97–0.98)
Female (Ref: male)	1.08	0.79***	1.79***	1.92***	1.76***
	(0.86–1.36)	(0.69–0.91)	(1.56–2.05)	(1.65–2.23)	(1.53–2.02)
Non-Hispanic White (Ref: Others)	0.64***	0.86*	1.41***	1.42***	1.40***
	(0.50–0.82)	(0.74–0.99)	(1.21–1.63)	(1.23–1.65)	(1.20–1.62)
Married (Ref: Not married)	1.03	1.17*	0.79**	0.79**	0.78***
	(0.82–1.29)	(1.00–1.35)	(0.68–0.92)	(0.68–0.91)	(0.67–0.90)
Education	0.80**	0.74***	1.10*	1.10*	1.10*
	(0.70–0.92)	(0.68–0.80)	(1.01–1.20)	(1.01–1.19)	(1.01–1.20)
Employed (Ref: Not employed)	0.83	1.50***	0.73***	0.72***	0.80**
	(0.64–1.07)	(1.29–1.75)	(0.63–0.85)	(0.62–0.84)	(0.68–0.94)
Income Ranges	0.93*	1.01	0.88***	0.88***	0.88***
	(0.87–1.00)	(0.97–1.04)	(0.85–0.91)	(0.85–0.91)	(0.85–0.91)
BMI (Ref: Normal)					
Overweight	1.40*	–	1.24*	1.26**	1.26**
	(1.04–1.87)		(1.05–1.47)	(1.06–1.49)	(1.06–1.49)

Variables	General Health	BMI3	Psychological Distress		
	(1)	(2)	(3)	(4)	(5)
Obesity	2.30*** (1.74–3.04)	–	1.15 (0.97–1.36)	1.15 (0.97–1.37)	1.15 (0.97–1.36)
Smoking (Ref: Current smoker)					
Former	0.70 (0.48–1.04)	1.22 (0.97–1.53)	0.77* (0.61–0.97)	0.77* (0.61–0.97)	0.77* (0.61–0.96)
Never	0.58** (0.40–0.83)	1.07 (0.88–1.30)	0.67*** (0.55–0.81)	0.67*** (0.55–0.81)	0.67*** (0.55–0.81)
Drinking (Ref: Not)	0.65*** (0.51–0.82)	0.74*** (0.64–0.85)	1.11 (0.97–1.28)	1.11 (0.97–1.28)	1.11 (0.97–1.28)
Physical Activity (Ref: <150 minutes per week)	0.72** (0.57–0.90)	0.65*** (0.56–0.74)	0.90 (0.78–1.05)	0.90 (0.78–1.05)	0.89 (0.77–1.04)
Having Health Insurance (Ref: not)	1.50 (0.90–2.51)	1.07 (0.85–1.34)	0.95 (0.75–1.19)	0.95 (0.75–1.20)	0.95 (0.76–1.20)
Emotional Support	1.06 (0.94–1.19)	0.97 (0.91–1.04)	0.81*** (0.76–0.87)	0.81*** (0.76–0.87)	0.81*** (0.76–0.87)
Psychological Distress	1.15*** (1.10–1.20)	1.02 (1.00–1.05)	–	–	–
Caregiver × Female				0.63* (0.43–0.91)	
Caregiver × Employed					0.61** (0.43–0.88)
Observations	3,264	3,264	3,264	3,264	3,264
95% confidence intervals in parentheses; *** p < 0.001, ** p < 0.01, *p < 0.05					

Results on factors associated with self-rated health, BMI, and psychological distress were presented in Table 2. Both the interaction effect between caregiver and gender (OR = 0.63, 95% CI = 0.43–0.91) and the interaction effect between caregiver and employment status (OR = 0.61, 95% CI = 0.43–0.88) were statistically significant. That is, caregivers experienced greater psychological distress for men than women, and unemployed caregivers experienced greater psychological distress than employed caregivers.

As presented in Table 4, caregivers who were female, older, had lower levels of education, SES status, physical inactivity, unmarried, unemployed, not having health insurance experienced greatest caregiver burden and worst health outcomes. Patients' disease types significantly influenced caregiving time and caregiver burden. In terms of time caregiving hours spent weekly, caregivers of patients with neurological or related conditions spent the greatest amount of time in caregiving (44.6 hours per week), followed by caregivers undertake multiple disease conditions (32.3 h), chronic conditions (32.0 h), unknown disease conditions (31.7 h), cancer (31.1 h), orthopedic or related conditions (29.5 h), Alzheimer's or related conditions (27.1 h), other disease conditions (22.7 h), mental health or related conditions (17.34), aging or aging related conditions (14.9 h), and acute conditions (12.9 h).

Table 4

The characteristics and the mean scores of general health, BMI, and psychological distress, caregiving duration, and hours per week of caregivers

Variables	Freq.	Percent	SRH*	BMI*	Psychological distress	Length of caregiving*	Caregiving hours/week*
Patients' Disease Types							
Aging/Aging related	16	3.37	2.81	1.19	3.40	3.56	14.86
Cancer	10	2.11	2.80	1.20	4.20	2.80	31.14
Orthopedic/Musculoskeletal	17	3.58	2.71	1.35	3.18	4.00	29.50
Alzheimer's and related	30	6.32	2.70	1.13	1.73	3.55	27.08
Multiple disease conditions	253	53.26	2.60	1.20	2.25	3.93	32.30
Mental health and related	36	7.58	2.58	1.19	2.85	4.24	17.34
Chronic conditions	28	5.89	2.50	1.18	2.39	4.26	32.04
Neurological or related	21	4.42	2.43	1.19	1.14	4.81	44.57
Other conditions	38	8	2.39	0.97	1.58	3.74	31.69
Acute conditions	7	1.47	2.29	0.71	3.57	4.00	12.86
Unknown conditions	19	4	2.21	0.79	2.47	3.50	22.70
Age							
~ 45	109	22.95	2.66	1.11	3.20	3.76	34.05
45~	233	49.05	2.48	1.21	2.14	4.00	25.29
65~	133	28.00	2.65	1.11	1.85	3.92	35.86
Sex							
Male	139	29.26	2.51	1.13	1.99	3.91	22.21
Female	336	70.74	2.59	1.17	2.44	3.93	33.41
Race							
Others	189	39.79	2.73	1.25	2.48	3.88	28.86
Non-Hispanic White	286	60.21	2.46	1.09	2.19	3.95	30.88
Residence							
Non-metropolitan	67	14.11	2.71	1.16	2.26	3.98	29.49
Metropolitan	408	85.89	2.55	1.16	2.31	3.91	30.22
Marital status							
Unmarried	187	39.37	2.64	1.20	2.85	4.08	34.41
Married	288	60.63	2.53	1.13	1.96	3.82	27.31
Educational level							

Variables	Freq.	Percent	SRH*	BMI*	Psychological distress	Length of caregiving*	Caregiving hours/week*
Less than High S	32	6.74	3.10	1.25	3.63	3.85	44.21
High School Grad	66	13.89	2.83	1.20	2.72	3.75	41.86
Some College	149	31.37	2.78	1.29	2.65	4.09	32.56
College Graduate	228	48.00	2.29	1.05	1.79	3.87	24.83
Employment status							
Unemployed	226	47.88	2.75	1.18	2.94	3.97	41.44
Employed	246	52.12	2.40	1.13	1.72	3.88	20.51
Income Ranges							
\$0 to \$9,999	30	6.32	3.33	1.27	5.86	3.79	58.28
\$10,000 to \$14,9	22	4.63	3.11	1.27	3.33	4.30	40.00
\$15,000 to \$19,9	20	4.21	2.75	1.05	3.15	4.05	38.60
\$20,000 to \$34,9	66	13.89	2.65	1.12	2.78	3.71	38.50
\$35,000 to \$49,9	88	18.53	2.74	1.27	2.43	4.14	40.16
\$50,000 to \$74,9	67	14.11	2.54	1.12	1.81	4.09	22.29
\$75,000 to \$99,9	46	9.68	2.47	1.26	1.65	4.00	26.00
\$100,000 to \$199	99	20.84	2.24	1.05	1.43	3.80	20.79
\$200,000 or more	37	7.79	2.11	1.08	1.35	3.54	13.95
Smoking							
Current	53	11.16	2.81	0.98	4.08	4.08	32.70
Former	111	23.37	2.50	1.26	2.06	3.77	37.21
Never	311	65.47	2.56	1.15	2.09	3.95	27.08
Drinking							
Not	292	61.47	2.69	1.21	2.29	3.94	32.91
Yes	183	38.53	2.38	1.08	2.33	3.89	26.19
Recommended Physical Activity							
Not	324	68.21	2.65	1.21	2.44	3.96	31.08
Yes	151	31.79	2.41	1.04	2.02	3.84	27.98
Having Health Insurance							
Not	34	7.16	2.69	0.88	3.06	4.15	54.38
Yes	441	92.84	2.56	1.18	2.25	3.91	28.42

Variables	Freq.	Percent	SRH*	BMI*	Psychological distress	Length of caregiving*	Caregiving hours/week*
Emotional Support							
Never	18	3.79	2.65	1.00	5.56	4.13	47.64
Rarely	29	6.11	3.00	1.31	4.41	4.14	38.24
Sometimes	80	16.84	2.79	1.21	3.00	3.91	36.00
Often	103	21.68	2.59	1.17	2.34	3.96	29.34
Always	245	51.58	2.43	1.13	1.59	3.87	26.60
*Mean; SRH = self-rated health; BMI = body mass index							

Discussion

In this study, we aim to investigate the impact of patients' disease types on direct and indirect caregiving consequences, measured by caregiving time and caregiver burden, respectively. This is the first study that investigated the association between patients' disease types on caregiving time and caregiver burden, using data from a national survey that gauged a representative list of patients' disease types. Our study finds that compared with non-caregivers, caregivers experienced significantly worse levels of self-rated health, BMI, and psychological distress. This finding resonates with what reported in previous studies [38, 43, 44], and further highlights the need for intervention studies that could acknowledge and address caregiver burden. As approximately 21.3% of U.S. adults or 53.0 million Americans are informal caregivers who often do not have the adequate knowledge or skills needed to take care of the patients [18], whether or not successful interventions can deliver much-needed health solutions to these caregivers may impact not only the health of patients and caregivers, but also the health of the society [45, 46].

Adding insights to the literature [38, 47–49], findings of this study further suggest that caregivers who are female, older, had lower levels of education, physical inactivity, SES, unmarried, unemployed, not having health insurance experienced greater levels of caregiver burden. In other words, caregivers who belong to underserved communities are most likely to experience worse levels of caregiver burden. This worrying finding underscores the urgent need for timely and effective interventions that could alleviate these underserved populations' caregiver burden, such as intervention programs that are tailored to these caregivers' unique unmet needs [50–52]. As these disadvantaged caregivers are often difficult to reach via traditional intervention measures [53, 54], researchers may consider using more agile and flexible programs, such as local reach programs [55–59] or technology-based solutions [60, 61], to deliver relevant and effective health solutions to these caregivers in a convenient and cost-effective fashion.

Results indicate that while caregivers of patients with neurological or related disease spent the greatest amount of time on caregiving, both in terms of overall caregiving duration and caregiving hours spent per week, their self-rated health, BMI status, and psychological stress are not the worst among all caregivers. Rather, caregivers of patients with aging-related disease or cancer reported worst self-rated health, caregivers of patients with orthopedic or related disease had the most worrisome BMI status, and caregivers of cancer patients experienced worst levels of psychological distress. In other words, medical conditions that require the greatest caregiving time may not exert the greatest levels of burden to caregivers. One way to explain this finding is that though some medical conditions may require a less alarming amount of caregiving time, the intensity and emotion strain of caregiving involved in taking care of the patients may be equally, if not more, burdensome [18, 28, 31, 32, 62–64]. While this finding helps shed

light on the relationship between caregiving time and caregiver burden, it also emphasizes the need for more research to further chart factors that influence caregiving time and caregiver burden (e.g., disease severity [65]). To extend our understanding on how patients' disease characteristics influence caregiving consequences, future research could examine a more comprehensive list of disease-related characteristics to identify which factors have the greatest impact on caregiving consequences.

Based on findings of this study, researchers could also consider tailoring interventions based on patients and caregivers' needs and preferences [66–69]. Findings suggest though tailored and generic interventions both have potential to decrease caregivers' anxiety and depression symptoms, tailored interventions are more likely to induce sustained long-term health improvements in caregivers [66]. Evidence further indicates that dyad-based interventions can often take account of both patients' and caregivers' characteristics and preferences, and therefore have greater potential in improving patients and caregivers' coping skills and health outcomes than interventions designed solely for patients or caregivers [70–72]. Overall, findings of this study fill considerable gaps in the literature and offer critical insights that could help further the research field.

Limitations

First, the survey was cross-sectional in nature, which limits causal inference. We adopted a validated and reliable nationally representative survey, HINTS 5 Cycle 2, as our data source. While there are many benefits in secondary data analysis of a nationally representative survey (e.g., cost-effective, time-efficient, and ability to generate findings with greater replicability and comparability) [73–75], as the survey is not specifically designed for this study, substantial research rigor could be lost due to the lack of purposeful survey design. To address these drawbacks, future research could develop research with tailored and robust survey design (e.g., longitudinal or mixed-methods) to increase research rigor.

Conclusion

This is the first study that investigated the impact of patients' disease types on caregiving time and caregiver burden, using a comprehensive list of disease types surveyed in a nationally representative survey. Findings of this study show that underserved caregiver populations often subject to greater levels of caregiver burden in terms of self-rated health, BMI, and psychological distress. Results also indicate that great variations are found in the impact of patients' disease types on caregiving time and caregiver burden. These insights extend our understanding towards the relationship between patients' disease types and caregiving consequences. Furthermore, findings of this study also underscore the need for healthcare researchers to adopt a nuanced approach in acknowledging and addressing caregiver burden, such as tailoring interventions based on patients and caregivers' needs and preferences. Overall, our study fills important gaps in the literature and offers great opportunities for better understanding the interaction between patients' disease characteristics and caregivers' burden and health outcomes.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

None.

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None

Authors' contributions

ZS developed the research idea, oversaw the data analysis, and wrote the manuscript. ZZ conducted the data analysis, wrote the results section, and reviewed the manuscript. JG reviewed and edited the manuscript. All three authors participated in the process of building of the manuscript.

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