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A Population-Based Survey of the Workplace Costs for Caregivers of Persons With Treatment-Resistant Depression Compared With Other Health Conditions

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Objective: To describe caregiving work outcomes and related indirect (ie, productivity) and direct (ie, caregiving hours and expenses) costs. **Methods:** A national, population-based survey to identify employed caregivers assisting a person with treatment-resistant depression (TRD) and a comparison group of employed caregivers assisting others (No TRD). **Results:** Screening identified 169 TRD caregivers and 1070 No TRD caregivers providing 23.3 and 14.6 mean weekly caregiving hours, respectively. Adjusted annual indirect cost estimates were \$11,121 for caregivers of TRD and \$7761 for caregivers in the No TRD group ($P \leq 0.0001$). At-work productivity loss (presenteeism) was the largest component. Adjusted annual direct cost estimates were \$29,805 for caregivers of TRD and \$20,642 for caregivers in the No TRD group ($P \leq 0.0001$). **Conclusions:** TRD exacts a toll on caregivers and their employers exceeding that for other caregivers.

Keywords: absenteeism, caregiver, depression, presenteeism, productivity

An estimated 53 million Americans serve as family caregivers providing assistance to a family member or friend who needs help due to an illness, disability, or aging.^{1,2} Caregiving tasks vary but typically involve assistance with activities of daily living (ADLs) and instrumental ADLs (IADLs). ADLs include tasks such as assisting with personal hygiene, feeding, and transferring the care recipient.¹ IADLs include tasks such as providing transportation,

shopping, housework, preparing meals, managing finances, and helping with medical regimens.¹ Currently, the average caregiver provides an estimated 24 hours of caregiving per week.¹ In the majority of cases, caregiving is provided without compensation and sometimes at a significant cost to the health, well-being, and finances of the caregiver.^{1,3,4} Despite challenges, many caregivers do not want to relinquish this role.

While little acknowledged, caregiving is a workplace issue affecting employees and employers. Sixty-one percent of caregivers are employed¹ signifying that most need and/or want to work. Caregivers are found in many different occupations and business sectors and are diverse demographically and occupationally. Given the large time and financial commitment of caregiving, an estimated 60% of employed caregivers encounter serious difficulties managing their dual caregiving and job roles. Problems with conflicting demands, role overload, and other issues may exact a price both professionally and personally.^{1,5} For example, compared with employees who are not caregivers, caregivers have lower lifetime earnings, which partly reflects job churning. Specifically, many caregivers periodically leave and re-enter the labor market, retire early, and/or change career paths to tradeoff earnings with jobs that offer a better work-life balance.^{6–8} Employed caregivers also are in poorer health than employed non-caregivers,⁹ and commonly experience physical, emotional, and financial strains. The difficulties inherent in caregiving are concerning because of the implications for caregiver well-being, and because caregiver strain may snowball into poorer care recipient health outcomes and increased healthcare costs.¹⁰ On the employer side, observational studies are finding that caregivers have more absences and at-work performance losses than non-caregivers.⁹

The large proportion of caregivers who are also employed is unlikely to decline anytime soon. Their numbers are fueled by social trends in labor market participation, including an increased number of female and older workers, growth in the number of older adults including those who prefer to live out their older years at home, briefer lengths of inpatient stay and gaps in the availability of community-based care. However, research has not kept pace with the need for knowledge that could reduce the individual, family, and workplace caregiving burdens. Thus, this study's primary aim is to increase knowledge of the work outcomes of caregiving and related indirect (ie, productivity) costs. These costs accrue to both employers and employees. A second aim is to increase knowledge of the direct costs of caregiving due to hours spent caregiving and expenses for resources and supports.

Much of the extant caregiver research includes non-working caregivers and those involved in the care of persons with memory disorders such as Alzheimer's disease. We focus on caregiving for persons with treatment-resistant depression (TRD) as a case example of an important hidden population. In a large diverse employed caregiver sample, we compare TRD caregiving costs to those of caregivers assisting persons with other chronic conditions. TRD is an illness that involves a substantial burden on the person with the illness. It is a chronic form of clinical depression, which is a prevalent and costly condition involving symptoms and functional

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Ethical considerations: The study protocol was reviewed and approved by the Tufts Health Sciences Institutional Review Board (Protocol No. 13149).

Clinical significance: Treatment-resistant depression is a chronic, disabling health problem that has an impact on family caregivers who are also working, and employers. Employed caregivers experience high productivity loss primarily due to presenteeism. They also have high out-of-pocket expenses, reflecting the many hours spent performing unpaid caregiving tasks.

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limitations that interfere with life activities including working. TRD occurs in approximately 30% of pharmacologically-treated depression cases (with an estimated 1% population prevalence).¹¹ While many people with depression do not obtain treatment, TRD is defined within patients treated for depression but who have not had an adequate improvement in symptom severity. TRD includes patients whose depression symptoms have not remitted after at least two full courses of anti-depressant treatment at the required, guideline-concordant durations, and dosages.¹² In prior research on TRD, the presence of depression symptoms for 12 months or longer has been used as a stringent criterion.¹² In patient studies, TRD has been found to be more costly than treatment-responsive depression¹³ with care costs averaging \$3000¹⁴ more annually and \$1811 more in annual productivity loss.¹⁵ In a systematic review,¹⁶ excess indirect and direct costs of TRD compared with treatment-responsive depression were \$5481 and \$4048 higher, respectively. In the present study, we consider the secondary impact of TRD on caregivers who are also employed.

METHODS

In 2019, we conducted a cross-sectional, anonymous caregiver survey, which was administered on a privacy-protected study website. The study protocol was reviewed and approved by the Tufts Health Sciences Institutional Review Board (Protocol No. 13149). The study included caregivers of persons with TRD, employed and unemployed, and caregivers of persons with health conditions other than TRD (No TRD). We collected data from employed caregivers on four work outcomes that contribute to indirect costs: presenteeism, absenteeism, cut back in work hours, and leaves of absence; and two direct cost components: out-of-pocket expenses for services provided to the care recipient or related to managing the household, and the cost of caregiving hours.

Potentially eligible study participants were recruited through: (1) the Dear Abby online newspaper column, which appears in 1400 newspapers with a combined circulation of 110 million; (2) employer members of the Employers Health Coalition, Inc., an employer-led business group headquartered in Canton, OH; (3) the Tufts Medical Center in Boston, MA; and (4) the National Alliance for Caregiving, Bethesda, MD and Colorado Respite Care, Lakewood, CO. Each site posted information about the study on its website and provided a study URL. The ads invited all caregivers to participate, and mentioned that we were seeking to include a group of caregivers of persons with depression.

Interested individuals were asked to take an online eligibility screening questionnaire. Eligible caregivers were defined as individuals that had to provide or arrange for assistance in the past 12 months for a relative or friend at least 18 years of age with an illness or disability that leaves that person unable to do some things, or who needs assistance because he/she is simply getting older. Help was characterized as assistance with household chores, finances, or personal or medical needs. The care recipient could live in his or her own home in the caregiver's home, or in another home or facility. Screening questions were adapted from the National Survey of Caregivers.^{1,2} Eligible caregivers also were not paid for their assistance, lived within 50 miles of the care recipient, were between 18 and 67 years of age, and were able to read and speak English. Caregivers considered to be "employed" worked for pay at least 10 hours per week. Because we anticipated finding a large number of caregivers of persons with dementia or Alzheimer disease that would overwhelm the comparison group, we excluded most (80%) of those potentially eligible caregivers and included only a randomly selected 20%. This exclusion increased clinical and demographic diversity in the sample. We identified this caregiver group based on responses to a single question asking if the care recipient had a memory disorder such as dementia or Alzheimer disease. Finally, if the caregiver reported the presence of bipolar disorder or

schizophrenia in the care recipient, the caregiver was excluded from the TRD group.

As part of the screener, eligible caregivers were asked questions aimed at determining whether the care recipient may have TRD. We wrote a series of questions operationalizing and augmenting the AHRQ criteria for TRD.¹² First, the screener asked caregivers if the care recipient had received a diagnosis of depression and were prescribed anti-depressant treatment, and the duration of depression symptoms. Caregivers were classified in a Possible TRD group if, in the past 12 months, the care recipient had depressive symptoms, the symptoms persisted all or most of the time, and a physician had prescribed antidepressants. Caregivers who did not meet these criteria advanced to the No TRD portions of the core study questionnaire.

Caregivers who met the Possible TRD screening criteria were advanced to a special portion of the core study questionnaire asking about the specific antidepressants prescribed, adherence to the prescribed duration and dosage, and use of an augmentation medication (see online supplement, <http://links.lww.com/JOM/A787>). The questions were: (1) "in the past 12 months, has (care recipient) taken any of these for depression," which was followed by a list of antidepressant names; (2) "was there another medication taken with a name you don't remember"; (3) "what is the name of the medication that (care recipient) was taking most recently"; (4) "to the best of your knowledge, did (care recipient) take this medication as prescribed?" followed by yes, no, and do not know response options; (5) "to the best of your knowledge, was (care recipient) prescribed another medication to improve or boost (the name of the most recent antidepressant)"; and (6) which medication (on the list) was it? "That is, the one taken to improve the effect of (the name of the most recent antidepressant)." Caregivers were assigned to the TRD group if they reported their care recipient had taken two or more prescribed antidepressants at the prescribed dosage and duration, or one antidepressant plus an augmentation medication. Caregivers who initially qualified as Possible TRD but did not meet all of the TRD criteria ($n = 24$) or had incomplete data ($n = 38$), were subsequently excluded from the sample. The remaining caregivers were included in the analytic sample either in the TRD or No TRD caregiver groups.

In addition to establishing TRD, the study questionnaire asked all eligible caregivers further demographic, health, employment, and caregiving questions. At the end of the questionnaire, an Amazon coupon code for \$10 popped up automatically for sites approving the incentive.

To obtain the main outcome variable, total indirect costs, four components were measured. (1) Presenteeism related to caregiving was measured with the validated Caregiver-WLQ (C-WLQ).^{17,5} The C-WLQ includes 22 items capturing the extent to which caregiving has impacted work performance and productivity. Its four scale scores reflect the percentage of time (0% to 100%) in the past 4 weeks the caregiver was limited in performing time management, physical tasks, mental and interpersonal tasks, and output tasks. Item responses range from all of the time (5) to none of the time (1) with a "does not apply to my job" option (assigned as missing). Scale scores are computed as the average of non-missing item scores within each scale and then converted to a score ranging from 0 to 100 (higher score = more limitations). The C-WLQ is based substantially on the WLQ,¹⁸ which measures the impact of health problems on work performance and productivity. Therefore, we converted scale score to percentage of at-work productivity loss in the past 4 weeks using the WLQ's algorithm. The algorithm is the sum of each scale score multiplied by a scale coefficient. Coefficients are based on models estimating objectively-measured productivity loss from WLQ scores.¹⁹ (2) Absenteeism was measured with the validated Caregiver Time Loss Module,^{17,5} which asks about full and part days missed in the past 4 weeks due to caregiving,

computed as number of days missed assigning full days a value of 1 and half days a value of 0.5. The percentage of productivity loss due to absences is the ratio of total time missed due to caregiving to the total time usually spent working. (3) Cut back on work hours is based on a single yes/no item asking about change in scheduled work hours in the past 12 months. For those answering “yes,” we assumed a 10% reduction in the caregiver’s report of weekly work hours, which was then annualized by multiplying by 52. The 10% figure was assumed to be conservative relative to assuming a change from full-time to part-time status. For those answering “no,” we assigned a value of zero. (4) Leave of absence is based on three questions asking about the availability of paid leave, whether any leave has been used in the past 12 months and, if yes, the number of leave days taken. The four indirect cost indicators were translated into annual dollars using the following procedures. The percentage of productivity loss due to presenteeism and percentage of productivity loss due to absenteeism were assumed to be annual rates. Each rate was multiplied by a \$25 per hour wage rate, which is the 2018 average wage for all occupations.²⁰ Next, each result was multiplied by 2080 annual hours. The 12-month reduction in work hours was multiplied by daily earnings ($\$25 \times 8$ hours) as was the number of leave of absence days. The four annualized costs were summed to generate a total indirect cost.

To assess the direct costs of caregiving, questions asked about the amount of time spent on specific caregiving role demands and out-of-pocket expenses related to caregiving. The sum of the two amounts was the total direct cost. Time spent caregiving was based on responses to a modified version of the validated Family Experiences Interview Schedule (FEIS)²¹ asking, during the past 4 weeks, how much of the time did you help with grooming, bathing, or dressing; taking medicine; doing housework or laundry; shopping for groceries, clothes, and other things; cooking or helping with preparing meals; providing transportation or using public transportation; managing money; encouraging him/her to go to work, school or aftercare, or visit with friends; The responses were: (1) not at all; (2) less than once a week; (3) one or two times a week; (4) three to six times a week; or (5) every day. Responses were converted to hours as follows: not at all = 0; less than once a week = 0.5 hours; one or two times a week = 1.5 hours; three to six times a week = 4.5 hours; every day = 7 hours. Hours were converted to annualized costs by multiplying the number of weekly hours by \$25 per hour and 52 weeks.

Out-of-pocket caregiving expenses were assessed by asking: in the past 12 months, did you pay all or part of the cost of services for someone to assist the named care recipient and, if yes, which services did you pay for? The choices were: personal care services, not including home health care (eg, people helping with grooming, dressing, etc, which may be covered by insurance); housekeeping services (eg, people doing cleaning, cooking, laundry, etc); sitter services; food or meal delivery services; landscaping, grounds keeping, snow removal services; transportation services; employment training or vocational training services; financial management services; legal services; services for your family or household you are unable to do yourself when helping the care recipient; and other services. A follow-up question asked “to the best of your knowledge, what was the total amount you spent for all of these services in the past 12 months?” Choices were 0 to \$500; \$500 to \$999; \$1000 to \$1999; \$2000 to \$3999; \$4000 to \$7999; \$8000 to \$15,999; (8) \$16,000 or more. We used the mid-point of the range to estimate the 12-month cost for responses 1 to 7, and \$18,000 for response 8.

We generated descriptive statistics (means and standard deviations, *N*'s and percentages) for each variable and tested for differences between the TRD caregiver group and the No TRD caregiver group. Group differences were tested with chi-square, *t* tests, or analysis of variance as appropriate. To estimate indirect costs and direct costs and determine the degree to which TRD costs

differed from No TRD costs, a series of generalized linear model (GLM) were tested, described in detail below.

Prior to modeling, we reviewed data quality and completeness. A total of 36% of the caregivers had at least one of the four components of indirect costs missing, we explored the sources of missing data and evaluated various data imputation approaches. Generally speaking, we used imputation methods that introduced the least amount of bias to the values based on the non-missing data. First, at-work productivity cost was imputed using regression methods. At-work productivity cost from available data was regressed on the number of days absent in the past 4 weeks and the four scale scores from the C-WLQ to identify significant predictor variables. A series of models then quantified coefficients for each predictor separately. If a caregiver had data for one or more of these predictors, then at-work productivity was predicted using the variable coefficient(s) for their data. Next, productivity loss due to absenteeism was imputed using the total sample mean score. Third, cut back in weekly work hours was set to zero for three subgroups with missing data: (1) caregivers who were self-employed (whose work may be less structured than not self-employed), and two groups at the ceiling and floor of the weekly work hours distribution, (2) those reporting weekly work hours exceeding 40, and (3) those reporting fewer than 20 weekly work hours and at least 30 annual leave days. Days on leave were imputed using the respective TRD and No TRD group means, which had less of a biasing effect than using the overall sample mean.

We also identified several demographic and health differences between the caregiver groups. Thus, we present both unadjusted and adjusted models to estimate indirect costs and separately to estimate direct costs. The adjusted cost models used GLM procedures in which the total cost variable (eg, indirect costs or direct costs) was regressed on a TRD indicator variable ($1 = \text{TRD}$ vs $0 = \text{No TRD}$), caregiver age, sex (male = 1; female = 0/other), race/ethnicity (white = 1; non-white = 0), and part-time job (1) versus full-time job status (0). Prior to GLM modeling, the Park test was used to select the probability distribution family most appropriate for analyzing the cost data. We chose to run the GLM with a Gaussian distribution and a log link function. After the model fitting, the coefficient for each independent variable was converted back into dollars using the recycled predictions method. For example, the predicted indirect cost (in dollars) for “TRD” was calculated by setting the TRD indicator variable to 1 for each observation and then averaging the predicted cost across the entire dataset. A similar procedure was used for No TRD. Finally, the regression coefficient quantifying the TRD versus No TRD difference was converted to dollars by taking the difference in costs for TRD versus No TRD predictions across entire dataset.

To assess potential sources of bias in the cost estimates, we repeated the modeling procedure omitting self-employed caregivers, based on the assumption that access and use of benefits such as paid leaves may be related to employment type. Self-employment could also reflect a need to reduce work hours due to caregiving, leading to underestimation of indirect costs. Further details on missing values are provided in the Supplemental Appendix, <http://links.lww.com/JOM/A787>. Additionally, bias in the estimates may also have been introduced by caregiver mental health status. Thus, we tested the sensitivity of model results to caregiver depression based on the PHQ-2 score (defining a positive depression screen as a score of 4 or higher on each symptom), (ie, occurring at least some of the time in the past 2 weeks).²² We attempted to minimize bias by estimating productivity loss using the US mean wage rate for all workers.

RESULTS

Website hits totaled 14,127, resulting in 3773 completed screeners, and 1708 (45.2%) eligible caregivers. Of 2065 (54.7%) deemed ineligible, 595 (28.9%) did not meet caregiver

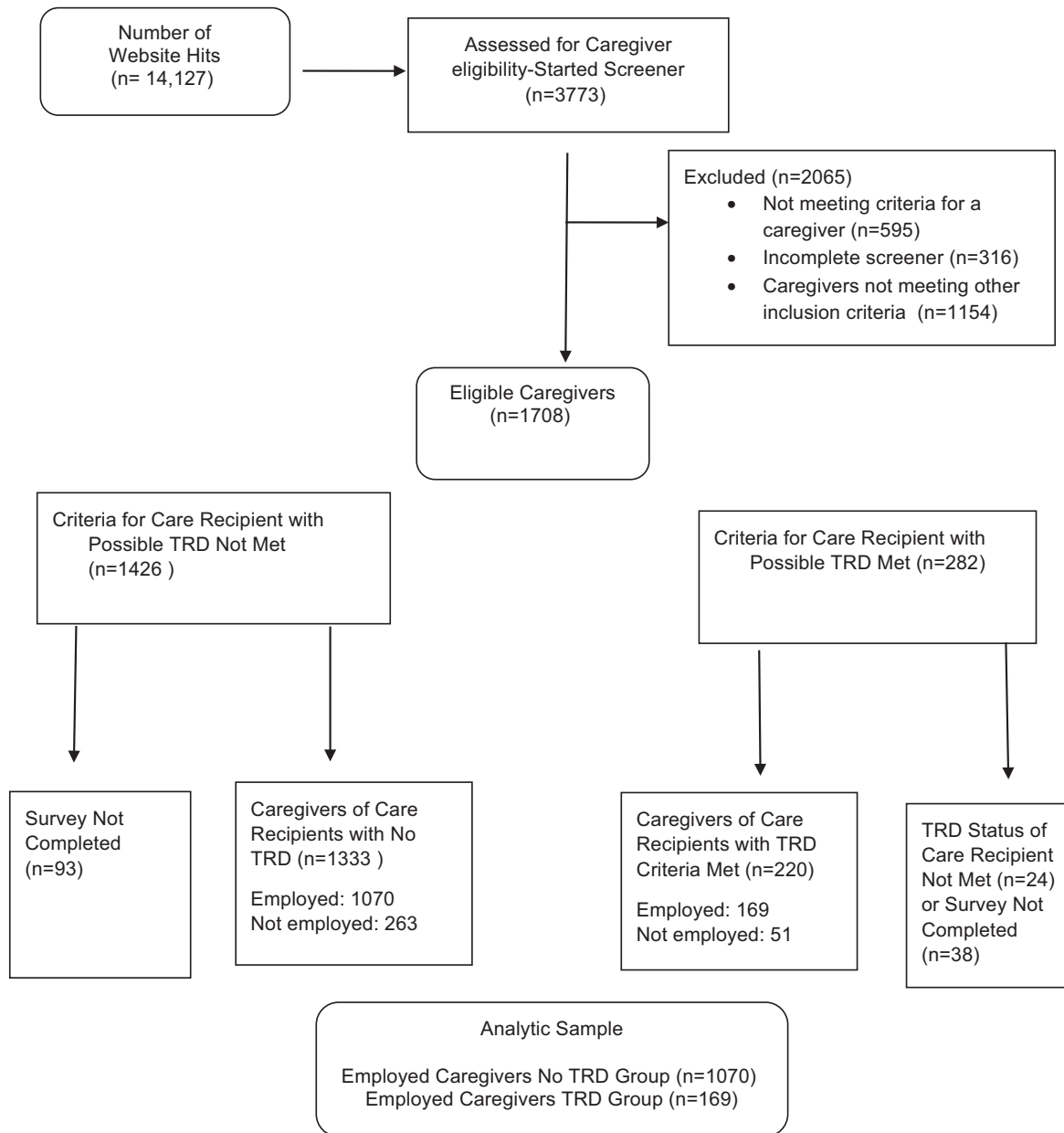


FIGURE 1. CONSolidated Standards of Reporting Trials flow diagram of enrollment in group of caregivers of persons with treatment-resistant depression group (TRD) and caregivers of persons with other conditions (No TRD). TRD, treatment-resistant depression.

criteria, 1154 (55.9%) had one or more of the other exclusionary criteria (eg, care recipient age, distance from caregiver, and/or exceeding the 20% limit for care recipient dementia), and 316 (15.3%) had incomplete data (Fig. 1). Based on screener responses, eligible caregivers were further classified into a No TRD group of 1426 (83.5%) and a Possible TRD group of 282 (16.5%).

Of the 282 caregivers in the Possible TRD group, 220 (78.0%) met criteria for a care recipient with TRD (TRD group) and 62 (27.2%) did not meet criteria for TRD status based on responses or due to missing data. These cases were excluded from further analyses. In the TRD group, 169 caregivers (76.8%) were employed and 51 (23.1%) were not employed. In the No TRD caregiver group (n = 1426), 93 (6.5%) did not complete the survey and were excluded from the analyses, leaving 1333 in the No TRD

caregiver group, 1070 (80.2%) who were employed, and 263 (19.7%) who were not employed (Fig. 1).

Caregivers in the TRD and No TRD groups were compared (Table 1). More caregivers in the TRD group were women (83.4% vs 66.9%), over age 30 (81.6% vs 48.0%), white (89.9% vs 64.4%), single (20.7% vs 9.9%), and held a bachelor's degree or higher (43.8% vs 29.2%). More than half of the No TRD group (51.5%) was between 21 and 30 years of age. All of the differences were statistically significant at $P \leq 0.001$.

Caregivers in both groups had similar levels of health-related difficulty concentrating on work (49.7% of the time in the past 2 weeks for the TRD group versus 51.3%; NS). Caregivers in the TRD group had significantly less health-related difficulty getting to work on time ($P \leq 0.0001$), though the percentage

TABLE 1. Sample Characteristics of Employed Caregivers

	Missing <i>n</i>	TRD <i>N</i> = 169	No TRD <i>N</i> = 1070	<i>P</i>
Caregivers				
Gender, % (<i>N</i>)	12			0.0001
Male		16.6 (28)	32.7 (346)	
Female		83.4 (141)	66.9 (708)	
Other		0 (0)	0.4 (4)	
Age, % (<i>N</i>)	6			0.0000
18–20		0.6 (1)	0.6 (6)	
21–30		17.8 (30)	51.5 (547)	
31–44		34.3 (58)	20.9 (223)	
45–54		18.3 (31)	8.7 (93)	
55–64		23.7 (40)	15.2 (161)	
65–67		5.3 (9)	3.2 (34)	
Race/Ethnicity, % (<i>N</i>)	0			0.0000
White		89.9 (152)	64.4 (689)	
Non-white				
Marital status, % (<i>N</i>)	9			0.0010
Single		20.7 (35)	9.9 (105)	
Married		68.0 (115)	79.5 (844)	
Separated		1.2 (2)	1.9 (20)	
Divorced		5.9 (10)	5.3 (56)	
Widowed		3.0 (5)	1.5 (15)	
Living with a partner		1.2 (2)	2.0 (21)	
Education, % (<i>N</i>)				0.0000
Less than high school		0.0 (0)	0.4 (4)	
High school		4.1 (7)	3.3 (35)	
Post-HS vocational		7.7 (13)	1.9 (20)	
Some college		27.2 (46)	14.0 (149)	
2-year college		17.2 (29)	51.3 (545)	
4-year college		29.0 (49)	19.3 (205)	
Master's degree		12.4 (21)	7.6 (81)	
Doctoral degree		2.4 (4)	2.3 (24)	
Health-related work limitations past 2 weeks—work limitations questionnaire items				
Difficulty concentrating on work, mean (SD)	65*			
Percentage time with difficulty, mean (SD)		49.7 (23.8)	51.3 (23.5)	0.4183
Difficulty getting to work on time, mean (SD)	92*			0.0000
Percentage time with difficulty, mean (SD)		37.6 (27.5)	47.7 (25.3)	
Weekly work hours, mean (SD)	3	38.3 (9.9)	35.8 (9.6)	0.0018
Health-related work absences past 4 weeks, mean (SD)				
No. of days absent	52*	2.9 (3.2)	2.7 (2.9)	0.5318
Percentage of productivity lost due to absences	53*	7.2 (8.3)	8.1 (10.2)	0.2772
Depression screener—PHQ-2, % (<i>N</i>)				0.0000
Anhedonia	20			
Not at all		19.0 (32)	10.8 (114)	
On several days		26.8 (45)	69.9 (734)	
On more than half the days		32.1 (54)	11.0 (116)	
Nearly everyday		22.0 (37)	8.3 (87)	
Depressed mood	80			0.0000
Not at all		8.7 (14)	12.0 (120)	
On several days		37.3 (60)	53.4 (533)	
On more than half the days		33.5 (54)	25.3 (253)	
Nearly everyday		20.5 (33)	9.2 (92)	
Positive depression screen, % (<i>N</i>) [†]	85	16.8 (161)	6.7 (993)	0.0001

Bold values indicate the *P*-value less than or equal to 0.0500 is statistically significant.

*Includes does not apply to my job and missing/not at work.

[†]To be classified as positive for depression on the PHQ-2 screener, the person had to have a score of 4 or higher on each symptom (ie, occurring at least some of the time in the past 2 weeks).

of time with difficulty was substantial (37.6% vs 47.7%). In both groups, caregivers missed approximately 3 days in the past 2 weeks due to health (2.9 in TRD group vs 2.7; NS) and similar levels of productivity loss due to missed work time (7.2% in TRD group vs 8.1%; NS). Caregivers in the TRD group also reported more frequent depression symptoms of anhedonia (ie, loss of the capacity to experience pleasure) and depressed mood

($P \leq 0.0001$), and 16.8% versus 6.7% screened positive for depression ($P \leq 0.001$).

Regardless of caregiver group, most caregivers were the children of the care recipients (43.8% in the TRD group vs 65.3%); (Table 2). In the TRD group, the percentage of caregivers who were spouses or partners to care recipients was twice as high as the No TRD group (27.8% vs 12.7%); (difference in relationship

TABLE 2. Care Recipient Characteristics

	Missing	TRD	No TRD	P
Caregiver/care recipient relationship (% , N)	9			0.0000
Parent or step-parent		20.1 (34)	13.7 (145)	
Child		43.8 (74)	65.3 (693)	
Sibling or step-sibling		3.0 (5)	3.5 (37)	
Spouse or partner		27.8 (47)	12.7 (135)	
Other relative		1.2 (2)	3.1 (33)	
Friend or other non-relative		4.1 (7)	1.5 (16)	
Legal guardian		0 (0)	0.2 (2)	
Care recipient				
Gender (% , N)	10			0.0268
Male		38.1 (64)	28.1 (298)	
Female		61.9 (104)	71.7 (761)	
Other		0 (0)	0.2 (2)	
Age (% , N)	222			0.0000
18–29		9.5 (16)	13.5 (114)	
30–44		15.4 (26)	9.4 (80)	
45–54		8.3 (14)	6.0 (51)	
55–64		28.4 (48)	50.0 (424)	
65–79		30.2 (51)	11.9 (101)	
80+		8.3 (14)	9.2 (78)	
Health conditions [†]				
Hypertension, % (N)	18	60.2 (100)	25.1 (265)	0.0000
Diabetes (% , N)	26	45.1 (74)	34.4 (361)	0.0239
Cancer, not skin (% , N)	28	29.9 (49)	61.0 (638)	0.0000
Respiratory (% , N)	37	11.7 (19)	31.5 (327)	0.0000
Heart conditions (% , N)	26	30.9 (51)	35.5 (372)	0.1755
Schizophrenia	31	0	3.0 (31)	0.2128
Stroke (% , N)	32	17.9 (29)	30.3 (317)	0.0018
Dementia, memory (% , N)	37	3.7 (6)	3.9 (40)	0.5878
Psychiatric (% , N)	18	100.0 (169)	22.0 (231)	0.0000
Obesity (% , N)	27	30.9 (51)	13.2 (138)	0.0000
Hypothyroidism (% , N)	62	6.1 (10)	5.0 (52)	0.8379
No. conditions excluding TRD, % (N)	0			0.0000
None on list*		2.4 (4)	12.4 (133)	
1		23.1 (39)	39.1 (418)	
2		13.0 (22)	9.8 (105)	
3 [†]		61.5 (104)	43.8 (469)	
Major conditions, [‡] % (N)	0			0.0000
Yes		56.8 (96)	74.6 (798)	
No		43.2 (73)	25.4 (272)	

Bold values indicate the *P*-value less than or equal to 0.0500 is statistically significant.

*Care recipients with TRD may have other psychiatric comorbidities.

†Condition *P*-values compare yes, no, and do not know response categories.

‡Includes cancer (not skin), heart disease, lung disease (not asthma), and stroke.

type $P \leq 0.0001$). In both groups, most of the care recipients were women, though in the TRD group, the percentage was smaller (61.9% vs 71.7%; $P = 0.027$); the TRD group also reported more care recipients age 65 or older (eg, 38.5% in the TRD group vs 21.1% in the No TRD group; $P \leq 0.000$). However, there was a large number of missing care recipient age data for the No TRD group.

We observed several differences in the health status of care recipients in the TRD versus No TRD groups. For example, in addition to having a higher rate of psychiatric disorders (100.0% vs 22.0%), caregivers in the TRD group reported more care recipient hypertension (60.2% vs 25.1%), diabetes (45.1% vs 34.4%), and obesity (30.9% vs 13.2%), but less care recipient cancer (29.9% vs 61.0%), respiratory ailments (11.7% vs 31.5%), and strokes (17.9% vs 30.3%). Each comparison was statistically significant ($P \leq 0.024$). The groups were similar in the prevalence of dementia and hypothyroidism (each NS). In addition to these contrasts, results identify the heterogeneity in the health of care recipients in the No TRD group. The number of chronic conditions (other than TRD)

was significantly higher among care recipients in the TRD group (eg, 61.5% had three or more compared with 43.8%); ($P \leq 0.0001$), though the list did not include all conditions and 7.8% of caregivers answered “do not know” to one or more (data not shown). Additionally, the number reporting major conditions (cancer, heart disease, lung disease, and stroke) was 56.8% for TRD and 74.6% for No TRD ($P < 0.0001$).

In both caregiver groups, almost 90% of the caregivers self-identified as the primary caregiver, suggesting they had most if not all of the caregiving responsibility (Table 3); (overall *p* NS). Similar proportions, almost half, further reported that the care recipient lived in his or her own home (approximately 49%). However, more than twice as many caregivers in the TRD group (46.1% vs 21.6%) reported that they shared a home with the care recipient, while a much larger proportion of the No TRD group reported that the care recipient lived with another relative or friend (24.3% vs 3.6%); (overall $P \leq 0.0001$).

Consistent with the larger proportion of caregivers and recipients sharing a home, 88.0% of the TRD group reported having

TABLE 3. Characteristics of Caregiving-Employed Caregivers Only

	Missing	TRD	No TRD	P
<i>N</i>		169	1,070	
Primary caregiver, % (<i>N</i>)	6			0.0566
Me		89.9 (151)	89.3 (951)	
Another relative		0.6 (1)	3.2 (34)	
A friend		0.6 (1)	1.0 (11)	
Someone else		0.0 (0)	1.2 (13)	
No primary-shared		8.9 (15)	5.2 (56)	
Where care recipient lives, % (<i>N</i>)	23			0.0000
His/her own home		49.1 (82)	48.0 (504)	
Caregiver's home		46.1 (77)	21.6 (227)	
In home of another relative or friend		3.6 (6)	24.3 (255)	
He/she is hospitalized		0.6 (1)	1.4 (15)	
Group home or independent living		0.0 (0)	1.9 (20)	
Assisted living or long-term care facility		0.6 (1)	1.7 (18)	
Somewhere else		0.0 (0)	1.0 (10)	
Frequency of contact with care recipient past 4 weeks, % (<i>N</i>)	19			0.0000
Everyday		88.0 (147)	33.0 (348)	
One or more times each week but not everyday		9.0 (15)	62.8 (661)	
Several times a month, not every week		2.4 (4)	3.2 (34)	
Once or not at all		0.6 (1)	0.9 (10)	
Imputed weekly caregiving hours,* mean (SD)				
Grooming	43	2.3 (2.6)	1.4 (1.8)	0.0000
Medications	52	3.5 (3.0)	2.0 (2.2)	0.0000
Housework	43	2.8 (2.9)	1.8 (2.0)	0.0000
Shopping	47	2.3 (2.6)	2.2 (2.1)	0.5315
Preparing meals	48	3.6 (2.9)	1.9 (2.2)	0.0000
Transporting	46	3.1 (2.7)	1.7 (1.8)	0.0000
Finances	44	4.1 (2.8)	2.0 (2.1)	0.0000
Encouragement	46	2.1 (2.5)	2.2 (2.2)	0.7781
Total caregiving hours	0	23.3 (13.6)	14.6 (10.6)	0.0000

Bold values indicate the *P*-value less than or equal to 0.0500 is statistically significant.

*Questionnaire response categories were recoded using the following formula: Not at all = 0; less than once a week = 0.5 hours; 1 or 2 times a week = 1.5 hours; 3 to 6 times a week = 4.5 hours; every day = 7 hours.

daily contact (vs 33.0% in the No TRD group; overall $P \leq 0.0001$); (Table 3). Two-thirds of the No TRD group had contact with care recipients several times each week. The total number of weekly hours spent caregiving was 23.3 in the TRD group and 14.6 in the No TRD group (overall $P \leq 0.0001$). Caregiving hours for six of the eight task categories were significantly higher ($P \leq 0.0001$ on each of six tasks). For example, weekly hours spent administering and/or monitoring medications was higher for the TRD group (3.5 vs 2.0; $P \leq 0.0001$).

We found several occupational differences in the caregiver groups (Table 4). These included a higher percentage of hourly workers among caregivers in the TRD group (51.9% vs 27.0%), less self-employment (11.2% vs 31.3%), and longer duration in the same job (26.5% vs 15.5% for 10 years or longer); (each comparison $P \leq 0.0001$). Caregivers in the TRD group had more difficulty taking time off for family matters (eg, rated very hard by 18.6% vs 6.7%) and more frequent interference between personal and professional life, though most caregivers in either group reported these problems occurred sometimes or often (each comparison $P \leq 0.0001$). Caregivers in the TRD group reported less access to paid or unpaid family or medical leave ($P \leq 0.0001$). In contrast, more caregivers in the No TRD group reported they did not have flexible work hours (66.1% vs 38.9%), workdays (70.9% vs 44.7%) or work arrangements (eg, remote work; 74.3% vs 63.9%); $P \leq 0.0001$ for all comparisons except work arrangements ($P = 0.007$). Finally, lack of access to health insurance through work was twice as high in the No TRD group (58.6% vs 23.5%) as was lack of access to insurance for the care recipient (72.5% vs 48.4%); (each comparison $P \leq 0.0001$).

The total unadjusted indirect cost of caregiving was \$10,098 for TRD caregivers versus \$7959 per year for No-TRD caregivers ($P < 0.0001$). Of the four cost components, at-work productivity loss contributed the most to indirect costs in either group (Table 5). Mean at-work productivity lost was 10.0% for the TRD group and 10.6% for the No TRD group (NS). Of the four types of at-work limitations contributing to productivity loss, the highest degree of limitation in either group affected time management at work, with difficulties averaging approximately 40% of the time (the equivalent of 2 full workdays in a 40-hour period). On the other three scales, limitations were still high, with means indicating difficulties occurring between 32.1% and 37.2% of the time. Group differences were significant on one scale, performance of physical tasks, with the No TRD reporting significantly higher limitations (38.1% vs 32.1%).

In unadjusted annualized dollars, the productivity cost of presenteeism was \$4979 for the TRD group and \$5281 for the No TRD group, a non-significant difference (Table 5). Caregiving-related work absences were higher in the TRD group (5.0 days vs 3.2 days). Caregivers in the TRD group had a larger percentage of productivity lost due to absences (3.0% vs 2.2%; $P = 0.0009$) resulting in an unadjusted annualized cost of \$1514 versus \$1123. A larger proportion of caregivers in the TRD group reduced their work hours (29.0% vs 11.5%), resulting in an unadjusted, annualized cost of \$1369 versus \$512 ($P < 0.0001$). Finally, the proportion taking a leave of absence was higher in the TRD group as well (11.1% vs 5.2%), resulting in a difference in the unadjusted annualized cost (\$4367 vs \$1047; $P < 0.0001$).

Total unadjusted direct caregiving costs for TRD versus No TRD were \$2759 and \$1282, respectively, for service payments

TABLE 4. Caregiver Employment and Impact on Employment

	Missing	TRD	No TRD	<i>P</i>
<i>N</i>		169	1070	
Pay arrangement, % (<i>N</i>)	149			0.0000
Salaried		43.8 (70)	66.6 (619)	
Hourly		51.9 (83)	27.0 (251)	
Other		4.4 (7)	6.5 (60)	
Self-employment, % (<i>N</i>)	139			0.0000
Not self-employed		88.8 (143)	68.7 (645)	
Self-employed, business owner		8.1 (13)	28.6 (269)	
Self-employed not business owner		3.1 (5)	2.7 (25)	
Time in job, % (<i>N</i>)	144			0.0000
Less than 1 year		14.8 (24)	28.3 (264)	
1–5 years		42.0 (68)	39.8 (371)	
5–10 years		16.7 (27)	16.4 (153)	
10+ years		26.5 (43)	15.5 (145)	
Difficulty taking time off, % (<i>N</i>)	122			0.0000
Not at all hard		13.7 (22)	7.9 (76)	
Not too hard		29.2 (47)	63.3 (605)	
Somewhat hard		38.5 (62)	22.1 (211)	
Very hard		18.6 (30)	6.7 (64)	
Job interferes with personal life, % (<i>N</i>)	133			0.0000
Often		30.6 (49)	10.3 (97)	
Sometimes		40.6 (65)	70.4 (666)	
Rarely		26.3 (42)	16.1 (152)	
Never		2.5 (4)	3.3 (31)	
Personal life interferes with job, % (<i>N</i>)	138			0.0000
Often		42.1 (67)	10.7 (101)	
Sometimes		36.5 (58)	67.2 (633)	
Rarely		17.6 (28)	19.1 (180)	
Never		3.8 (6)	3.0 (28)	
Resources available past 12 months, % (<i>N</i>)				
Paid family/medical leave	158			0.0000
No		72.5 (116)	47.8 (440)	
Yes, used		12.5 (20)	40.1 (369)	
Yes, did not use		15.0 (24)	12.2 (112)	
Unpaid family/medical leave	171			0.0000
No		60.2 (97)	40.1 (364)	
Yes, used		14.3 (23)	41.3 (375)	
Yes, did not use		25.5 (41)	18.5 (168)	
Flexible work hours	171			0.0000
No		38.9 (63)	66.1 (599)	
Yes, used		56.8 (92)	30.0 (272)	
Yes, did not use		4.3 (7)	3.9 (35)	
Flexible workdays	184			0.0000
No		44.7 (71)	70.9 (635)	
Yes, used		49.7 (79)	23.9 (214)	
Yes, did not use		5.7 (9)	5.2 (47)	
Flexible work arrangements	186			0.0070
No		63.6 (103)	74.3 (662)	
Yes, used		30.2 (49)	22.9 (204)	
Yes, did not use		6.2 (10)	2.8 (25)	
Health Insurance	191			0.0000
No		23.5 (38)	58.6 (519)	
Yes, used		66.0 (107)	35.4 (314)	
Yes, did not use		10.5 (17)	6.0 (53)	
Health insurance available to care recipient	197			0.0000
No		48.4 (78)	72.5 (639)	
Yes, used		32.3 (52)	22.4 (197)	
Yes, did not use		19.3 (31)	5.1 (45)	

Bold values indicate the *P*-value less than or equal to 0.0500 is statistically significant.

($P < 0.0001$) and \$30,308 and \$18,953 respectively for caregiving hours ($P < 0.0001$; Table 5). The total unadjusted direct cost was \$33,067 versus \$20,235 per year with the greatest economic burden in the TRD group ($P < 0.0001$). The proportion of caregivers in the TRD group with out-of-pocket expenses for caregiving services was double the rate of the No TRD group (45.5% vs 22.2%; $P < 0.0001$).

In multiple linear regression analyses (Table 6), estimating the indirect costs of caregiving, the TRD versus No TRD indicator was associated with significantly higher total annual indirect costs ($P \leq 0.0001$). Younger caregiver age ($P < 0.002$) and care recipient major medical conditions further contributed to greater indirect costs ($P < 0.001$). Adjusted annual indirect cost estimates were

TABLE 5. Unadjusted Indirect and Direct Costs of Caregiving With Imputation of Missing Values

	Missing	TRD 169	No TRD 1070	P
Indirect costs				
Work limitations due to caregiving, at-work productivity loss				
Time management, mean (SD)	97	44.1 (25.8)	43.8 (19.7)	0.8819
Physical tasks, mean (SD)	115	32.1 (26.8)	38.1 (21.9)	0.0022
Mental-interpersonal tasks, mean (SD)	114	37.2 (19.5)	38.1 (15.6)	0.4822
Output tasks, mean (SD)	133	36.3 (23.2)	39.4 (18.3)	0.0584
Percentage at-work Productivity lost, mean (SD)	171	10.2 (5.3)	10.7 (4.1)	0.1588
Imputed percentage at-work productivity lost, mean (SD)	75	10.0 (5.2)	10.6 (4.2)	0.1007
Annualized cost, mean (SD)	75	4,978.5 (2,624.6)	5,280.7 (2,090.6)	0.1007
Days missed per week, mean (SD)	119	5.0 (4.3)	3.2 (3.7)	0.0000
Percentage productivity lost due to absenteeism mean (SD)	120	3.1 (2.6)	2.2 (3.0)	0.0009
Imputed percentage Productivity lost due to absenteeism, mean (SD)	0	3.0 (2.6)	2.2 (2.8)	0.0007
Annualized cost, mean (SD)	0	1,514.2 (1,292.5)	1,123.0 (1,398.7)	0.0007
Cut down hours, % (N)	216			0.0000
Yes		29.0 (47)	13.1 (113)	0.0000
No		71.0 (115)	86.9 (748)	
Imputed cut down hours, % (N)	96	29.0 (47)	11.5 (113)	0.0000
Annualized cost, mean (SD)	96	1,369.0 (2,244.2)	5,11.9 (1,498.0)	0.0000
Leave of absence days, mean (SD)				
Leave days taken, mean (SD)	469 [†]	11.1 (22.7)	5.2 (18.0)	0.0006
Imputed leave days taken, mean (SD)	0	11.1 (21.8)	5.2 (13.6)	0.0000
Annualized cost, mean (SD)	0	2,221.7 (4,366.9)	1,047.1 (2,716.8)	0.0000
Total indirect costs, mean (SD)*	114	10,098.0 (7,724.6)	7,959.9 (5,059.5)	0.0000
Direct costs				
Imputed caregiving hours (mean, SD)	0	23.3 (13.6)	14.6 (10.6)	0.0000
Annualized imputed cost of caregiving hours, mean (SD)	0	30,307.7 (17,675.3)	18,952.7 (13,732.3)	0.0000
Imputed caregiving out-of-pocket expenses (mean, SD)	0	2,759.4 (4,463.7)	1,282.3 (2,871.9)	0.0000
Total direct costs, mean (SD)*	0	33,067.1 (18,383.4)	20,234.9 (14,481.8)	0.0000

Bold values indicate the *P*-value less than or equal to 0.0500 is statistically significant.

*All costs are annualized and based on the United States Bureau of Labor Statistics estimated annual average hourly wage of \$25 per hour for 2018.

[†]Missing cases include no leave days taken and missing data.

\$11,121 for caregivers of TRD and \$7761 for caregivers in the No TRD group ($P \leq 0.0001$). After omitting data from self-employed caregivers, the results were \$9580 and \$7097, respectively ($P < 0.0001$) and having a full-time job became a significant predictor of higher indirect costs ($P < 0.001$). Similarly, after omitting data from caregivers who screened positive for depression, the results were \$10,240 and \$7371, respectively ($P < 0.0001$).

In multiple linear regression analyses estimating the direct costs of caregiving (Table 6), the TRD versus No TRD indicator was significantly associated with higher total annual direct costs ($P \leq 0.0001$). White race/ethnicity was also a significant predictor of higher direct costs ($P \leq 0.0001$) as was having a major condition ($P = 0.050$). Adjusted annual direct cost estimates were \$29,805 for caregivers of TRD and \$20,642 for caregivers in the No TRD group ($P \leq 0.0001$). After removing self-employed caregivers, the results were \$27,941 and \$20,917, respectively ($P \leq 0.0001$). Full-time status also became significant ($P = 0.002$) and the association with having a major condition declined (NS). After excluding caregivers screening positive for depression, the results were \$27,940 and \$19,776, respectively ($P \leq 0.0001$).

DISCUSSION

Caregiving has been a normative part of American family life but perhaps what has changed is the size of the caregiving population that is also working, who is caregiving and working, and the complexity and longevity of the caregiving role among those who are working.

Recent research has helped to make caregiving issues more transparent, essentially revealing what long has been considered a

private, family matter. This study's results, and those of other national caregiving surveys, make a strong case for a specific focus on caregiving as a workplace and societal issue as well, a perspective that has been adopted by several business groups. Currently, most of the discussion about policies to support caregivers have been at the federal level, exemplified by the RAISE Act,²³ which mandates the study of and recommendations for policy options. Additionally, public insurers, including Medicare and Medicaid, and some commercial insurers are instituting provisions that in some cases provide payments for family caregivers, covering home health services and respite care. Advocacy groups such as the National Alliance for the Mentally Ill have caregiver support programs.^{24,25} These initiatives may chip away at the human and economic costs of caregiving and some, such as those related to paid leave, may indirectly address some caregiver employee burdens, but none is focused specifically on employed caregivers and the business dimensions of this issue. However, a greater focus is required not only to help caregivers and care recipients but also because employers cannot afford to lose the talent and productivity of this group. In the absence of significant employee and business-focused solutions, and a dearth of data on the business impact of caregiving, it is important for individual employers to understand the prevalence of caregivers among their employees, how available resources and benefits are being used, and the impact on caregivers, both positive and negative, of current organizational policies and culture.

We found that the indirect costs of caregiving for TRD was 30% higher than the costs of the caregivers who were assisting other individuals, and that presenteeism accounted for the largest share of

TABLE 6. Results of Generalized Linear Models Estimating Caregiving Costs

	Model n	Coefficient (\$ amount)	SE	95% CI (Lower, Upper)	P
Model 1: total indirect costs*	1,122				
TRD (1) versus Non TRD (0)		0.360 (3360.16)	0.052	0.258, 0.462	0.0000
Age		-0.075 (-1088.42)	0.025	-0.124, -0.026	0.0021
Male		0.056 (783.65)	0.061	-0.064, 0.175	0.3566
White		0.104 (1467.88)	0.059	-0.012, 0.219	0.0773
Part-time job		0.035 (521.40)	0.062	-0.087, 0.156	0.5716
Major medical condition indicator		0.217 (3135.35)	0.057	0.105, 0.328	0.0002
		Coefficient (\$ amount)	SE	95% CI (Lower, Upper)	
	Model n	TRD	No TRD	Difference	P
Estimated indirect cost of TRD versus No TRD†		11,120.69	7,760.53	3,360.16	0.0000
Model 2: total direct costs	1,231				
TRD (1) versus Non TRD (0)		0.367 (9,162.98)	0.043	0.283, 0.452	0.0000
Age		0.008 (240.65)	0.018	-0.027, 0.044	0.6448
Male		-0.097 (-2,780.92)	0.050	-0.195, 0.001	0.0522
White		0.427 (1,0611.87)	0.065	0.300, .555	0.0000
Part-time job		-0.054 (-1,628.90)	0.050	-0.152, 0.044	0.2826
Major medical condition indicator		0.089 (2,581.84)	0.046	-0.001, 0.179	0.0504
		Coefficient (\$ amount)	SE	95% CI (Lower, Upper)	
	Model n	TRD	No TRD	Difference	P
Estimated direct cost of TRD versus No TRD†		29,805.47	20,642.49	9,162.98	0.0000

Bold values indicate the P-value less than or equal to 0.0500 is statistically significant.

*All costs are annualized and based on the United States Bureau of Labor Statistics estimated annual average hourly wage of \$25 per hour for 2018.

†Cost were estimated through GLM Models with Gaussian Family and log link functions. Negative values indicate with every one point increase in the covariate there is a corresponding decrease in cost.

that cost. Additionally, the direct costs of caregiving, which exceeded an astounding mean \$20,000 in either group, also were 30% higher among TRD caregivers, including costs associated with the average 23 hours of caregiving per week for the TRD group and 15 hours per week for the No TRD group; both equivalent to having a part-time job in addition to a main job. To further put this amount into perspective, a large national survey of caregivers found that out-of-pocket expenses averaged \$7000 annually.²⁶ These results speak to the hidden high cost of mental disorders. On an individual employer level, the prevalence of TRD may limit the number of employees who fit into this caregiver group (1% of their employees). However, employers may also be bearing the costs of TRD through medical claims and pharmacy claims for employees with TRD, dependents with TRD, and caregiver health problems.

This study had certain limitations. It was cross-sectional and the sample, though large, was a convenience sample. We did not delve into important questions such as whether the caregivers' current work hours and self-employment, for example, were a consequence of being a caregiver, and whether any changes in work were elective or not. We did not ask about programs and resources employers may sponsor such as adult day care and care coordination assistance, which may have influenced presenteeism, absenteeism, and leave. In this study, we found the caregiver self-employment rate to be 12% in the TRD group and approximately one-third of the No TRD group. A 2015 national survey found that one in six caregivers is self-employed or owns his/her business, which is almost twice the national average for non-caregivers.¹ More research is needed to understand the relationship of caregiving and self-employment, and the pros and cons to caregivers of self-

employment over other work arrangements. A further caveat applies to the fact that this study relied entirely on self-report from caregivers including self-report of detailed care recipient information. This was the first time that self-report has been used to operationalize the TRD criteria, and though following rigorous survey methods, the assessment tool was not tested for reliability and validity. The study also had missing values on several key variables. Some of the missing data is related to the high proportion of self-employed caregivers. Also, we cannot discern whether the caregiving needs of persons with TRD are measurably greater than those of other care recipients. Finally, the percentages of productivity lost due to presenteeism and absenteeism in a 4-week period were annualized. We also did not evaluate the household impact of caregiving costs such as the proportion of caregiving expenses to total household income.

We were conservative in terms of some of the cost assessments. We used a standard \$25 per hour wage estimate. Validated measurement tools were used to capture comprehensively multiple indirect and direct cost components. We assumed that a caregiver's need to "cut back in work hours" would not exceed 10% of weekly work hours. Also, we did not include work impacts that occurred prior to the 12-month period, though some of the caregivers may have modified their work and careers already. We also excluded caregivers of minors and a large portion of those caring for persons with memory disorders.

This study contributes new information about the high degree of time and effort associated with caregiving among employed individuals and the associated costs to the caregivers and employers, reporting the relatively high costs of caring for a person with TRD. While the caregiving costs associated with serious mental illnesses

such as schizophrenia have been documented, this study's results provide a new perspective of the high personal and workplace costs of depression.

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