EMPLOYERS HEALTH

Caregiving and Work

- America increasingly depends on family and friends to assist family members or friends who, because of health, disability or aging, need assistance with everyday activities. These helpers are called informal caregivers.
- Almost one-fifth of the adult population, 43.5 million Americans, are informal caregivers.(1) Many informal caregivers, 8.4 million, assist a family member or friend with an emotional or mental health issue (1).
- Three-fourths of informal caregivers themselves suffer from chronic stress, and four in ten have difficultly taking care of their own health (2). Stress, anxiety, and depression are common problems (3).
- Most informal caregivers are also employed. Over 70 percent of the employed caregivers have difficulty balancing caregiving and work. As a result, caregivers frequently end up reducing their work hours, taking less demanding jobs, turning down promotions, taking leaves of absence, and/or retiring early (1).
- Also, 54 percent of employed informal caregivers report that their personal caregiving responsibilities had been detrimental to their work performance (5).
- In a study conducted within a large financial services company, employee caregivers had worse physical and mental health limitations than employees who were not caregivers and were more limited in their ability to perform work tasks (6).

Impact in the Workplace

- The economic impact of this caregiving on employers and the nation is substantial.
- Employed caregivers responsible for assisting individuals 50-years-old or older are estimated to cost U.S. businesses $17 billion to $34 billion annually in productivity loss (7,8).
- Work absences due to caregiving are estimated to cost businesses at least $25.2 billion annually (9).
- Most informal caregivers need to work and want to work. Many depend on a job for their own economic security and quality of life as well as the economic security and quality of life of those they assist. Though they may pay a price for caregiving, given the choice, few would give up the caregiving role.

Study Overview

Approximately 6.6 percent of the U.S. adult population has major depressive disorder (10). Many individuals with depression do not receive treatment and the treatment provided is often substandard. Even among those receiving adequate treatment, approximately 30 percent (or 3 percent of those with major depression) do not respond to treatment and fail to improve significantly or achieve remission. This group has a form of depression called Treatment Resistant Depression (TRD). Research indicates that among patients with major depression, TRD has the highest direct (medical care) and indirect (productivity) costs (11). This study will determine the work and economic impact of TRD, with a specific focus on the impact on employment and the workplace.

Study Aims

The primary aim of this study is to determine the economic impact of caregiving for persons with TRD related to various types of work loss (e.g., caregiver unemployment, reduced hours and reduced work productivity), and caregiving-related expenses. We will also evaluate the impact of caregiving on personal well-being.

In order to determine how caregiving influences employment and productivity, we will be comparing employed caregivers of persons with TRD to several other groups: employed non-caregivers, employed caregivers of adult care recipients who do not have TRD, and unemployed caregivers of persons with TRD. We plan to obtain all except the last group (unemployed) from employers associated with Employers Health.

The secondary study aim is to determine the economic impact of TRD on persons with the condition that are related specifically to work loss (e.g., loss of employment in the past year, reduced work hours and reduced work productivity). This aim is limited to assessing the costs related to employment and productivity impact. We will include persons with TRD who are employed and those who are not employed. The first group only will be obtained from employers associated with Employers Health.

The study seeks participants who are:

- employed caregivers of persons with TRD;
- employed caregivers of adults with conditions other than TRD;
- employed non-caregivers (Non-CG Employed); and
- employed persons with TRD

Study Design

This will be a cross-sectional study in which data will be collected using online questionnaires at eligibility screening and a one-time survey.

Measures and Key Variables

All data will be collected using self-report questionnaires administered on a privacy-protected study website located behind the Tufts Medical Center firewalls, which has been used in prior workplace research. The screening survey and study questionnaire will rely, whenever possible, on validated survey instruments. The total time for the screening will not exceed 10 minutes. The time for the full questionnaire, caregiver or patient, will not exceed 30 minutes on average, but is likely to be 15 minutes in length.

Employer role:

- Agree to participate by disseminating information about the electronic questionnaire and survey to employees.
- Send follow up reminders to encourage participation.
- Field questions from employees with provided FAQs.
- Promote the study during the study period (e.g. newsletters, emails, etc.).
- Request (or not) report out at conclusion of the study.

Employers Health role:

- Provide content and collateral to employers for promotion of the survey to employees, including:
    - Study overview/explanation for internal use
    - Timeline for execution
    - Introductory language/content to be used for email and other appropriate communication channels
    - Follow up language/content to encourage employee participation
    - FAQ documents to use when fielding questions from employees
- Provide reporting back to participating employers at conclusion of survey project. (Employer-specific report with at least 50 employee participants. Data are aggregate and de-identified. Must confirm desire for report in advance of survey execution.)

Study Workplan

The Tufts Medical Center study team will include:

- Debra Lerner, MSc, Ph.D., Principal Investigator,
- William H. Rogers, Ph.D., Chief Statistician,
- David Adler, M.D., Psychiatrist,
- Tara Lavalle, Ph.D., Health Economist
- Research Assistant (TBN)

Employers Health representative:

- Marcas Miles, MA

Study Period

During the period spanning approximately October 15 through December 31, 2018.

Additional info: Study announcements will briefly describe the purpose, procedures and participant requirements and invite interested individuals to take a brief online screening survey. The entire process of screening, eligibility determination, informed consent and enrollment will occur online on the study's privacy protected secure website. Each sample will be asked to complete a questionnaire (specific to that sample).

Please click here to let us know of your interest by Friday, October 5 so that we can support your efforts to promote the opportunity to your employees. Additional information and the survey link will be provided in early October.

FAQs

What is the study about? Caregiver and Patient Costs of Treatment-Resistant Depression (TRD): Indirect Costs and Humanistic Outcomes

Who is conducting the survey? Scientists from the Tufts Medical Center Program on Health, Work and Productivity and Tufts University School of Medicine and the Sackler School of Graduate Biomedical Sciences. Participant recruitment by Employers Health Coalition, of which our company is affiliated.

How is the study conducted? An initial screening will be provided to determine study eligibility. If eligible a full questionnaire will be presented. Data will be collected using online questionnaires for eligibility screening and a one-time survey.

How long will it take? The total time for the initial screening will not exceed 10 minutes. The time for the full questionnaire, caregiver or patient, will not exceed 30 minutes on average, but is likely to be 15 minutes in length.

How will the information be used? Any information will be treated with confidentiality and the survey respondents will remain anonymous. Data gathered will help researchers understand the magnitude and dimensions of the caregiving burden and promote the development of new approaches and policies to supporting caregivers in the workplace and persons with TRD.

Why is this important? An estimated 18 percent of the adult population, 43.5 million Americans, are informal caregivers (1). With 8.4 million providing assistance to a person with an emotional or mental health issue (1). Employment problems are prevalent among those in the caregiver role.

Who can participate? Employers Health member organizations have the opportunity to participate, by engaging employees to complete a screener for participation. If eligible, the full survey questionnaire will be available to employee.

Will I be able to see the results? Organizations that elect to provide the survey opportunity to employees are able to request a report out that includes aggregate results of the survey. Those with more than 50 employee survey participants may request an organization-specific report. Please make the request for the report at the beginning of the process.

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