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# Work incapacity among family caregivers: a record linkage study

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## ABSTRACT

**Background** Family caregiving-related physical and mental health problems may lead to work incapacity in employed caregivers. The aim of this study was to quantify sickness absences and disability pensions (SADP) among high-intensity family caregivers available to the labour market compared with a control population.

**Methods** The study sample included all individuals in Finland, who had received caregiver's allowance and were available to the labour market in 2012 (n=16 982) and their controls (n=35 371). Information on the number of sickness absence (spells >10 days) and disability pension (SADP) days and related diagnoses according to ICD-10 were obtained from national registers for the years 2012–2017. The analyses were adjusted for age, sex, occupational status, education, income and degree of urbanisation.

**Results** During the follow-up, 40.9% of caregivers and 39.5% of controls had at least one sickness absence spell and 6.1% and 4.7%, respectively, received disability pension. The mean annual number of SADP days was 23.2 (95% CI 22.3 to 24.1) for caregivers and 18.5 (95% CI 18.0 to 19.0) for controls (adjusted incidence rate ratio (IRR)=1.16, 95% CI 1.10 to 1.22). The number of annual SADP days due to mental disorders was higher in caregivers (7.2, 95% CI 6.7 to 7.8) than controls (4.0, 95% CI 3.8 to 4.3; adjusted IRR 1.58, 95% CI 1.42 to 1.75). There were no differences in SADP days due to cancer, neurological, cardiovascular, respiratory, or musculoskeletal diseases, or external causes.

**Discussion** Higher number of SADP days due to mental disorders in caregivers suggests that family caregiving has an adverse effect on work capacity and that caregivers are at increased risk for mental disorders.

compete for the same available limited resources, such as time and psychological resources, leading to stress.<sup>5</sup> Continuous stress may, in the long-term, result in impaired mental wellness and mental health problems.<sup>6</sup> Population-based caregiver studies have reported that mental health problems,<sup>7–10</sup> and more specifically depressive and anxiety symptoms,<sup>8–10</sup> are more prevalent in caregivers than in non-caregivers in general, and that working caregivers report more depressive symptoms,<sup>11,12</sup> poorer general mental well-being<sup>12</sup> and poorer self-reported physical health<sup>12</sup> compared with non-caregivers. Hence, caregiving and resulting health problems might threaten caregiver's work capacity.

However, only a few studies have investigated the association between caregiving and work incapacity, namely sickness absences.<sup>13–16</sup> In a Swedish study, caregiving workers were more likely to report a long-term sickness absence than non-caregiving workers.<sup>13</sup> Further, a study on European working adults reported that among women, family caregivers had an increased risk of a long-term sickness absence, while among men, no associations were found.<sup>14</sup> However, these previous studies did not analyse the risk according to diagnostic causes of the sickness absences. Knowledge of the underlying causes could help in directing preventive measures, screening and treatment more effectively. Some studies have also suggested that caregivers tend to exit labour markets prematurely.<sup>17,18</sup> To our knowledge, no studies have investigated the association of caregiving with disability pensions. Besides being a marker of work incapacity, disability pension can be viewed as a marker of long-term or permanent impairment in health, which usually has a major impact on functioning on several areas of life not only on work life.

The aim of this study was to quantify the number of sickness absence and disability pension (SADP) days among family caregivers compared with a control population using register-based data. In order to get a deeper understanding on the reasons underlying the SADP days, the data were analysed according to diagnostic groups.

## METHODS

### Material

All Finnish formally recognised family caregivers were identified based on a record of receiving family caregivers' allowance during the year 2012. In Finland, family caregiver's allowance can be granted by municipalities to a person, who provides care or attendance at home due to care recipient's

## INTRODUCTION

Family caregivers, that is, those who take care of another person who cannot manage everyday life independently because of illness or disability, are responsible for the majority of long-term care.<sup>1</sup> Many caregivers are of working age and consequently, actively participating in working life.<sup>2,3</sup> Due to population ageing and increasing life expectancy in individuals with a disability or long-term illness, the need for family caregivers is growing. Hence, it is expected that a greater proportion of working adults will be caregivers in the near future.

In general, family life may interfere with work and vice versa.<sup>4</sup> Drawing on the theory of conservation of resources, caregiving and work demands may



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functional limitation, illness, disability or other comparable reason. These formally recognised caregivers typically provide high-intensity care; according to a Finnish survey in 2012, 85% of formally recognised caregivers provided care 7 hours or more per day.<sup>19</sup> Granting of family caregiver's allowance does not depend on the family caregiver's income or employment status. Altogether 42 256 caregivers were identified (for more detailed description see<sup>20</sup>). Two controls—matched according to year of birth, sex, and municipality of residence (index date 1 January 2012)—per one caregiver were drawn without replacement from the register of the Population Register Centre. After removing individuals in institutional care, the final number of controls was 83 618. The matching yielded comparable groups of caregivers and controls with regard to the matched variables.<sup>20</sup>

Of these caregivers and controls, we identified those who were available to the labour market in 2012 based on the subjects' age and pension status. We defined a subject being available to the labour market if the subject's age was 18–65 years and the subject had not transitioned into old-age pension or permanent full-time or part-time disability pension prior to or on 1 January 2012 (age 65 years is the general statutory pension age in Finland). Information on the pensions in effect was obtained from the Finnish Center for Pensions (FCP) and from the Social Insurance Institution (SII). The number of caregivers fulfilling these criteria was 16 982 and the number of controls was 35 371.

### Follow-up time

Follow-up time was calculated in person-years as the difference between 1 January 2012 and either the date of moving abroad, turning 65 years, starting date of old-age pension, the date of death, or the end of follow-up, that is, 31 December 2017, whichever occurred first. The dates of moving abroad were obtained from the Population Register Centre, and the dates of death from the Causes of Death Register maintained by Statistics Finland.

### SADP days

Information on sickness absence spells longer than 10 days was based on the payment of sickness allowance and were obtained from the SII. Disability pension days and diagnoses were obtained from SII and FCP (a brief description of these work incapacity benefits in online supplemental material 1. Diagnoses were recorded according to International Classification of Diseases 10th Revision (ICD-10). The number of SADP days within the follow-up time were calculated. In case of part-time disability pension, the disability days were multiplied by 0.5. Diagnostic main categories with mean annual SADP days of 0.5 or higher (in either caregivers or controls) were reported: cancer (ICD-10 code C00–D48); mental disorders (F00–F99); schizophrenia, schizotypal and delusional disorders (F20–F29); mood disorders (F30–F39); depressive disorders (F32–F34); neurotic, stress-related and somatoform disorders (F40–F48); neurological diseases (G00–G99), cardiovascular diseases (I00–I99), respiratory diseases (J00–J99), musculoskeletal diseases (M00–M99); arthrosis (M15–M19); back disorders (M40–M54) and external causes (S00–Y98). The rest of the causes were collapsed into 'other' category.

### Other variables

Information on sex and birth year was obtained from the Population Register Centre. Occupational class was derived from the information on socioeconomic position provided by Statistics Finland<sup>21</sup> and it was classified as: (1) upper non-manual (2) lower

non-manual (3) manual (4) self-employed (5) other (subcategories unknown and unemployed were the most prevalent). Years of education were calculated based on the highest degree attained by 2012, obtained from Statistics Finland.<sup>22</sup> Information on the annual wage income, caregiver's allowance and capital income were retrieved from the register of the Finnish Tax Administration. Socioeconomic score was calculated based on years of education and total income as the average of Van der Waerden rank-based z-scores derived from the present analytical sample of subjects.<sup>23</sup> Information on the degree of urbanisation (urban/semiurban/rural) of the subjects' municipality of residence was retrieved from the Statistics Finland.<sup>24 25</sup>

Data extraction and linkages across the multiple registers were performed by register-keeping authorities using personal identity codes.

### Statistical analysis

Unadjusted mean annual sickness SADP days, separately and combined (SADP), were calculated for caregivers and controls in total and according to diagnostic categories. Poisson regression model was used to compute the incidence rate ratio (IRR) of SADP days for caregivers compared with controls in total and according to diagnostic categories. Follow-up time was taken into account in the analysis to yield annual SADP days. The analyses were adjusted for sex, age, education years, total income, occupational class and degree of urbanisation. Although nearly all Finnish residents of working age are entitled to sickness allowance those not employed may be less likely to apply for sickness allowance because they may receive other benefits (eg, unemployment benefit or student benefit). Therefore, SADP days in caregivers and controls and adjusted IRRs were also computed excluding individuals with 'other' as the occupational class. Interactions between caregiving and the covariates on SADP days were tested using Poisson models. Socioeconomic score had a significant interaction with caregiving (IRR 1.31, 95% CI 1.12 to 1.53) and hence, this interaction was examined further. To allow for non-linearity in the relationship between caregiving and SADP days according to socioeconomic score, restricted cubic spline Poisson regression models were used. This model with four knots and adjusted for age, sex, occupational class, and degree of urbanisation were used to derive caregivers' IRR for SADP days as a function of socioeconomic score. The knots were located at the 5th, 35th, 65th and 95th percentiles of age based on Harrell's recommended percentiles.<sup>26</sup> Stata V.16.0 (StataCorp) statistical package was used analysing the data.

### RESULTS

Descriptive data on caregivers and controls are presented in [table 1](#).

About two-thirds of SADP days were composed of sickness absence days and one third of disability pension days ([table 2](#)). When analysing all subjects, caregivers had a moderately higher incidence rate of SADP, and SADP days (IRR=1.13–1.18). When including only subjects with a record of occupation (ie, excluding subjects with the occupational class as 'other'), the difference between caregivers and controls in sickness absence days, disability pension days and SADP days increased (IRR=1.24–1.28).

SADP days according to diagnostic categories are shown in [table 3](#). The most common causes for SADP days were mental disorders (ICD-10 F00–F99) and musculoskeletal diseases (M00–M99), which accounted for more than half of the total SADP days. Adjusted for the covariates, caregivers had more

**Table 1** Descriptive data on caregivers and controls

	Control N=35 371	Caregiver N=16 982
Women, n (%)	27 085 (76.6)	13 183 (77.6)
Age in years, mean (SD)	46.5 (11.1)	46.0 (11.0)
Occupational class, n (%)		
Upper non-manual	6186 (17.5)	1754 (10.3)
Lower non-manual	12 514 (35.4)	5280 (31.1)
Manual	6479 (18.3)	3176 (18.7)
Self-employed	3198 (9.0)	1624 (9.6)
Other	6994 (19.8)	5148 (30.3)
Yearly income in euros, median (IQR)		
Total	29 562 (19 174–40 060)	24 789 (13 048–36 055)
Without caregiver's allowance	29 562 (19 174–40 060)	20 778 (8557–31 898)
Education years, mean (SD)	13.5 (2.5)	12.9 (2.4)
Socioeconomic score, mean (SD)*	0.080 (0.842)	-0.167 (0.793)
Degree of urbanisation in municipality of residence, n (%)		
Urban	21 966 (62.1)	10 518 (61.9)
Semi-urban	6236 (17.6)	3002 (17.7)
Rural	7169 (20.3)	3462 (20.4)
Sickness absence, n (%)	13 953 (39.5)	6950 (40.9)
Disability pension, n (%)	1678 (4.7)	1036 (6.1)
Median caregiver's allowance (IQR): €4372 (€2415–€5339) euros.		
*Socioeconomic score is the average of rank-normalised education years and total income.		

SADP days per person-year than controls (IRR) in total, and for mental disorders in total (F00–F99), mood disorders (F30–F39), depressive disorders (F32–F34), neurotic disorders (F40–F48) and for other reasons. The highest IRR in caregivers was found for neurotic disorders (F40–F48). There were no significant differences between caregivers and controls in SADP days due to cancer, neurological diseases, cardiovascular diseases, respiratory diseases, musculoskeletal diseases or external causes.

When analysing SADP days according to socioeconomic score in caregivers and controls, a socioeconomic gradient was observed in both caregivers and controls; those with a

higher socioeconomic score had a lower number of SADP days (figure 1A). The highest absolute numbers of SADP days were observed among those scoring between low to average (-1 to 0) on the socioeconomic score. IRR of SADP days according to socioeconomic score (figure 1B) showed that among those with a lower socioeconomic score (less than -0.6) caregivers had a lower incidence rate for SADP days than controls, while among those with a higher socioeconomic score, caregivers had a higher incidence rate for SADP days than controls.

## DISCUSSION

This is the first study to report family caregivers' work incapacity including both sickness absences and disability pensions. This study is also the first to examine sickness absences according to diagnostic groups in family caregivers. The study suggests that overall, caregivers had more SADP days than controls. This difference was almost fully explained by mental disorders.

To the best of our knowledge, no previous study has explicitly investigated the associations between caregiving and disability pension. However, previous studies have suggested that caregivers appear to be more prone than others to exit the labour markets prematurely. Previous studies have suggested that female family caregivers are more likely to stop working compared with non-caregivers<sup>17</sup> and that a marked proportion of caregivers report that they had quit working or retired prematurely due to caregiving demands.<sup>27 28</sup> Although previous studies made no distinctions between possible underlying causes for the exits from labour markets some of the exits may have been due to disability pensions. However, investigating specifically disability pensions is important because disability pension is a marker of a long-term or a permanent impairment in health or functioning, which often has a major impact on other areas of life as well, not only work life. Although disability pension days were calculated only for the 6-year follow-up it should be noted that permanent disability pensions continue until old-age retirement and in the worst case, decades of work input can be lost.

The findings on sickness absences are largely in line with previous studies, which have reported a higher likelihood of long-term sickness absence in occupationally active caregivers compared with non-caregivers. A study by Mortensen *et al*, using multiple cohorts from France, Finland and UK, reported a higher hazard (HR 1.13) of long-term sickness absence in female caregivers than non-caregivers but found no difference in males.<sup>14</sup> According to a Swedish study, caregivers providing high-intensity care were more likely to report long-term sickness absence than non-caregivers.<sup>13</sup> We are aware of two

**Table 2** SADP days in caregivers and controls including the whole sample (all) and only those with a record of occupation

	Control Mean annual days (95% CI)	Caregiver Mean annual days (95% CI)	IRR* (95% CI)
All subjects			
Sickness absence	12.0 (11.7 to 12.3)	14.8 (14.3 to 15.3)	1.18 (1.13 to 1.23)
Disability pension	6.6 (6.2 to 6.9)	8.4 (7.8 to 9.0)	1.13 (1.03 to 1.24)
SADP	18.5 (18.0 to 19.0)	23.2 (22.3 to 24.1)	1.16 (1.10 to 1.22)
Subjects with a record of occupation†			
Sickness absence	11.7 (11.4 to 12.1)	15.1 (14.5 to 15.7)	1.24 (1.18 to 1.30)
Disability pension	5.4 (5.0 to 5.8)	7.0 (6.3 to 7.6)	1.28 (1.14 to 1.44)
SADP	17.2 (16.6 to 17.7)	22.1 (21.1 to 23.1)	1.25 (1.18 to 1.33)
Incidence rate ratio (IRR) is for the caregivers compared with controls.			
*Analysis adjusted for sex, age, education years, total income, occupational class, degree of urbanisation.			
†The analysis excluded subjects with 'other' as the occupational class.			
SADP, sickness absence and disability pension.			

**Table 3** Mean annual sickness absence and disability pension (SADP) days combined according to diagnostic category and adjusted incidence rate ratio (IRR) for SADP days in caregivers compared with controls

Diagnostic category	Control Mean annual days (95% CI)	Caregiver Mean annual days (95% CI)	IRR* (95% CI)
C00–D48 Cancer	1.6 (1.4 to 1.8)	1.5 (1.2 to 1.7)	0.93 (0.77 to 1.13)
F00–F99 Mental disorders, all	4.0 (3.8 to 4.3)	7.2 (6.7 to 7.8)	1.58 (1.42 to 1.75)
F20–F29 Schizophrenia, schizotypal and delusional disorders	0.3 (0.2 to 0.4)	0.3 (0.2 to 0.4)	0.66 (0.40 to 1.10)
F30–F39 Mood disorders	2.8 (2.6 to 3.0)	5.3 (4.8 to 5.8)	1.68 (1.48 to 1.90)
F32–F34 Depressive disorders	2.5 (2.3 to 2.7)	5.0 (4.5 to 5.4)	1.76 (1.55 to 2.00)
F40–F48 Neurotic, stress-related and somatoform disorders	0.6 (0.5 to 0.7)	1.3 (1.1 to 1.4)	2.08 (1.76 to 2.46)
G00–G99 Neurological diseases	1.2 (1.0 to 1.3)	1.2 (1.0 to 1.4)	1.00 (0.80 to 1.24)
I00–I99 Cardiovascular diseases	1.0 (0.9 to 1.1)	1.2 (0.9 to 1.4)	1.09 (0.86 to 1.38)
J00–J99 Respiratory diseases	0.4 (0.3 to 0.5)	0.5 (0.4 to 0.6)	1.13 (0.84 to 1.52)
M00–M99 Musculoskeletal diseases, all	7.0 (6.7 to 7.4)	7.8 (7.2 to 8.3)	1.05 (0.96 to 1.14)
M15–M19 Arthrosis	1.8 (1.6 to 2.0)	2.1 (1.8 to 2.5)	1.15 (0.97 to 1.37)
M40–M54 Back disorders	2.9 (2.7 to 3.1)	3.2 (2.8 to 3.5)	1.03 (0.90 to 1.18)
S00–Y98 External causes	1.7 (1.6 to 1.9)	1.8 (1.6 to 2.0)	0.99 (0.86 to 1.13)
Other	1.5 (1.4 to 1.6)	2.0 (1.8 to 2.2)	1.24 (1.08 to 1.42)

\*Adjusted for sex, age, education years, total income, occupational class, degree of urbanisation.

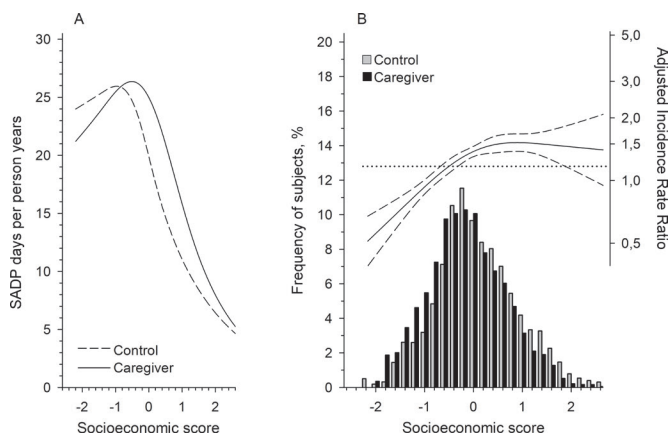
other studies that have examined the association between caregiving and sickness absences.<sup>15 16</sup> However, these studies did not find any clear associations between caregiving and sickness absences, most likely because of a low number of caregivers included in the study samples. This study included all formally recognised caregivers of working age in Finland, who typically provide high-intensity care. According to a Finnish survey 85% of Finnish formally recognised caregivers provide care 7 hours or more per day.<sup>19</sup> The study by Mortensen *et al* defined caregiving as providing care for 5 hours or more per week<sup>14</sup> and the Swedish study defined high-intensity caregiving as providing care more than 15 hours per week.<sup>13</sup> Hence, the previous studies suggest that also lower-intensity caregiving may be related to sickness absences.

The differences in SADP days according to caregiver status were almost fully explained by mental disorders. Previous studies have reported that caregivers have overall poorer mental health than non-caregivers.<sup>7–10</sup> Those providing most care appear to report

psychiatric symptoms most often.<sup>8</sup> It has also been reported that caregivers are more likely to have been prescribed antidepressants than non-caregivers<sup>29</sup> and our study suggested that caregivers use more antidepressants than non-caregivers.<sup>30</sup> In that study, the relative risk for antidepressant use over 6 years was 1.2–1.5 among the caregivers of working age compared with the controls. However, it has not been known that it is mental disorders that underlie increased number of sickness absences in caregivers. The findings of this study suggest that the number of SADP days due to depressive disorders and neurotic, stress-related and somatoform disorders is particularly high in caregivers compared with controls. The present and previous findings are well in agreement with the caregiver stress model presented by Pearlin *et al*,<sup>31</sup> in which stressors related to caregiving may lead to intrapsychic strains and further to mental health problems, such as depression and anxiety. The model further proposes that secondary stressors arising from caregiving, such as job—caregiving conflicts and economic problems, may amplify the stress process. Hence, caregiving per se may be the source of chronic stress in caregivers leading to mental disorders but also conflicting demands between work and caregiving may play a role. Empirical studies have also supported the role of both.<sup>27 32</sup>

According to the Pearlin's model, caregiver stress may also lead to somatic problems<sup>31</sup> but we did not find any support for this. Even musculoskeletal diseases showed no differences between caregivers and controls although musculoskeletal strain could be linked to caregiving, at least in cases where caregiving requires performing heavy physical tasks such as assistance in basic movements. A multicohort study on caregivers suggested that working caregivers providing more care (>20 hour weekly) have a higher risk of cardiovascular diseases compared with those providing less care (1–8 hour weekly).<sup>33</sup> However, that study lacked a non-caregiver group preventing comparisons between caregivers and non-caregivers. In line with our findings, the follow-up of the Whitehall II cohort did not observe any clear association between caregiving status and coronary heart disease.<sup>34</sup>

Analysis of the impact of socioeconomic status suggested that among those with average to high socioeconomic status, caregivers had more SADP days than controls while among those with low socioeconomic status caregivers had less SADP days. However, as a whole those with a high socioeconomic status had markedly less



**Figure 1** (A) Sickness absence and disability pension (SADP) days combined according to socioeconomic score. (B) Frequency of socioeconomic score in caregivers and controls as a bar diagram and a line diagram indicating the incidence rate ratio (IRR) of SADP days for caregivers compared with controls according to socioeconomic score adjusted for sex, age, occupational class and degree of urbanisation. Dashed lines show the 95% CI for IRR.

SADP days and the highest absolute number of SADP days was observed in caregivers with average socioeconomic status. More caregivers (30%) than controls (20%) belonged to the occupational class 'other', which includes the unemployed and students, and is likely to also include full-time caregivers. After excluding those without a record of occupation the relative difference in SADP days between caregivers and controls increased further. This was expected as although these groups in most cases qualify for the sickness allowance, they may not be prone to apply the sickness allowance because they receive other benefits and the amount of sickness allowance may be lower than the benefit.

The strengths of the study include a large sample that was population-based and comprised all Finnish caregivers who received caregiver's allowance and who were a part of the workforce. Because the data were totally based on register data the study had no non-participation and non-response biases. The study had a long follow-up, 6 years. The validity of the data is considered to be high as the data were based on records of administrative decisions and not on self-report. Although using register-based data has many advantages the other side of the coin is the lack of detailed information on the caregivers and no information on the care recipients. We also lacked information on the short sickness absence spells, <10 days. As granting of the Finnish caregiver's allowance in practice requires caregiving to be of high-intensity the results are only applicable to high-intensity caregivers. Moreover, confirmed work incapacity may vary between countries because of differences in social security and pension systems. Nevertheless, the findings reflect more broadly morbidity of high-intensity caregivers of working age and hence, are very likely to be applicable to high-intensity caregivers also in other contexts than just in the Finnish context.

Our findings call for screening and adequate treatment of mental health problems among caregivers of working age. In case of employed caregivers, occupational healthcare should be aware of the increased risk for mental health problems in caregivers and promote caregivers' work capacity accordingly. Flexibility in working arrangements, for example, in working hours, has been suggested to reduce the burden caused by combining work and caregiving,<sup>35</sup> but more research is needed on the means of minimising work incapacity among caregivers. Provision of formal care to the care recipient in addition to family

caregiving and caregiver training programmes provided by the society might also be potential means to support well-being and consequently work capacity among caregivers.

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**Contributors** TMM contributed to the conception and design of the study, acquired the data, participated in the analysis and interpretation of the data, and drafted the manuscript. TMM is responsible for the overall content as guarantor. HKa contributed to the conception and design of the study, analysed the data, participated in the interpretation of the data, and substantively revised the manuscript draft. MM, MvB, MH, HKo and TK contributed to the interpretation of the data and substantively revised the manuscript draft. JE contributed to the conception and design of the study, interpretation of the data interpretation of the data, and substantively revised the manuscript draft. All authors read and approved the final manuscript.

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**Ethics approval** This study involves human participants and was approved by Ethics Committee of the Helsinki and Uusimaa Health Care District (HUS/1955/2018). The researchers got only pseudonymised data from the register-keeping authorities and hence, could not contact the subjects. Consent for participation is not required when a study uses only register data.

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**Data availability statement** Data are available on reasonable request. Data may be obtained from a third party and are not publicly available. The data that support the findings of this study are available from Finnish Tax Administration, and Findata but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors on reasonable request and with permission of Finnish Tax Administration, and Findata.

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#### What is already known on this subject

- ⇒ An increasing number of adults in work life are expected to provide care in the near future as family caregivers.
- ⇒ Family caregivers are known to suffer from poorer mental well-being than non-caregivers.
- ⇒ It is not known whether this translates into work incapacity among family caregivers at work life.

#### What this study adds

- ⇒ Sickness absences and disability pensions due to mental disorders were more prevalent among caregivers than non-caregivers.
- ⇒ Societies and work places need to find ways to better support combining family caregiving and work to avoid severe mental health problems and consequent sickness absences and premature exits from labour markets in caregivers.

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