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The Health of Older Family Caregivers – A 6-Year Follow-up

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ABSTRACT

It is unclear whether caregiving has an impact on the physical, mental and functional health of older caregivers. This study aimed to describe physical, mental and functional health in relation to family caregiving in old age (60+) over a six-year period. The study comprised 2,294 randomly selected individuals (60–96 years) from the Swedish National Study on Aging and Care, who answered the question on whether they were caregivers and who were followed up six years later. The prevalence of family caregivers was 13.1% and the incidence was 12.4%. Four tracks (T) were identified; T1) Family caregiver both at baseline and follow-up (n = 74), T2) Family caregiver at baseline but not at follow-up (n = 226), T3) non-caregiver at baseline but family caregiver at follow-up (n = 218), T4) non-caregiver both at baseline and follow-up (1,776). Only non-caregivers (T4) reported a decline in mental health, $p < .036$. Worries about health increased significantly in T2 and T4. The prevalence of caregivers was 13.1% with a high turnover. There are differences between family caregivers and non-caregivers in deterioration in physical and mental health as well as physical function over a six-year period.

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Introduction

The proportion of older adults in the population is increasing. As the risk of disease is higher in old age there is a greater need for care. This not only means that more people require public care but also informal care, leading to a rise in the number of family caregivers (Szebehely & Trydegård, 2012), despite the fact that family caregivers already provide more care than the public health care service (Wimo et al., 2017). Our definition of a family caregiver is a person who provides unpaid assistance with the activities of daily living (ADL) or instrumental activities of daily living (IADL) to a family member or a close relative with a disability (Dahlrup, 2015). Becoming a family caregiver in Sweden is voluntary. In Sweden, municipalities are required by law to provide care (Social Services Act, 2001). Nevertheless, the burden can be heavy on

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volunteer family carers. The intensity as well as the duration of the efforts varies from a few hours a week to several hours a day (Ekström et al., 2020).

Previous studies on caregiving and the situation of caregivers mainly focus on those who receive care from a family member (Denning et al., 2013; Gitlin et al., 2014). The focus of research in both longitudinal and cross-sectional studies has been on how family care recipients are affected in terms of health and function or only a specific subgroup, usually individuals with dementia, is investigated (Berry et al., 2012; Gitlin et al., 2014).

However, there is less emphasis on family caregivers' health and functional status, which is only partially elucidated, from a longitudinal perspective. The mental and physical health of family caregivers has been studied (Shaffer et al., 2017) as has their mental functioning (Buyck et al., 2011) but whether family caregiving is related to changes in functional health measured by IADL in a longitudinal perspective is not as well illuminated as other aspects. As the participants in our study constitute a random sample of the population, our hypothesis is that there is no difference between family caregivers and non-caregivers in terms of deterioration in mental and physical health and physical function over a six-year period.

The role of family caregiver may well remain the same for a long period but can also change over time, from being a caregiver to be a non-caregiver or vice versa, i.e., family caregiving transitions. Such changes may be related to variation in mental and physical health and physical function, in addition to worries about their own health.

Studies of caregivers' health and the relationship between caregiving and physical and mental health among older family caregivers have been conducted, but what happens over time is still unknown. What is known is that the care involves psychological stress (Blyth et al., 2008) and that women who act as family caregivers are especially vulnerable to negative consequences of the burden of being family carers (Kristensson Ekvall & Rahm Hallberg, 2007). Other aspects may concern the caregiver's motivation to provide care and her/his perception of the role as caregiver, which can affect well-being (Quinn et al., 2010) and increase the risk of health deterioration (Roth et al., 2015). As the care needs can change over time, it is necessary to be aware that caregivers may require tailored supportive interventions (Galvin et al., 2018). The longitudinal perspective is preferable as studies based on samples from the population often reveal better physical and mental health outcomes for family carers (Roth et al., 2015). Nevertheless, there is still a lack of knowledge about family caregiving and its relationship with physical functioning.

The annual cost in the form of production loss for family caregivers who are still employed has been estimated at 10,000 USD (Ganapathy et al., 2015) but a high variability in cost is reported depending on the disease and geographic location (Oliva-Moreno et al., 2017). To the best of the present authors' knowledge, how the financial situation of family caregivers is affected in the long term

by lower retirement benefits because they retired early or only worked part-time during the later years of their professional life and how this in turn affects their health-related quality of life has not been investigated before.

Family caregivers can be assumed to be physically as well as mentally healthier than the relatives they care for. While it is possible that they are at greater risk of cognitive impairment, research results are conflicting (Fung et al., 2018; Potvin et al., 2013). It is therefore important that control variables such as age, sex, civil status, financial situation, education, and physical functioning are included when studying the physical and mental health of family caregivers. The authors have been unable to find any study that explicitly examined family caregivers' cognitive function over time and whether it differs from the age-related decline in the general population. However, family caregivers also grow older and frail, with decreasing cognitive and physical resources, which increases the burden of being a caregiver (Brigola et al., 2017). The challenge to family caregivers becomes larger when they are expected to not only take responsibility for and assist with daily care needs, but also with tasks such as shopping and cleaning.

Aim: This study aimed to describe physical, mental, and functional health in relation to family caregiving in old age (60+) over a six-year period. An additional aim was to explore physical, mental, and functional health as well as demographic factors, financial resources, cognitive impairment, and attitudes to health in relation to different tracks of family caregivers and non-caregivers.

Materials and methods

Study population and research context

Individuals from the southern part of Sweden who participated in the Swedish National Study on Aging and Care (SNAC), which started in 2001, were included. The SNAC is a prospective longitudinal multicentre study initiated by the government and the Ministry of Social affairs, which included randomly selected individuals of 60–96 years in 10 age clusters. As the number of older adults decreases with increasing age, an oversampling of the 81-, 84-, 87-, 90-, 93- and 96-year age cohorts was performed, where all individuals were invited to participate. More details about the structure of the SNAC study are provided by Lagergren et al. (2004).

In the present study participants were recruited from SNAC-Blekinge (n = 1,402) and Good Aging in Skåne (GÅS) (n = 2,931). In the period 2001–2004, these two centers recruited participants in different age cohorts (60–96 years) from six municipalities covering a middle-sized town, small towns and rural areas. The response rate was 60%. The study population comprised 2,294 individuals in different age cohorts (60–96 years) from the two cohorts SNAC-Blekinge and GÅS included at baseline who answered the

questions whether they were caregivers or not, and who also took part in the follow-up six years later. The individuals included in this study participated in the study on two occasions, i.e. at the baseline and at the follow-up, 6-years after. The same protocol with questions were used on these two occasions.

Reexamination and testing were carried out on 2,384 individuals between 2007 and 2011. Only individuals from the first data collection were included in the six-year follow-up investigation ($n = 2,294$), see [Table 1](#).

Procedure

Potential participants, residents according to the National Population Registry, were randomly invited by letter to take part in the study. The only exclusion criterion was the inability to speak Swedish. If no answer was received after two weeks, three attempts were made to contact them by telephone. Medical examination and structured interview were conducted by research personnel (physicians and specially trained nurses) in two sessions. Informed consent was obtained from each participant and a questionnaire was completed in the period between the medical examination and structured interview. Home visits were offered to those unable to come to the study centre. The study was conducted in accordance with the Declaration of Helsinki (WMA, 2013). The SNAC study was approved by the ethics committee of Lund University (LU 128-00, LU 604-00, LU 744-00).

Measures

Demographic data (age, gender, living condition, civil status and financial situation) were self-reported and collected from the SNAC questionnaire. Getting old does not mean living in a social world separate from the rest of society (Krekula et al. (2005). Every individual is unique (Krekula et al. (2005). We have nevertheless chosen to adjust for age as well as for gender as older women have an increased risk of impaired function and that female caregivers are more vulnerable (Kristensson Ekvall and Rahm Hallberg (2007).

The question regarding the financial situation, i.e. whether the person had savings, or a low economic status was: If necessary, could you raise the sum of 14,000 SEK (about 2000 USD) for unexpected expenses within one week? The response alternatives were “Yes” and “No”.

Educational level was measured by the question: Did you finish secondary school? The response alternatives were “Yes” and “No”.

The Short Form Health Survey (SF12), which includes twelve questions, was used. The SF-12 provides a score estimate of an individual's health in eight dimensions; Physical functioning, Physical activity, Pain, General health, Vitality, Social functioning, Emotional capacity and Mental health (Sullivan et al., 2002). This validated and reliable instrument is well suited for gaining an

Table 1. Description of changes in demographics and functional, mental and physical health over a six year period. A comparison between individual changes and changes between the four tracks of family caregiving from the Swedish National study on Aging and Care-Blekinge and Good Aging in Skåne (n = 2,294).

Variables	Total (% at baseline and at follow-up (n = 2294)		Caregiver at baseline/care-giver at follow-up (n = 74) (T1)		Caregiver at baseline/non caregiver at follow-up (n = 226) (T2)		Non caregiver at baseline/caregiver at follow-up (n = 218) (T3)		Non caregiver at baseline/non caregiver at follow-up (n = 1776) (T4)		p-value ^b	p-value ^c
	BL	F-U-P	BL	F-U-P	BL	F-U-P	BL	F-U-P	BL	F-U-P		
Age mean (SD)	69.5 (8.84)	—	66.24 (7.07)	—	68.19 (8.34)	—	67.14 (7.55)	—	70.09 (9.0)	—	<.001***	—
Gender (women)	54.6	—	54.1	—	57.5	—	54.6	—	54.3	—	0.835	—
Low financial status	14.6	.005**	12.3	7.4	16.5	10.0	15.3	12.7	14.4	11.1	.067	.628
Education (low)	85.4	—	89.1	—	86.8	—	76.9	—	86.2	—	.006*	—
Dropped out of school at 14–16 years old	—	<.001***	—	—	—	—	—	—	—	—	—	—
Civil status	—	—	—	—	—	—	—	—	—	—	—	—
Married	62.2	54.1	74.0	69.4	68.8	50.9	71.6	67.5	59.7	53.9	<.001***	<.001***
widowed	12.7	6.6	4.1	4.2	13.4	10.9	9.3	5.2	13.4	6.6	—	—
unmarried	12.8	24.7	6.8	12.5	6.7	25.5	9.3	16.5	14.3	26.9	—	—
divorced	9.8	10	9.6	6.9	10.3	9.5	7.4	9.9	10.1	10.5	—	—
other	2.5	2.2	5.5	6.9	0.9	3.2	2.3	0.9	2.1	2.1	—	—
Living alone	35.1	44.6	23.0	28.8	28.4	51.6	26.0	30.7	37.6	44.3	<.001***	<.001***
MMSE	27.55 (2.39)	26.81 (3.17)	27.80 (1.94)	27.2 (2.46)	27.65 (2.38)	27.2 (2.73)	27.85 (2.55)	27.73 (2.18)	27.49 (2.29)	26.63 (3.33)	<.001***	<.001***
IADL %	—	<.001***	—	—	—	—	—	—	—	—	.083	.391
0 totally dependent	0.5	0.2	—	—	—	—	0.5	—	0.6	0.3	—	—
1	1.7	1.6	—	—	2.2	0.9	—	1.0	1.9	1.9	—	—
2	3.3	9.4	1.4	—	2.2	9.5	1.8	2.0	3.6	10.8	—	—
3	24.8	25.9	31.5	35.2	24.7	20.9	23.9	31.0	24.6	25.5	—	—
4 (independence)	69.8	62.8	67.1	64.8	70.9	68.7	73.9	66.0	69.2	61.5	—	—
I am worried about my health:	—	<.001***	—	—	—	—	—	—	—	—	—	—
Extremely worried	11.6	11.3	2.7	12.1	6.8	8.0	5.7	10.1	5.5	12.2	<.001***	.965
Very worried	30.3	25.5	27.4	30.3	20.0	34.9	25.9	30.7	24.3	29.6	—	—
Somewhat worried	43.8	44.0	52.1	45.5	56.4	45.3	44.3	37.4	50.8	44.3	—	—
Not worried	14.3	19.1	17.8	12.1	16.8	11.8	24.1	21.8	19.3	13.9	—	—

(Continued)

Table 1. (Continued).

Variables	Total (% at baseline and at follow-up (n = 2294))	Caregiver at baseline/care-giver at follow-up (n = 74) (T1)	Caregiver at baseline/non caregiver at follow-up (n = 226) (T2)	Non caregiver at baseline/caregiver at follow-up (n = 218) (T3)	Non caregiver at baseline/non caregiver at follow-up (n = 1776) (T4)
Mental HRQoL, MCS, mean (SD)	55.16 (8.04) 54.81 (8.03)	.056 55.23 (7.38) 55.42 (7.41)	.865 53.59 (8.97) 54.02 (8.43)	.491 55.42 (7.48) 54.77 (7.16)	.220 55.49 (7.89) 55.02 (8.01)
HRQoL, PCS, mean (SD)	43.61 (8.01) <0.001***	49.19 (9.09) 45.01 (7.6)	48.37 (9.61) 43.99 (8.02)	47.36 (9.78) 45.96 (7.04)	48.01 (9.17) 43.37 (8.05)

BL = baseline, F-UP = Follow-up, * n.a. due to small sample size in each cell.

The McNemar, Wilcoxon, Paired Student T-test, Chi-square, Kruskal-Wallis test, and Student T-test were used to test differences between groups. a) Comparison within group changes, b) Changes between the 4 tracks (T) at baseline, c) comparisons between the 4 tracks at follow-up. Post hoc test with Bonferroni and a reduced p -value: 0.0125, of Age: T1-4 < 0.001***, T2-4 0.013*, T3-4 < 0.001***, MMSE at 6 years: T3-4 < 0.001***, physical health 6 years T3-4 < 0.001***, Civil status at baseline: T1-2 0.036*, T1-4 0.017*, T2-4 0.009*, T3-4 0.019*, Civil status at 6 year follow-up T1-2 0.015*, T1-4 0.002** T2-3 0.003** T3-4 0.003**, Living alone at baseline: T1-4 0.018*, T2-4 0.021*, T3-4 0.002**, Living alone at 6 year follow-up T1-2 0.003** T1-4 0.028**, T2-3 < 0.001***, T3-4 0.001***, Education T1-3 0.048*, T2-3 0.015*, T3-4 0.001***.

understanding of both the physical and mental health of older adults (Gandek et al., 1998; Ware et al., 1966). The scores were processed in accordance with the Swedish Manual and interpretation Guide (Sullivan et al., 2002). The SF12 includes two dimensions: The Physical Component Summary (PCS) and Mental Component Summary (MCS). The MCS and the PCS each contain six of the twelve items and are summarized into a score ranging from 0 to 100, where a higher score indicates better physical and mental health.

The instrument Mini Mental State Examination (MMSE) measures a person's cognitive function and is an often-used short screening tool. The instrument consists of 20 questions divided into 11 areas. The questions cover orientation to time and space, memory, language, and visuospatial functions (which refer to visual and spatial interpretation ability). Results below 24 points (out of 30) indicate dementia. The test was used both at inclusion and at follow-up since decline in cognitive function could be predicted by MMSE changes over time (Arevalo-Rodriguez et al., 2015).

IADL are activities related to independent living and valuable for evaluating persons with early-stage disease. IADL were investigated by questions about driving or using public transportation, shopping, cooking, and cleaning. There were four response alternatives: Independent, Need help, Dependent and Unable to do, with a value of 0 or 1. The questions were summarized, where a lower score indicates dependence (0) and a higher score (4) independence. (Lawton & Brody, 1969).

Health attitudes were investigated by the statement: I am worried about my health. The response alternatives were Extremely worried; Very worried; Somewhat worried; and Not worried.

Family caregivers were assessed by a single item; Do you give any help to relatives with reduced health? The response alternatives were "Yes" and "No". It was possible for the participants to get clarifications about the intended meaning of the terms from the research staff.

Statistical analysis

The total number of participants in the study sample was divided into the following tracks, 1) Caregivers at baseline who were still caregivers after 6 years. 2) Caregivers at baseline but no longer caregivers after 6 years. 3) Non-caregivers at baseline who were caregivers at follow-up. 4) Non-caregivers at both baseline and follow-up.

Descriptive analyses were performed on the total data and within the tracks of family caregiving and over the six-year follow-up period. For descriptive statistics, the mean and standard deviations (SD) were used for continuous variables, while numbers and percentages (%) were used for categorical (binary and ordinary) variables. To enable comparisons between tracks of family caregiving at baseline and follow-up, the Chi-

squared test was used for the nominal data level and Kruskal-Wallis test for the original and the Student T-test for the interval data levels. For comparisons over time between baseline and follow-up, we used the McNemar test at nominal data level, the Wilcoxon signed-rank test at categorical level and the paired Student T-test for continuous variables in each track of family caregivers, non-caregivers and the whole group. Post hoc test with Bonferroni and a reduced p -value (0.0125) was applied to minimize the risk of type I error. Spearman's rho (r_s) was used to calculate the correlations between the independent variables: tracks of family caregivers, covariates and the outcome variables: health variables (IADL, PCS and MCS). All included variables, except for PCS at baseline and follow-up ($r_s = 0.45$) and MCS at baseline and follow up ($r_s = 0.41$), showed correlations of $r_s = 0.32$ or less. Multiple linear regression models were performed on the total sample (see Table 2) and for each health outcomes (IADL, PCS and MCS) to separately investigate associations between follow-up health variables and family caregiving tracks when adjusted for baseline health and covariates. To compare the three tracks of family caregiving we created three dummy variables with the non-caregivers (T4) as a reference. For each health variable, we designed two models. The first crude model included the family caregiving tracks, covariates (age and gender) and one of the health variables (IADL, PCS and MCS, respectively). Using the baseline value of a specific measure as a covariate is acceptable by means of raw change scores, which hinder the potential false correlation between baseline and follow-up scores (Kenny, 2005). Collinearity diagnostics (variance inflation factors and tolerance) were used to check for multicollinearity in the included variables and the factors were shown to be acceptable. In the second full model, the basic model plus education, financial situation, cognitive status, and attitude to health were entered. The results were presented as a Standardized Beta coefficient (β) together with a 95% confidence interval (CI). The analyses were conducted in SPSS version 24 (SPSS Inc., Chicago, IL, USA). Alpha levels were set at 0.05.

Results

Four tracks of family caregivers

Of the 2,294 individuals included in this study, 300 (10.0%), reported that they were caregivers at baseline and 292 were caregivers at the 6-year follow-up. Four groups were identified; Track 1, (T1), caregivers at both baseline and follow-up ($n = 74$), Track 2, (T2), caregivers at baseline but not at follow-up ($n = 226$), Track 3, (T3), non-caregivers at baseline but caregivers at follow-up ($n = 218$) and Track 4, (T4), non-caregivers at both baseline and follow-up ($n = 1,776$), see Table 1.

Table 2. Study of the relationship between functional, physical and mental health in family caregiving among older adults from the Swedish National study on Aging and Care-Blekinge and Good Aging in Skåne (n = 2,294). Multivariate linear regression models of functional, physical and mental health levels in relation to type of family caregiving.

	Functional health			Physical health			Mental health												
	Basic model		Full model	Basic model		Full model	Basic model		Full model										
	β	p-value	β	p-value	β	p-value	β	p-value	β	p-value									
Non-caregiver (T4)	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.									
Exit (T2)	.01	-.07-.12	.610	.00	-.10-.12	.901	.00	-.86-1.08	0.826	-.02	-1.54-.65	.426	-.01	-1.42-.68	.489	-.02	-1.57-.81	.529	
Entry (T3)	.02	-.04-.16	.222	.02	-.06-.16	.356	.09	1.33-3.33	<0.001***	.07	.66-2.80	.002**	-.02	-1.50-.66	.442	-.01	-1.13-1.04	.844	
On-going (T1)	.02	-.09-.23	.407	.01	-.16-.21	.807	.01	-1.35-2.03	0.693	.02	-.88-3.05	.278	.00	-1.68-1.95	.882	-.01	-2.33-1.90	.843	
Covariates (baseline)																			
Age	-.34	-.03- -.03	<0.001***	-.32	-.03- -.02	<0.001***	-.24	-.26- -.19	<0.001***	-.24	-.26- -.18	<0.001***	-.10	-.14- -.06	<0.001***	-.09	-.13- -.04	<0.001***	
Gender	.08	.07-.18	<0.001***	.05	.01-.15	.025*	-.05	-1.35- -.16	0.013*	-.04	-1.23- -.12	.106	-.03	-.11- -.19	.165	-.04	-1.34- -.12	.099	
Education	-	-	-	-.09	-.28- -.10	<0.001***	-	-	-	.03	-.31- -1.58	.186	-	-	-	-.04	-1.79- -.25	.139	
Financial situation	-	-	-	-.04	-.18- -.02	.104	-	-	-	.02	-.47- -1.50	.307	-	-	-	-.02	-1.45- -.63	.430	
Living conditions	-	-	-	-.04	-.14- -.01	.085	-	-	-	.08	.63- -2.11	<0.01***	-	-	-	.01	-.61- -1.00	.636	
Cognitive status (MMSE)	-	-	-	.06	.00- -.04	.014*	-	-	-	.03	-.05- -.27	.169	-	-	-	.01	-.13- -.22	.625	
Attitude to health	-	-	-	.02	-.02- -.06	.283	-	-	-	-.02	-.57- -.27	.477	-	-	-	.04	-.05- -.86	.078	
Functional health	.28	.28-37	<0.001***	.27	.25- -.36	<0.001***	-	-	-	0.43	.33- -.40	<0.01***	0.43	.32- -.40	<0.001***	.41	.37- -.45	<0.001***	
Physical health																			
Mental health																			
R ²		0.227			.219			0.299			0.322			0.183			0.184		

β = Standardized Beta coefficient. The models comprise the participants n = 2,294 who provided complete information about family caring at baseline and follow-up. The basic model was adjusted for: age gender and one of the health variables (functional health (IADL), physical health or mental health) at baseline. The full model was adjusted for the basic model plus education, financial situation, living conditions, cognitive status and attitude to own health at baseline.

Age

Caregivers at baseline or follow-up were younger (T1 66.24, SD 7.07); (T2 68.19 SD 8.34); (T3 67.14, SD 7.55); (T4 70.09, SD 9.0), ($p < .001$), had more often low education (T1 89.1%); (T2 86.6%); (T3 76.9%); (T4 86.2%), ($p < .006$), than non-caregivers, see [Table 1](#).

Financial status

Those who were caregivers at baseline but not at follow-up reported a lower financial status (T2 baseline 16%, follow-up 10.0%), ($p < .031$) but when comparing the four groups at baseline and follow-up no difference could be detected, see [Table 1](#).

Gender and civil status

There were no gender differences, but differences in civil status between the groups at follow-up were observed, ($p < .001$). In all groups except T1 (caregivers on both occasions), the number living alone increased; T4 (Non-caregiver at baseline/non-caregiver at follow-up), had the oldest participants, the highest proportion of widows with poorer health at baseline and significantly worse health at follow-up, see [Table 1](#).

MMSE

The MMSE did not differ between the four groups at baseline ($p < .238$) but T3 (Non-caregiver at baseline/caregiver at follow-up), differed significantly from T4 (Non-caregiver at baseline/non-caregiver at follow-up), at follow-up ($p < .001$), see [Table 1](#).

Attitude to health

Worries about their own health showed a significant change in the total population during the six year follow-up, $p < .001$; as well as among those (T2) who were caregivers at baseline but stopped caring at follow-up, $p < .004$; and among those (T4) who were non-caregivers at both baseline and follow-up, $p < .001$, see [Table 1](#).

Physical, mental and functional health

When examining the physical and mental health no difference between the 4 tracks (T) were detected at baseline.

When examining IADL, no individual reported overall dependency at baseline. At the 6-year follow-up, 5 individuals reported total dependency and 60% of the sample were no longer totally independent.

The number of individuals who reported total independence at follow-up was 1,303/2,076 (62.8%); slight dependency 539 (26.0%); fairly dependent 196 (9.4%); very dependent 33 (1.6%) and totally dependent 5 (0.2%).

Multivariate linear regression

To study the relationship between caregiving and the health outcomes: physical, mental and functional health, (PCS, MCS and IADL) after 6 years controlling for demographic, financial resources, cognitive impairment and health attitude, we started to create a basic multivariate linear regression model adjusted for age and gender, followed by a full model adjusted for the basic model in addition to education, financial situation, living conditions, cognitive status and attitude to the own health. Both the basic model (stand. beta 0.09 C.I. 1.33–3.33, $p < .001$) and the full model (stand. beta 0.07 C.I. 0.66–2.80, $p < .002$) show that only those who became a caregiver during the 6 year period was positively associated with the health outcomes i.e. higher physical health at the follow-up, see [Table 2](#). No other relationships between tracks of caregiving and health outcomes at the 6 years follow up were obtained.

Age significantly affected the outcome of all three health measures at follow-up; higher age at baseline was associated with all impairment in the three health outcomes PCS, MCS and IADL at the 6 year follow-up, $p < .001$.

In addition to age, covariates that affect the functional health (IADL) at the 6 years follow up are; (female) gender (stand. beta 0.05, C.I. 0.01–0.15), $p < .25$; (low) education (stand. beta -0.09 , C.I. $-0.28 - -0.10$), $p < .001$ and (lower score) MMSE, (stand. beta 0.06, C.I. 0.00–0.04), $p < .014$ as well as functional health at baseline (stand. beta 0.27 CI 0.25–0.36), $p < .001$ see [Table 2](#). The covariates explaining the variance in the health outcome measure physical health at the 6 year follow up is (in addition to age) living conditions (stand. beta 0.08, C.I. 0.63–2.11), as well as physical health at baseline (stand. beta 0.43, C.I. 0.33–0.40) $p < .001$. The multivariate linear regression analyses of mental health levels after 6 years in the full model showed no relation to family caregiving but with age and mental health at baseline, see [Table 2](#).

Discussion

The findings of this study can be summarized as follows: transitions and turn-overs are high among family caregivers. Family caregiving had only limited effects on the participants' physical, mental, and functional health except for those who had become caregivers at follow-up. No differences were noted between groups related to low financial status, and gender. Caregivers at baseline

were slightly younger and a higher proportion of them were cohabitant. No difference in cognition was noted between groups at baseline.

Our results contrast with findings from the US, where caregivers' mental health was worse than that of the general population, although their physical health was better (Shaffer et al., 2017). Before making any general conclusions from this, differences in legislation about social service and family constellations in the studied countries must be taken into account. The present study could not demonstrate that caregivers' physical health was better at baseline, although less deterioration in physical health was found among those who became caregivers compared to the other three tracks, which may explain why these participants became caregivers. They also differed from the other groups in that they worried less about their own health, see Table I. If this slower deterioration in physical health exists or if the physical health of these carers as well as those who provide care at baseline will deteriorate needs to be investigated in future studies. A possible explanation may be that these participants have a significantly better financial situation, meaning that they can pay someone else to provide care that they perceive to be onerous and stressful, but future studies should examine the phenomenon more closely.

Previous research from the SNAC has shown that the care beneficiary's diagnosis affects the perception of burden (Elmståhl et al., 2018). Those who care for relatives with dementia experience the greatest burden (Elmståhl et al., 2018). However, it is important to become familiar with the caregivers' characteristics and what kind of interventions they need to encourage, support and train them, even if it means diverting funds from the public sector (Roche, 2009).

The finding that the deterioration in functional health of those who became caregivers at follow-up was slower may be in line with recent cohort studies where functional disability in IADL has decreased during the last 30 years among individuals aged 75 (Falk et al., 2014). Furthermore, this group also differed from the other groups in that they did not show any decline measured by the cognitive impairment, which could be expected as the MMSE is related to IADL (Włodarczyk et al., 2004). Moreover, this group worried less about their health, which could indicate that they had better health. Another possible explanation may be that the caregiver is familiar with doing the things measured by the scale, for example, handling money and arranging transportation as they have to perform these and other tasks to manage the daily life of the care recipient. An interesting finding is that participants in T2 (Caregiver at baseline/non caregiver at follow-up), did not express any worries about their own health at baseline but every third one reported being worried about her/his own health after ceasing to be a caregiver. An explanation could be that family caregiving shifts the onset of health problems to a later stage. Another explanation may be that caregivers differ from non-caregivers, who were significantly older at the start of the study.

Our finding that both physical and mental health were affected and that ceasing to be a caregiver led to an improvement, even if the participants did not return to the same level as before the caregiving, is not supported by previous findings (Rafnsson et al., 2017).

The aging process can have both medical and social consequences, but health is one of the most important factors as physical fragility increases with age (Prieto-Flores et al., 2010). The finding that the participants were very concerned about health and that worries about their own health increased significantly at follow-up, both among family caregivers and non-caregivers, may be related to the aging process. The concerns expressed involved age-related losses, which increase with age. Worry about one's own health is associated with low HRQoL among caregivers as well as non-caregivers (Ekström et al., 2020).

A similar increase in concern and worry was not found in those who were still caregivers (T1), or those who had recently become caregivers (T3). However, the small sample size in T1 (Caregiver at baseline/caregiver at follow-up), needs to be taken into consideration. On the other hand, there may be reasons for being concerned about health, as only 1,303 (62.8%) individuals reported IADL scores indicating that they were completely independent at the six-year follow-up compared to 69.8% at baseline.

Generally, those who were caregivers at baseline but not at follow-up (T2), and those who were non-caregivers at both baseline and follow-up (T4), appear to report greater change in both physical, mental and functional health as well as increased health concerns during the six-year follow-up than those who are caregivers at both baseline and follow-up (T1) or those who were non-caregivers at baseline but caregivers at follow-up (T3). More studies are needed to find an explanation for the differences between different groups of caregivers and non-caregivers.

Some limitations must be mentioned. Data about caregiving are self-reported and the study spans several years, which is why there may have been a break in care for some caregivers. It is also possible that non-caregivers could have been a caregiver for a period of time in between the baseline and follow up assessments, i.e. there is a lack of information on caregiver transitions between the two time points that would not be captured here. A lack of information on other caregiver factors such as for example: time spent caregiving, use of other formal/paid or informal/unpaid help is also a limitation.

Some groups also became small, which must be considered before generalizations can be made. This study includes 300 caregivers, which represents 13.1% of the 2,294 individuals recruited. This is low compared with other OECD countries, where more than 30% report themselves as caregivers (Marjolein et al., 2016). A possible explanation for the low number is that becoming a family caregiver in Sweden is voluntary, in parallel with legislation that municipalities are obliged to provide care (Social Services Act, 2001). It

may also be difficult to study all carers irrespective of the care recipient's diagnosis (Elmståhl et al., 2018). Another factor that needs to be mentioned is that those who have never been caregivers (T4) were used as a reference. This group is older with more widowed and divorced individuals, while several in the group have a lower educational level. This study does not cover any large city and it is possible that there may be differences in the willingness/possibility to be a family caregiver depending on whether you live in a large city or in the areas covered by this study. Furthermore, participants with inability to speak Swedish have also been excluded. Both are important research areas for future studies. The most recent data in this study is from 2011. The big change in Public Policy in 2020 caused by the pandemic of Covid 19 may have contributed to a deterioration in the situation for family caregivers since older people are recommended to stay at home and avoid social contacts to prevent becoming infected as they are considered a risk group. This can lead to an increased feeling of loneliness and thus experience a heavier burden of being a family caregiver. Further studies are therefore necessary to understand how this affects family caregivers.

However, the material still shows differences between caregivers, irrespective of whether they were caregivers all the time, stopped or became a caregiver later, and those who were never caregivers. The need for support and help can also change over time (Galvin et al., 2018), which poses a major challenge to the established care services and society, thus more research is required to meet the need for support.

Why some of the participants ceased to be caregivers is unknown due to the study design, but a reason might be their own poor health. Other possible explanations could be that they themselves became cognitively impaired (MMSE) and could no longer manage to be caregivers or that the person they cared for died. Among the strengths of the present study is the prospective design of the SNAC study, which allowed us to examine different caregiving transitions among older (60+) adults. To the best of the authors' knowledge, there is no previous long-term study that investigates how older family caregivers' financial situation, MMSE and health-related quality of life in terms of PCS, MCS and IADL are influenced by their caregiving role.

Conclusion

The prevalence of family caregivers was 13.1% with a high turnover. The findings highlight the fact that older age is negatively related to physical, mental, and functional health.

Becoming a caregiver (T3) (Non-caregiver at baseline/caregiver at follow-up), appears to be related to health in a positive way. Therefore our hypothesis must be rejected. There are differences between family caregivers and non-caregivers in terms of deterioration in physical and mental health as well as in physical

function over a six-year period. It is important to consider individual circumstances and health at baseline when attempting to improve the long-term health of family caregivers.

Clinical implication

According to Swedish law The Social Welfare Board shall offer support to make it easier for those persons who care for a close relative who is long-term ill or older or who support a close relative who has a disability (Social Services Act, 2001). Due to the high turnover among family caregivers over a 6-year period, supportive interventions should be highlighted and repeated to identify the health trajectory in different tracks of caregiving. Planning for and facilitating family caregiver's situation seems to become more and more important for the planners in the municipalities. Cooperation between actors – both in the public and private sectors, and in networks and associations focusing on situations for family carers – must be developed to improve the living conditions of older people who take on the tasks performed by caregivers.

Conflicts of interest

We have no conflicts of interest to disclose.

Contributors

Study design: C.F., L.S.W., and S.E. Data collection: S.E.

Data analysis: C.F., L.S.W., and S.E. Manuscript writing: L.S.W., C.F., and S.E.

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