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Factors associated with experiencing informal caregiving as demanding and ability to work among working carers: a national survey from Sweden

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ABSTRACT

Informal carers in paid work are known as working carers (WKC). This combination of care and work is particular to them, and their support needs may differ from other informal carers. This exploratory study describes the caregiving-related factors associated with experiencing caregiving as demanding and a decreased ability to work in WKCs. The Swedish National Carer Survey was conducted in a stratified random sample ($N=30,009$) of the population (≥ 18 years) between October 2018 and January 2019. Of 11,168 respondents, 818 (7.32%) met the study criteria for WKCs, i.e. they provide informal care to another person on a regular basis, and they work full time. Almost half (49.3%) of WKCs report experiencing caregiving as demanding, while 40.4% indicated that their ability to work had been reduced due to providing informal care. Two ordinal logistic regression models were developed, one each for caregiving is demanding and ability to work is decreased. Psychological stress and financial problems caused by caregiving increased the odds of both experiencing caregiving as demanding and having one's ability to work decrease, while finding caregiving satisfying decreased the odds of both. Further research is needed to establish how caregiving-related factors affect WKCs in both their care and working roles.

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Introduction

Informal care is a societal complement or replacement for formal care (Houtven et al., 2019), in which unpaid care and support are provided to one or several people, with variable frequency and intensity and over different periods of time, by family members, friends, or acquaintances (Eurocarers, 2016). Informal carers have diverse backgrounds and vary in

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age and motivation for providing care (Caracciolo di Torella & Masselot, 2020). The long-term benefits of support strategies targeting informal carers have been described showing that if support measures are in place carers experience positive long-term outcomes of providing care (Linnosmaa et al., 2024). However, recent studies show how carers experience work productivity loss related to caregiving (Maningbè et al., 2023) showing that more knowledge is needed on the impact of informal care provision in the working age carer's population. Within the European Union (EU), in 2018 one third of the population aged 18 to 64 years of age had care responsibilities, with more women than men providing care and many combining their care responsibilities with paid employment (Eurostat, 2021). Working age informal carers who combine caregiving with paid work are termed working carers (WKC) (Kröger & Yeandle, 2014). This paper describes a Swedish national survey designed to identify informal carers of working age and explore their caregiving experience and the extent to which it affects their ability to work.

Due to the rising need for long-term care in Europe, the connection between informal care and employment is becoming increasingly important, and several countries have consequently recognised and started to address WKC as a group. Indeed, this trend together with a greater awareness of the crucial role played by informal carers during the COVID-19 pandemic led to the development and launch of the European Care Strategy (European Commission, 2022). The strategy recognises informal carers and gender equality in caregiving and aims to sustain informal carers as healthy and resilient as possible in their caring and paid work roles. Furthermore, the EU Work/Life Balance directive (European Union, 2019) introduced new terms for informal carers, namely the right to five days of unpaid leave per year and the right to request flexible working arrangements. It is hoped this prioritisation in the EU social agenda will aid WKC, especially female WKC, manage their care responsibilities without damaging their careers (Eurofound, 2022).

Providing informal care is associated with both positive and negative outcomes for the carer. Positive outcomes include feelings of meaningfulness and satisfaction (Ulmanen, 2017), while there can be negative social and economic outcomes as well as psychological effects, such as reduced well-being and mental health (Lynch et al., 2018). Such outcomes are related to factors such as carer and care-recipient characteristics, and the intensity, type, and frequency of care provided (European Commission, 2021). WKC are a special group of informal carers as the combination of carer and paid worker roles is particular to them and thus provides a unique experience (CIPD, 2020). Spasova et al. (2018) argued that WKC's support needs should therefore be considered differently from other carers if they are to be sufficiently addressed. The negative impacts of combining work and care include reduced labour market participation (Vangen, 2021), high levels of burden and stress (Grünwald et al., 2020) and reduced health and well-being (Rocard, 2022), with the intensity of care provided by WKC strongly related to the effects of caregiving on their employment (Dixley et al., 2019). Compared to non-working carers, WKC may, however, experience greater financial security, be better placed to maintain social contacts and relationships and be able to focus on activities other than caregiving (European Commission, 2021). Other studies have identified various factors associated with work-related outcomes of informal care, such as: gender (with women WKC experiencing greater carer burden and subsequently more likely to reduce their paid working hours or leave their employment altogether to a greater extent than male WKC (Labbas, 2022)); ethnicity (with carers from ethnic minority

groups more likely to have their work affected compared to carers from a majority population (Kong et al., 2021)); received training and no assistance with providing care (WKC who received training and no assistance with care of their relative were more likely to have their work affected, compared to those WKC who did not receive training and had assistance (Kong et al., 2021)); and carer recognition (a sense of recognition is diminished among carers who do not have the support to participate adequately in employment, contributing to poorer well-being outcomes (Hamilton et al., 2024)).

Further knowledge is needed, however, on what caregiving-related factors are associated with how WKC experience care and their ability to work, to provide evidence to underpin the development of more responsive supports for WKC. For example, the impact of sleep disturbance and ability to meet friends have not been widely explored in prior research on WKC. Further, there remains a dearth of studies that have focused on the positive impacts of caregiving among WKC, such as finding caregiving satisfying, on both the caregiving situation and ability to work.

Although historically having a relatively generous welfare system, in recent decades Sweden has experienced economic cutbacks to local authority services, which together with demographic trends in ageing have led to 're-familiarization', an increasing dependence on family members to provide care to frail older and/or disabled people (Aldman et al., 2024; Szebehely & Meagher, 2018). Ekman et al. (2021) conducted a cost analysis study which estimated that around 15% of the adult population in Sweden provides informal care with a value of SEK 152 billion per year. Further, several recent quantitative studies focusing on WKC in Sweden have confirmed, similarly to the international literature, the adverse impacts of caring with regards to the mental health of female WKC compared to their male counterparts (Czajkowski et al., 2025; Ekman et al., 2021; Stanfors & Jacobs, 2023). At a policy level, an increased awareness of the role of informal carers has led to the launch of the first Swedish National Carers Strategy (SNCS; Ministry of Health and Social Affairs, 2022). The strategy recognises the importance of adopting a carer perspective within both health and social care services and the need to provide more individualised and equitable support across the country that is evidence based.

Even if WKC's main characteristics have previously been described both in general and in a Swedish context, few studies have been based on nationally representative population surveys, or have focused on how factors related to the caregiving situation are associated with both their negative and positive experiences of caregiving and their ability to work. Even if the relevance of workplace support for WKC has been previously discussed (Williams & Bank, 2022), there is still a knowledge gap regarding WKC's experiences and the impact of informal care provision on their ability to work. This exploratory study describes data collected in a Swedish national survey on informal care and examines which care-related factors are associated with (i) WKC's experience of caregiving as demanding and (ii) their ability to work.

Methods

Design, sampling and participants

The study, the Swedish National Carer Survey, was a cross-sectional questionnaire-based survey conducted between October 2018 and January 2019. A stratified random sample of 30,009 adults (aged 18 years or older) was drawn by Statistics Sweden (SCB) from the

Swedish National Population Registry at the end of July 2018 (total population 8,063,051). The sampling frame ensured equal representation from all Swedish regions. All sampled individuals received a questionnaire from SCB for self-completion and return. A total of 365 cases (questionnaire returned, wrong address $n = 316$; person not contactable $n = 49$) were excluded and the 11,168 individuals (6,432 (57.6%) of whom were of working age, 18–64 years) who completed and returned the questionnaire represented a response rate of 37.3%. Reasons for non-response were: not returned $n = 17,503$; declined participation $n = 480$; prevented from participating $n = 120$; wrong person answered questionnaire $n = 195$; returned spoiled $n = 86$; promised to send in $n = 5$.

Individuals met the inclusion criterion for being an informal carer if they indicated in the questionnaire that the definition provided of an informal carer described them: someone who provides help, care, or support to one or more persons (family members, someone in a close relationship such as friend, neighbour or work colleague) in a personal capacity (not in an employee role or as a parent to a child or children without special needs) due to their old age, disability or physical/mental illness. An exclusion criterion was that they provided such care less often than once a month. WKC's were defined as employed or self-employed informal carers of working age. Out of the 6,432 working age respondents, 1,093 met the informal carer criteria (16.9% of the working age sample and 9.78% of the total sample) and of these 818 (74.8% of working age informal carers) met the definition of a WKC and constituted the analytic sample for this study. When estimated to the 2018 Swedish population, WKC's constituted 7.4% of the total population, that is, 602,926 individuals. This estimate is lower than the 9.4% estimate provided in 2012 (Swedish National Board of Health and Welfare, 2012). This discrepancy might be because the 2012 survey had a higher response rate (55%) than ours, while our definition of WKC's excluded those who were on paid leave, on parental leave, and students.

Material

The questionnaire was developed by the research team based on a 2012 questionnaire from a Swedish national survey on informal care (Swedish National Board of Health and Welfare, 2012). The adaptation of the earlier questionnaire was carried out with two aims in mind: (a) to maintain as far as possible comparability with the original questionnaire; and (b) to add new questions judged by the research team to be relevant and important but missing from the earlier survey. The judgement of a new question's relevance or importance could be based on findings from previous research, theoretical considerations, or significance for practice and/or policy. See supplementary material (S1 – Appendix) for a full description of the variables included in the study questionnaire.

The final questionnaire included 28 main questions that addressed eight different areas: sociodemographic characteristics ('Carer characteristics' in Table 1 and in supplementary material S1); caregiving characteristics; caregiving context; local authority support to care-recipient; support to the informal carer; perceived care needs of care-recipient and type of care provided. As the survey targeted the general population including people above retirement age and covered a broad range of topics, it was not possible to include any questions about the participants' workplace conditions.

Table 1. Carer characteristics, care recipient characteristics and caregiving relationship ($N = 835$).

Variable	
Age (years, <i>M</i> , <i>SD</i>)	48.5 (11.09)
Gender, <i>n</i> (%)	
Female	469 (56.1)
Self-reported health, <i>n</i> (%)	
Very good	216 (26.1)
Pretty good	380 (45.9)
So-so	164 (19.8)
Pretty bad	56 (6.8)
Very bad	11 (1.3)
Number of care recipients, <i>n</i> (%)	
One person	647 (77.4)
Two people	143 (17.1)
Three people	17 (2.1)
More than three people	28 (3.4)
Frequency of care, <i>n</i> (%)	
Everyday	327 (39.6)
At least once a week	357 (43.2)
At least once a month	141 (17.1)
Intensity of care, <i>n</i> (%)	
<1 hour/week	75 (9.4)
1–10 hours/week	512 (64.5)
11–29 hours/week	122 (15.4)
30–59 hours/week	54 (6.8)
60 or more hours/week	31 (3.9)
Care recipient's age, <i>n</i> (%)	
<18 years	132 (16.0)
18–29 years	96 (11.7)
30–44 years	52 (6.3)
45–64 years	116 (14.0)
65–79 years	140 (17.0)
>80 years	288 (35.0)
Care-recipient's relationship to carer, <i>n</i> (%)	
Husband/wife/partner	85 (10.4)
Child	209 (25.5)
Parent	393 (47.9)
Sibling, relative	92 (11.2)
Legal guardian, neighbour, acquaintance	41 (5.0)
Co-residence, <i>n</i> (%)	
No	541 (65.5)
Care-recipient's condition, (%)	
Dementia illness, memory problems	88 (11.3)
Neurological disability or learning difficulty (not dementia and memory problems)	174 (22.3)
Malignant disease, cancer or leukaemia	43 (5.4)
Reduced physical health, impaired physical function or physical disability	347 (44.6)
Reduced mental health, social/personal problems or addiction problems	127 (16.3)

Note: due to internal missing values *n* will vary across variables.

Source: Authors.

Procedure

Approval for the study was provided by the Regional Ethics Review Board in Linköping (no. 2018/135-31).

The questionnaire was sent to sampled individuals by SCB in October 2018, together with an information letter, a postage pre-paid reply envelope and a link to a web-version of the questionnaire as an optional mode of completion. Where no completed questionnaire was received by the end of October, SCB sent a reminder letter and, if required, up to two further reminder letters, each with a new questionnaire. SCB extracted the data from the physical and web-based questionnaires and entered it into a dataset, to

which information was added on, inter alia, participants' age, gender, educational qualifications and occupational status from the National Population Registry. Following quality checks SCB then sent the anonymised dataset to the research team.

Data analysis

For the analysis two survey questions were selected as dependent variables (DVs) to measure the outcomes of the study. The first question asked participants 'Does it feel demanding to provide care and support?', with the response options coded on a scale from 'Never or seldom (0)' to 'Almost always or always (3)'. This DV is subsequently labelled 'caregiving is demanding'. The second question asked participants 'Has your ability to work/study decreased because you provide care or support?', with the response options coded in five response categories on a scale from 'No, not at all (0)' to 'Yes, my ability to work/study has decreased by more than 25% (3)'. This DV is subsequently labelled 'ability to work is decreased'. The remaining questions were considered as potential independent variables (IVs) where relevant theory and/or previous research justified their selection. For some questions, response options were recoded to combine neighbouring categories due to a small number of cases within categories to facilitate further analysis and/or to reduce the number of empty cells in the multivariable models (see S1 – Appendix).

IBM SPSS v.27 was used to describe and summarise the characteristics of the sample and to perform univariate, bivariate and multivariable ordinal logistic regression (OLR) analysis. For univariate analyses, nominal variables were described by count and percentage by response category while interval variables were described by mean, standard deviation and range. For analysis of the bivariate associations between IVs and DVs, the chi-square test for association was used for nominal IVs and Spearman's rank-order coefficient (ρ , r_s) calculated for interval IVs.

Two OLR models were developed, one for each DV. In developing the models, our goal was to achieve parsimonious models with significant IVs and good model fit and explanatory power. Given the large number of IVs, only those with a significant bivariate association with either of the DVs were initially considered for model entry. However, some of these IVs were conceptually similar and strongly associated with each other. So that the OLR models should be parsimonious, where IVs were confounded conceptually and/or statistically, those with the strongest bivariate associations with the study DVs were generally selected for multivariable analysis and the other IVs excluded. However, weight was also given in this process to an IV's relevance for theory and policy. As an example, the IVs frequency of care (daily to monthly) and intensity of care (hours per week) are conceptually related both are commonly-used indicators of caregiver burden (Liu et al., 2020) and were strongly statistically associated. Of the two, intensity of care had the strongest bivariate association with a DV and had greater measurement sensitivity, potentially useful for e.g. assessing the effect of interventions. As such, intensity of care was selected for the multivariable models, and frequency of care excluded. Through this evaluative process, the following IVs were excluded from the OLR models: frequency of care; care recipient's age; carer co-residence; care recipient's relationship to carer; unable to engage in exercise; physically stressful; difficulties in relationship with care-recipient. See supplementary material (S2 – Summary of confounds among IVs) for a full description

of confounds among the study IVs. Subsequently, trial runs of OLR models with the remaining IVs indicated that some IVs were non-significant in the models for both DVs. Again, applying the principle of parsimony these IVs were not included in the final models: carer age, self-reported health, and perceived need for support. There was no evidence of significant multicollinearity in either of the final models, as indicated by VIF values \leq to 10 and Tolerance values $>$ 0.1 (Field, 2018).

For all bivariate analyses and tests of individual IVs in the OLR models, a p -value of less than 0.05 was the criterion for statistical significance. Due to multiple testing inflating the family-wise error rate each significance test should be considered in the context of the obtained effect size. The OLR models were evaluated by (a) the likelihood ratio test which indicates if there is an improvement in the final model including IVs relative to the initial (null) model without IVs; (b) the deviance chi-square which tests the model's goodness-of-fit in terms of whether there is a difference between the final model and a 'best possible' model; and (c) the Nagelkerke pseudo R-square statistic that approximates to the R-square statistic in a linear regression which indicates the amount of variance explained in the DV by the IVs. Within the models, the odds ratios for the relationship between individual IVs and the DV indicate the multiplicative change in the odds of being in a higher category on the DV for every unit increase on the IV, adjusted for all other IVs in the model, with a ratio $>$ 1 indicating increasing odds and a ratio $<$ 1 indicating decreasing odds. Adjusted marginal predictions are presented for selected IVs in the models as supplementary material (S3 – Adjusted marginal predictions for selected IVs).

For all analyses appropriate survey weights provided by SCB and based on a participant's gender, age, education, and region were used to compensate for sampling bias generated by non-random non-response and the sampling frame.¹

Results

Univariate analyses

Just over half of WKC's (56.1%) were female and the average age was 48.5 years. Just under half (45.9%) of WKC's indicated their health to be pretty good. WKC's predominantly cared for their parents (47.9%) or their child (25.5%), while 35.0% of care-recipients were over 80 years of age. Most WKC's (77.4%) provided care to one person, while approximately 40% provided daily care and a comparable proportion provided care at least once a week.

A majority (64.5%) of WKC's provided care for 1 to 10 hours per week, and a comparable majority (65.5%) cared for a non-co-resident. Over a third of WKC's (44.6%) provided care to someone due to their reduced physical health, impaired physical function, or physical disability while 22.3% of WKC's provided care due to a person's neurological disability or learning difficulties.

For more than two out of five WKC's (41%) no formal support was provided to the care-recipient while for 38.4% formal support was provided and was found satisfactory. Almost half (47.1%) of WKC's felt that all the care-recipient's care needs were met while a comparable proportion (47%) indicated that they would like more help to meet those care needs (Table 2).

Out of 10 domains of care in which the care-recipient might have required support, WKC's provided care alone in 1.38 domains on average (SD 2.20). Out of 10 different types of support for carers, WKC's received 1.06 supports on average (SD 1.69).

Table 2. Support received by carer and care-recipient ($N = 835$).

Variables	
Number of care domains where care is provided alone, (Mean, (SD))	1.38 (2.20)
Formal support to care-recipient, (%)	
No	336 (41.0)
Yes, declined	55 (6.7)
Yes, dissatisfied	113 (13.9)
Yes, satisfied	314 (38.4)
Perceived need for support (%)	
All care needs met	385 (47.1)
I will provide more support to meet care needs	47 (5.8)
I would like more help to meet needs	384 (47.0)
Number of types of carer support received by carer, (Mean, SD)	1.06 (1.69)

Note: due to internal missing values n will vary across variables.

Source: Authors.

The largest proportion (43.3%) of WKC's never or seldom felt unable to spend time with friends due to caregiving, while a comparable proportion (44.4%) never or seldom felt unable to engage in exercise. The largest proportion (35.0%) of WKC's sometimes experienced caregiving as psychologically stressful, while the majority never or seldom: experienced caregiving as physically stressful (59%); felt that it led to difficulties in the relationship with the care-recipient (50.3%); felt that it caused financial problems (70.6%); or felt that it caused problems with family members (55.9%) (Table 3).

Almost half (49.3%) of WKC's sometimes experienced caregiving as demanding. A majority of WKC's reported that they experienced no sleep disturbance due to caregiving (59.8%) while a comparable proportion (59.6%) indicated their ability to work had not decreased.

The largest proportion (35%) of WKC's sometimes experienced caring as satisfying, while just less than half (46%) always or almost always felt that caregiving brought them closer to the care-recipient.

Bivariate analyses

Table 4 presents the bivariate associations between the study IVs and caregiving is demanding and ability to work (DVs). When considering the DV caregiving is demanding and its associations with the interval IVs, more frequently experiencing caregiving as demanding was significantly associated with: female gender; poorer self-reported health; providing care more frequently (daily/weekly); providing care more intensely (more hours per week); lower age of the care recipient; being a co-resident carer; more care domains where care was provided alone; more types of carer support received; more frequent inability to spend time with friends; more frequent inability to engage in exercise; more frequently experiencing caregiving as physical stressful; more frequently experiencing caregiving as psychologically stressful; more frequently experiencing difficulties in the relationship with the care-recipient; more frequently experiencing problems with other family members; more frequently experiencing financial problems; more frequent sleep disturbance; less frequently experiencing caring as satisfying; and less frequently experiencing being brought closer to the care-recipient.

There were significant associations between caregiving is demanding and all four categorical IVs. More frequently experiencing caregiving as demanding was observed more

Table 3. Psychosocial impact of care – negative and positive ($N = 835$).

Variables	WKC's			
	Never or seldom	Sometimes	Often	Almost always or always
Negative				
Unable to spend time with friends, n (%)	346 (43.3)	236 (29.6)	124 (15.5)	93 (11.6)
Unable to engage in exercise, n (%)	354 (44.4)	206 (25.9)	150 (18.9)	86 (10.8)
Psychologically stressful, n (%)	192 (23.9)	281 (35.0)	150 (18.7)	180 (22.4)
Physically stressful, n (%)	469 (59.0)	203 (25.6)	65 (8.1)	58 (7.3)
Difficulties in relationship with care-recipient, n (%)	405 (50.3)	282 (35.0)	70 (8.7)	48 (5.9)
Causes financial problems, n (%)	559 (70.6)	117 (14.8)	71 (8.9)	45 (5.7)
Problems in relationships with family members, n (%)	446 (55.9)	243 (30.4)	75 (9.4)	34 (4.3)
Caring is demanding n (%)	186 (22.9)	401 (49.3)	149 (18.3)	77 (9.5)
Sleep disturbance, n (%)				
My sleep is not disturbed at all	496 (59.8)	–	–	–
Roughly one night per week	134 (16.1)	–	–	–
Between 2 and 3 nights a week	116 (14.0)	–	–	–
Between 4 and 6 nights a week	48 (5.8)	–	–	–
Every night	36 (4.3)	–	–	–
Ability to work decreased n (%)				
No, not at all	490 (59.6)	–	–	–
Yes, my ability to work / study has decreased by about 10% (i.e. very little)	174 (21.2)	–	–	–
Yes, my ability to work / study has decreased between 10% to 25% (i.e. a bit)	89 (10.8)	–	–	–
Yes, my ability to work / study has decreased between 25% to 50% (i.e. quite a bit)	59 (7.1)	–	–	–
Yes, my ability to work / study has decreased by more than 50% (i.e. a lot)	10 (1.2)	–	–	–
Positive				
Caring is satisfying, n (%)	173 (21.9)	277 (35.0)	214 (27.1)	127 (16.0)
Caring brings me closer to the care-recipient, n (%)	58 (7.2)	165 (20.6)	209 (26.1)	368 (46.0)

Note: due to internal missing values n will vary across variables.

Source: Authors.

often than expected among WKC's: caring for a partner or a child; caring for someone with a malignant disease, a neurological or learning disability, or impaired mental health/social function; dissatisfied with the formal support provided to the care-recipient; and those who wanted more support to meet the care-recipient's needs.

With regard to the associations between the second DV, ability to work is decreased, and the interval IVs, a greater decrease in the ability to work was associated with: lower carer age; poorer self-reported health; providing care more frequently (daily/weekly); providing care more intensely (more hours per week); lower age of the care recipient; being a co-resident carer; more care domains where care was provided alone; more types of carer support received; more frequent inability to spend time with friends; more frequent inability to engage in exercise; more frequently experiencing caregiving as physically stressful; more frequently experiencing caregiving as psychologically demanding; more frequently experiencing difficulties in the relationship with the care-recipient; more frequently experiencing problems with other family members; more frequently experiencing financial problems; more frequent sleep disturbance; and less frequently experiencing caregiving as satisfying.

There were significant associations between ability to work and all four categorical IVs. A greater decrease in the ability to work was observed more often than expected among

Table 4. Bivariate associations between study variables and caregiving is demanding and ability to work ($N = 835$).

Variable	Caring is demanding rs	Ability to work rs
Age	-.05	-.19**
(Female) Gender	.20**	.02
(Poorer) Self-reported health	.410**	.28**
Number of care recipients	.04	.01
Frequency of care	-.38**	-.37**
Intensity of care	.34**	.47**
Care recipient's age	-.28**	-.34**
Co-resident carer	.31**	.30**
Number of care domains where care is provided alone	.27**	.22**
Number of types of carer support received by carer	.21**	.29**
Unable to spend time with friends	.51**	.59**
Unable to engage in exercise	.50**	.52**
Psychologically stressful	.67**	.59**
Physically stressful	.42**	.47**
Difficulties in relationship with care-recipient	.51**	.31**
Causes financial problems	.51**	.48**
Problems in relationships with family members	.46**	.35**
Sleep disturbance	.49**	.49**
Caring is satisfying	-.31**	-.23**
Caring brings me closer to the care-recipient	-.16**	.02
Care-recipient's relationship to carer	$\chi^2 (12) = 143.5^{**}$	$\chi^2 (12) = 102.7^{**}$
Care-recipient's condition	$\chi^2 (12) = 108.2^{**}$	$\chi^2 (12) = 160.9^{**}$
Formal support to care-recipient	$\chi^2 (9) = 91.9^{**}$	$\chi^2 (9) = 58.3^{**}$
Perceived need for support	$\chi^2 (6) = 135.5^{**}$	$\chi^2 (6) = 88.5^{**}$

Note: n : Total number of participants that supplied information for the corresponding variable; rs: Spearman's correlation coefficient; χ^2 : Chi-square test; ** $p < .01$. Note: for analyses n varies between 762 and 799 due to internal missing values.

Source: Authors.

WKC's caring for a partner or a child; caring for someone with a neurological or learning disability or reduced mental health/social function; dissatisfied with the formal support provided to the care-recipient; and those who wanted more support to meet the care-recipient's needs.

The association between the two DVs, caregiving is demanding and ability to work, was significant ($r_s = .45$, $p < .001$).

OLR model: caregiving is demanding

The 'never or seldom' response category was used as the reference category for the DV in the model. All selected IVs were entered into the model simultaneously, weighted $n = 681$. In comparison to a constant-only model the model was reliable (Likelihood ratio $\chi^2 (18) = 649.0$, $p < .001$), with good model fit (Deviance $\chi^2 (1161) = 989.0$ $p > .05$, Nagelkerke $R^2 = .66$). Table 5 presents the final model Likelihood ratio chi-squares and odds ratios with 95% confidence intervals for each IV adjusted for each other.

Female WKC's had 2.66 times the odds of being at a higher category of caregiving is demanding than males. Local authority support for the care-recipient was significant in the model: compared to carers whose care recipient did not receive local authority support, those carers who expressed dissatisfaction with the support received had 2.77 times the odds of being in a higher category of caregiving is demanding, while for carers who expressed satisfaction with the support received the odds were 2.05.

Table 5. Logistic regression of caregiving is demanding on selected variables.

Variables	Likelihood ratio χ^2 (df)	OR	Lower 95% CI	Upper 95% CI
Intercept: Caregiving is demanding				
Sometimes		2.621*	1.076	6.384
Often		197.91**	71.49	547.90
Almost always or always		3037.4**	954.5	9665.9
Female gender	27.5 (1)**	2.662	1.835	3.863
Intensity of care (hours of care per week)	0.0 (1)	0.998	0.776	1.283
Number of care domains care provided alone	3.54 (1)	1.083	0.996	1.177
Care-recipient's condition (ref = dementia)	9.23 (4)			
Neurological		0.479*	0.252	0.909
Malignant		0.529	0.204	1.368
Reduced physical health		0.667	0.377	1.181
Reduced mental health		0.366**	0.181	0.740
Local authority support to care-recipient (ref = no)	18.8 (3)**			
Yes, declined		1.639	0.837	3.209
Yes, dissatisfied		2.766**	1.580	4.843
Yes, satisfied		2.054**	1.375	3.068
Number of carer supports received	0.55 (1)	0.959	0.858	1.072
Unable to spend time with friends	1.32 (1)	1.157	0.902	1.483
Psychologically stressful	66.0 (1)**	2.797	2.160	3.623
Problems in family relationships	44.5 (1)**	2.356	1.819	3.052
Financial problems	53.3 (1)**	2.349	1.854	2.975
Sleep disturbance	9.43 (1)**	1.359	1.116	1.655
Caring is satisfying	17.8 (1)**	0.637	0.516	0.788
Caring brings me closer to care-recipient	9.23 (1)**	0.728	0.592	0.894

Note: OR, odds ratio; CI, confidence interval; ref, reference category. * $p < .05$, ** $p < .01$.

Source: Authors.

The odds of being in a higher category of caregiving is demanding increased by 2.80 for every unit increase in experiencing caregiving as psychologically stressful; by 2.36 for every unit increase in caregiving causing problems in family relationships; by 2.35 for every unit increase in caregiving causing financial problems; and by 1.36 for every unit increase in caregiving causing sleep disturbance. For every unit increase in experiencing caregiving as satisfying, the odds of being in a higher category of caregiving is demanding were 0.64, while for a unit increase in caregiving brings the care-recipient closer, the odds were 0.73.

OLR model: ability to work is decreased

The 'No, not at all' response category was used as the reference category for the DV in the model. All the IVs were entered in the model simultaneously, weighted $n = 682$. In comparison to a constant only model, the model was reliable (Likelihood ratio χ^2 (18) = 505.8, $p < .001$), with good model fit (Deviance χ^2 (1155) = 976.9 $p > .05$, Nagelkerke $R^2 = .56$). Table 6 presents the final model Likelihood ratio chi-squares and odds ratios with 95% confidence intervals for each IV adjusted for each other.

Care-recipient's condition was significant in the model. Compared to caring for someone with dementia, those caring for someone with a neurological condition had 5.08 times the odds of being in a higher category of ability to work is decreased, those caring for someone with reduced physical health had 4.14 times the odds, while those caring for someone with reduced mental health had 10.61 times the odds. For every unit increase in the number of types of carer support received, the odds of being in a

Table 6. Logistic regression of ability to work is decreased on selected variables.

Variables	Likelihood ratio χ^2 (df)	OR	Lower 95% CI	Upper 95% CI
Intercept: Ability to work is decreased				
Yes, decreased by about 10% (i.e. very little)		28.61**	8.779	93.246
Yes, decreased between 10% to 25% (i.e. a bit)		244.80**	70.22	853.456
Yes, decreased by more than 25%		906.337**	247.41	3320.16
Female gender	7.4 (1)	0.582	0.394	0.861
Intensity of care (hours of care per week)	3.0 (1)	1.244	0.972	1.592
Number of care domains care provided alone	1.7 (1)	1.062	0.972	1.161
Care-recipient's condition (ref = dementia)	44.2 (4)**			
Neurological		5.083**	2.091	12.353
Malignant		1.207	0.367	3.965
Reduced physical health		4.143*	1.711	10.031
Reduced mental health		10.609**	4.175	26.958
Local authority support to care-recipient (ref = no)	5.1 (3)			
Yes, declined		1.171	0.563	2.436
Yes, dissatisfied		0.569	0.323	1.004
Yes, satisfied		0.754	0.483	1.178
Number of carer supports received	12.0 (1)**	1.246**	1.105	1.413
Unable to spend time with friends	56.9 (1)**	2.651**	2.047	3.433
Psychologically stressful	26.8 (1)**	2.002**	1.533	2.613
Problems in family relationships	0.05 (1)	0.972	0.759	1.243
Financial problems	9.56 (1)*	1.412*	1.134	1.757
Sleep disturbance	0.10 (1)	0.972	0.816	1.156
Caring is satisfying	9.33 (1)*	0.709*	0.567	0.885
Caring brings me closer to care-recipient	0.25 (1)	1.060	0.847	1.325

Note: OR, odds ratio; CI, confidence interval; ref, reference category. * $p < .05$, ** $p < .01$.

Source: Authors.

higher category of ability to work is decreased were 1.25. For every unit increase in being unable to spend time with friends, the odds of being in a higher category of ability to work is decreased were 2.65. For every unit increase in experiencing care as psychologically stressful, the odds of being at a higher level of ability to work is decreased were 2.00. For every unit increase in experiencing financial problems, the odds of being at a higher category of ability to work is decreased were 1.41. Finally, for every unit increase of experiencing caregiving as satisfying, the odds of being in a higher category of ability to work is decreased were 0.71.

Discussion

The aim of the present study was to examine what caregiving-related factors are associated with how Swedish WKC experience their caregiving and work situation. By using nationally representative survey data, we have been able to contribute to an improved understanding of these issues in a European context. Our findings broadly reflect those of previous studies in that we found experiencing caregiving as demanding to be associated with factors such as: carer gender and self-reported health; the frequency and intensity of care; co-habitation with the care-recipient and the care-recipient's condition; formal support received; and the influence of caregiving on the carer's social life, relationships with family and friends, level of stress and sleep disturbance. Our findings indicate that such factors are also associated with a reduced ability to work in WKC, an association not widely researched before. The answer to our first research question was that female gender, local authority support to the care-recipient, and psychological stress, sleep

disturbance and problems with finances and family relationships due to caregiving all increased the odds of experiencing caregiving as demanding; while finding that caregiving was satisfying and increased the closeness of the care relationship both decreased the odds of experiencing caregiving as demanding. The answer to our second research question was that the care-recipient's condition, receipt of more types of carer support, and psychological stress, being less able to spend time with friends, and financial problems due to caregiving all increased the odds of a reduced ability to work in WKC's; while finding that caregiving was satisfying decreased the odds of a reduced ability to work in WKC's. Thus, while some caregiving-related factors influenced both the experience of caregiving as demanding and a reduced ability to work (e.g. financial problems due to caregiving), some factors had a significant influence on only one of these outcomes (e.g. the care-recipient's condition was a significant variable only in the model of ability to work, while gender was significant only in the model of caregiving is demanding). The impact of informal caregiving on WKC's ability to work is explored in the present study and contributes to fill the knowledge gap on the impact of informal caregiving in this particular group of carers, in a country known to offer support for informal carers, Sweden.

Profile of Swedish WKC's

The profile of WKC's described in our study is in line with previous Swedish studies that indicate that a 'typical' WKC is a middle-aged women who cares at low intensity on a weekly basis for one person, someone in the immediate family who is likely to be aged over 65 and with reduced physical health or a neurological disability (Swedish National Board of Health and Welfare, 2014; Vicente et al., 2022). Our findings indicate that in general WKC's cope well with combining their care and work responsibilities: less than 10% of WKC's always or almost always found caregiving demanding, and the majority did not experience any sleep disturbance or decrease in their ability to work, or felt that caregiving caused financial problems or difficulties in their relationships with their family or the care-recipient. This picture of WKC's can be contrasted with that provided by much of the research on informal carers, in which the focus is predominantly on the high level of burden experienced and the consequent negative outcomes for informal carers' health and well-being. For example, attention has been drawn to the dual burden experienced by many female WKC's in a so called 'sandwich generation' where they provide informal care to both their children and their parents (Ekezie et al., 2022). When contrasting our findings with those from other studies, it should be considered that over two-thirds of the WKC's in our sample provided care for less than 10 hours per week. As such, many of the carers in our sample might be described as 'light' carers and might not have met the inclusion criteria for other studies on informal care where the focus is on burden. The relative low intensity of care provided in our sample might also partly explain why more than two out of five WKC's reported that the person they cared for did not receive any type of formal support, a finding which might otherwise be thought surprising given that formal health and social care support is relatively available in Sweden compared to many other countries. These low levels of formal support might also be due to a reluctance among WKC's to allow someone from outside the family to have responsibility for providing care (Lafferty et al., 2022).

Despite the generally positive picture of WKC's caregiving situation given by our findings, it should be remembered that nearly 50% of WKC's indicated they would like more help to meet their care-recipient's needs, while over a quarter often, almost always or always were unable to spend time with friends, unable to find time to exercise, found caregiving psychologically stressful or experienced caregiving as demanding.

Our bivariate analyses identified several factors associated with both WKC's experiencing caregiving as demanding and a reduced ability to work, most of which have been found to be linked to negative outcomes of caregiving in other studies. Female carers have been found to experience care burden more than males, while the intensity and frequency of care is a well-known predictor of burden (Lindt et al., 2020) and also linked to withdrawal from the labour market (Lilly et al., 2007). The financial situation of a carer does not only affect their ability and willingness to provide care (Vos et al., 2022), but also their experience of burden (Urwin et al., 2021). The relationship of the carer to the care-recipient is important, with spouse and child carers experiencing highest burden (Broese van Groenou et al., 2013), while reduced sleep quality has been shown to have consequences for the physical and mental health of the carer (Blom et al., 2020). Where a factor was significantly associated with one of our two outcomes, it was usually also significantly associated with the other, the only exceptions being carer age, carer gender, and being brought closer to the care-recipient by caregiving, each of which was significantly associated with only one outcome. However, the effect size for the associations between caregiving-related factors and outcomes in some cases differed substantially between outcomes. For example, self-reported health explained 16% of the variance in caregiving is demanding, but only 8% in ability to work. By comparison, intensity of care explained 22% of the variance in ability to work, but only 12% of the variance in caregiving is demanding. This variation in the effect of intensity of care may reflect how the experience of caregiving is likely moderated by a range of factors such as, e.g. one's reasons or motivations for being a carer. For some individuals, caregiving is a 'labour of love' (Finch & Groves, 1983), and this may ameliorate the effect of the intensity of care on experiencing care as demanding. However, no matter how much caregiving is a 'labour of love', an inflexible and unforgiving work environment may not be easily ameliorated, and thus the ability to work affected to a greater extent by the intensity of caregiving.

The most valuable results from our study were produced by the multivariable-level analysis. While the models for caregiving is demanding and ability to work contained several variables significant in both models, some variables were significant in only one model.

Caregiving as demanding

Considering the factors uniquely increasing or decreasing the odds of experiencing caregiving as demanding, both gender and family relationships have previously been identified as factors affecting the experience of informal care (Klerk et al., 2021; Lindt et al., 2020). Whereas some families can be a resource for informal carers, family relationships can be complex and where there are problems in those relationships families can become an additional source of stress. However, our findings also indicate that where a carer feels an increased closeness with the care-recipient, this can reduce the demands of caregiving. Sleeping problems have markedly increased in recent years in the

Swedish population (Blom et al., 2020) and the odds of experiencing sleep problems increases for co-habitant carers (Maun et al., 2019). The presence and delivery of support has been identified as an important factor affecting informal carers' ability and willingness to provide care (Vos et al., 2022). In our study WKC's whose care-recipient received support from the local authority were at increased odds of experiencing care as demanding compared to WKC's whose care-recipient did not receive support, regardless of whether the WKC was satisfied or dissatisfied with that support. Such a finding may seem surprising, but one explanation might be that the level of support received reflects the level of need for support, i.e. that the most demanding caregiving situations are those where support provision tends to be highest. As such, whether the WKC is satisfied or not with the support may have little influence on the level of demand they experience.

Ability to work

Considering the factors uniquely increasing or decreasing the odds of a reduced ability to work the nature of the care-recipient's condition is a principal factor in the level and kind of care required. Our study suggests that relative to caring for a person with dementia, WKC's who care for a person with a neurological condition or learning disability, or for a person with mental health problems or compromised social functioning, are more likely to have a decreased ability to work. By contrast, Sadavoy et al. (2022) found caring for a person with dementia increased work-related problems compared to caring for an older person without dementia. The lack of a social network has also been found to have negative consequences for a carer's employment (Neubert et al., 2019). Our findings suggest that even WKC's who do have a social network may experience work-related problems if they are unable, due to time restrictions related to caregiving, to access this network: the more frequently our WKC's were unable to be with their friends the greater the odds their ability to work was decreased. Regarding formal support, the receipt of carer support did not improve our participants' ability to work – indeed, the more different types of support received the greater the odds that their ability to work was decreased. As it is highly unlikely that receiving more carer support reduces WKC's' ability to work, a plausible explanation for this finding is that carers who have difficulty maintaining their work commitments seek out support or are offered support. Nevertheless, the fact that there is an association between carer support and greater odds of a reduced ability to work suggests that the support provided is not resolving whatever problems exist in the caregiving situation.

Caregiving as demanding and ability to work

Our finding of a strong association between how frequently WKC's experience caregiving as demanding and the degree to which their ability to work is decreased contributes to a growing body of evidence indicating that a caregiving situation can influence other spheres of life. Although our study did not consider our participants' workplace conditions, it is likely given the weight of research evidence that the relationship between caregiving and work situations is reciprocal, in that excessive stresses experienced at work will also negatively affect the caregiving experience. Another of our findings, that the odds of both experiencing care as demanding and a reduced ability to work are

related to a common set of factors, also has relevance here. Psychological stress and financial problems caused by caregiving increased the odds of both experiencing caregiving as demanding and a reduced ability to work, while finding caregiving satisfying decreased the odds of both. As such, these factors are likely to have considerable influence on the WKC's situation. One interpretation is that, unless the issues of psychological stress and financial problems due to caregiving are addressed there is a potential for a vicious circle to develop, with these factors increasingly eroding the quality of both care and work situations while the reciprocal relationship between care and work situations allows negative experiences in one to exacerbate the negative experiences in the other. There is also the potential, however, for a 'benign circle': as the WKC gains more satisfaction from caregiving there is a decrease in the odds for both experiencing caregiving as demanding and a reduced ability to work, with the beneficial effects in the caregiving situation positively influencing the work situation and vice versa. A caveat to this observation is that the beneficial effects of finding caregiving satisfying have not been found where care provision is very intense (Lakomý, 2020), and thus our finding might be due to the low intensity of care provided by many of our participants.

Further research is required to confirm the findings of our study but if more evidence is found that certain caregiving-related factors affect both the care and work situations of WKC's, then supports and interventions that effectively target those factors might bring most benefit to WKC's. For example, in relation to the present study, support to reduce the psychological stress of caregiving, mitigate financial problems, and enhance the satisfaction gained from caregiving, may have positive and direct effects on both care and work situations, with positive effects in one situation possibly leading to positive effects in the other.

Conversely, our finding that some caregiving-related factors were associated only with WKC's care situation while some only with their work situation does not mean that such factors are of lesser relevance for understanding how best to support WKC's, but rather that policy objectives on informal care need to be clearly specified and supports and interventions carefully targeted. This is in line with the SNCS (Ministry of Health and Social Affairs, 2022), which recognises the importance of both local authorities and health care regions in providing individualised and effective supports for carers. The SNCS also includes employers as a key stakeholder group for supporting carers, as appropriate workplace support can also help WKC's to better reconcile their caring and paid work roles (Eurofound, 2022b).

Since WKC's situation today is a global challenge, policies at a broader societal level also need consideration in keeping with the European Care Strategy (European Commission, 2022). These could address informal care provision and its combination with paid work in government pensions, unemployment benefits and even employment opportunities where the carer's role is addressed and relevant for both the employee and employer (Eurocarers, 2022). From a Swedish perspective this means that the current implementation work with the SNCS could usefully include WKC's and employers in co-developing targeted supports that focus on those factors affecting WKC's ability to work and experience of care as demanding. The expertise that WKC's can contribute to discussions on support should not be underestimated, with one study describing how WKC's developed reconciliation strategies to achieve a carer-friendly career (Lafferty et al., 2022).

Study strengths and limitations

The main strengths of the study are that our data come from a random stratified sample of the Swedish population aged 18 years and over, and that our sample size provides good statistical power for our analyses. The study is also novel as few previous studies have identified or described factors associated with both experiencing caregiving as demanding and ability to work in WKC. A key justification for our study is that WKC constitute an important and unique sub-group of informal carers, which does not receive sufficient attention. A corollary of this is that WKC are a selective group and that the findings of our study should not be generalised to the wider population of informal carers.

Our response rate was lower than desirable, but we weighted our analyses to reduce the influence of sampling bias. Our study is primarily descriptive and exploratory: as with all self-administered surveys much of the data is self-reported and thus its reliability is difficult to assess, while the cross-sectional nature of the study means that it is not possible to establish causal relationships between our variables. The selection of certain variables as IVs and DVs should therefore not be taken as implying a causal direction in the obtained associations. It is important also to acknowledge the measurement error and residual confounding present in our regression models when interpreting our findings. To cover a broad range of topics while keeping the questionnaire as short as possible, many of our study variables were single-item measures and the reliability of such measures cannot be determined. Our approach also meant that we could not cover any given topic in great depth, and some potential topics could not be covered at all. For example, we did not have specific measures of work-care balance or role strain or address how work-related factors influence the caregiving experience. Further research is required to examine these important topics.

The study results reflect the experiences of WKC in Sweden, a country that has established policies and support measures for informal carers in general. When extrapolating the study results to other contexts it is relevant to consider how national policies, provisions and support measures may affect and impact WKC's experiences.

Conclusion

How a WKC experiences their care situation is related to their ability to work, and a range of factors are associated with how frequently WKC experience caregiving as demanding and the degree to which their ability to work is decreased. In the present study, a subset of the caregiving factors that were explored – the psychological stress and financial problems due to caregiving and satisfaction gained from caregiving – were found to be associated with both the care and work situations of WKC. Further research is required to firmly establish those caregiving-related factors that affect WKC in both their care and working roles, as such evidence is important for developing policy on support that can most effectively benefit WKC in both contexts. National and European-level policy for carers should acknowledge the unique situation of WKC and promote joint action from both social and health care services and public and private employers.

Note

1. A technical report from SCB providing more details on how the survey weights were calculated can be obtained from the corresponding author on request.

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Data availability statement

Due to the risk of identification the full dataset cannot be shared publicly. A minimal dataset will be provided through the Open Science Framework platform (link) upon publication, in order to allow the replication of our analysis and results.

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