Deterioration of Health-Related Quality of Life: The Hidden Health Burden of Informal Caregiving

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Acknowledgement of Country

The University of Queensland (UQ) acknowledges the Traditional Owners and their custodianship of the lands on which we meet.

We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

We recognise their valuable contributions to Australian and global society.

Background

▪Informal caregiving is mostly an unpaid job provided by family members and friends to the elderly and people with disability or long-term health conditions [1].

▪About 65% of informal caregivers across Organization for Economic Co-operation and Development (OECD) countries were women in 2019 [2].

▪In 2018, one in ten Australians provided informal care, representing 2.65 million people [3].

▪Informal caregiving has known adverse effects on the health of carers, leads to high rates of depression and anxiety, and causes emotional and physical strain as well as stress [4, 5].

▪Informal caregiving involves millions of individuals who spend billions of hours caring for patients who would otherwise require care from the healthcare system. This resource should be seen as scarce and as valuable as any other health service within the health system. Therefore, it is important to consider the value of informal caregiving as part of the health technology assessment.

Methods

Data Source: The Household, Income and Labour Dynamics in Australia (HILDA) Survey.

Design: Retrospective longitudinal research design.

Subject: Individuals aged 15 years and over.

Period: The estimation sample spans 16 years, covering 16 waves (waves 6 through 21).

Sample: The authors have constructed an unbalanced panel data consisting of 198,669 person-year observations from 26,994 unique individuals.

Methods (Outcome variable)

- Informal The outcome of interest in the present analysis is the health-related quality of life (HRQoL) measured through the RAND 36-Item Short Form Survey Instrument (SF-36).

- The SF-36 health survey is made up of 36 questions that cover eight dimensions: physical functioning (PF), role physical (RP); bodily pain (BP), general health (GH), vitality (VT), social functioning (SF); role emotional (RE); and mental health (MH).

- Two summary measures of quality of life (QoL): physical component summary (PCS), and mental component summary (MCS) that reflect the physical and mental health-related quality of life, respectively, were derived from the SF-36 score.

- The PCS is based on four subscales of the SF-36: PF, RP, BP, and GH.

- The MCS is based on the other four subscales: RE, SF, MH, and VT.

Methods (Outcome variable)

- The summary scores, PCS and MCS, were calculated using the recommended scoring algorithms for Australians (Australian Bureau of Statistics., 1997) and standardised using a linear Z-score transformation with a mean of 50 and standard deviation (SD) of 10.
- The final values of PCS and MCS ranged from 4.54 to 76.09 and from − 1.21 to 76.19, respectively, with higher scores indicating better QoL (Perales et al., 2014).
- A related instrument that is widely used in economic evaluations as a measure of HRQoL is SF-6D.
- The SF-6D allows to obtain quality-adjusted life years (QALYs) from the SF-36.
- The SF-6D score is derived from responses from six dimensions of the SF-36, including PF, RP, RE, SF, VT, and BP.
- The value of SF-6D ranges from 0.29 to 1. The value 1 indicates full health, and 0.29 shows the worst health state.

Methods (Exposure variable)

Main exposure variable: Informal Caregiving

▪The self-completion questionnaire asks respondents about how much time they spent caring for a disabled spouse, adult relative or elderly parent/parent-in-law in a typical week.

▪The outcome variable informal caregiving was classified as non-caregiver, lighter caregiving (<5 hours/week), moderate caregiving (5–19 hours/week) and intensive caregiving (20 or more hours/week).

Methods (Covariates)

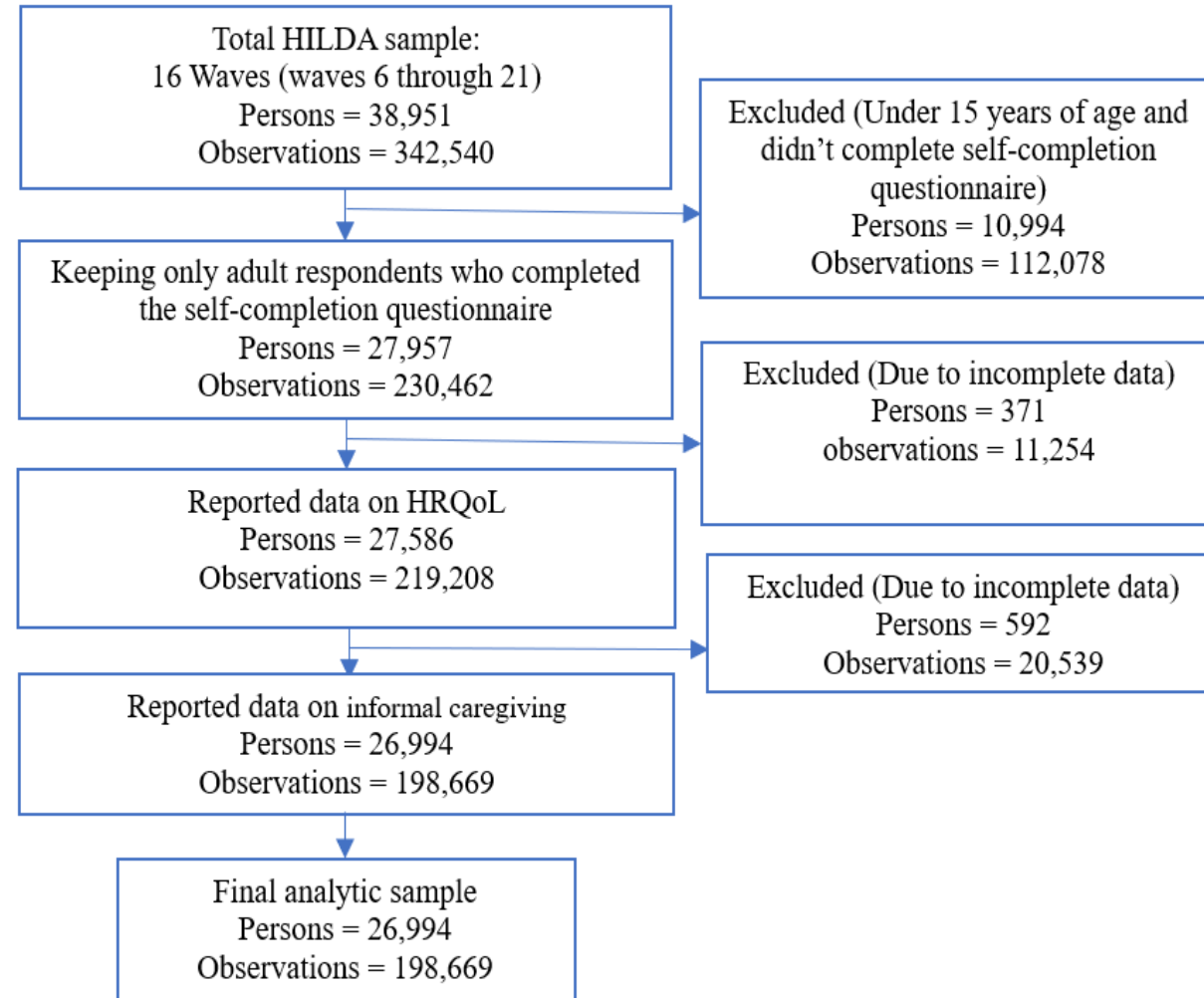| Domain	Variables
Socio-demographic characteristics (8)	Age, Gender, Relationship status, Education, Annual household income, Labour market status, Indigenous status, and Region of Residence.
Health-related characteristics (2)	BMI, and Disability
Health-related behaviours (3)	Smoking status, Alcohol consumption, and Physical activity.
Work-related stressful life events (3)	Retiring from the workforce, Getting fired, and Major worsening in financial situation.
Family-related stressful life events (3)	Serious injury/illness to family members, Death of spouse or child, and Death of close relative/family member.
Personal stressful life events (2)	Victim of physical violence, and Personal injury or illness to self.

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Methods (Sample Selection)

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Total HILDA sample:
16 Waves (waves 6 through 21)
Persons = 38,951
Observations = 342,540
                                    →    Excluded (Under 15 years of age and
                                         didn't complete self-completion
                                         questionnaire)
                                         Persons = 10,994
                                         Observations = 112,078

Keeping only adult respondents who completed
the self-completion questionnaire
Persons = 27,957
Observations = 230,462
                                    →    Excluded (Due to incomplete data)
                                         Persons = 371
                                         observations = 11,254

Reported data on HRQoL
Persons = 27,586
Observations = 219,208
                                    →    Excluded (Due to incomplete data)
                                         Persons = 592
                                         Observations = 20,539

Reported data on informal caregiving
Persons = 26,994
Observations = 198,669

Final analytic sample
Persons = 26,994
Observations = 198,669
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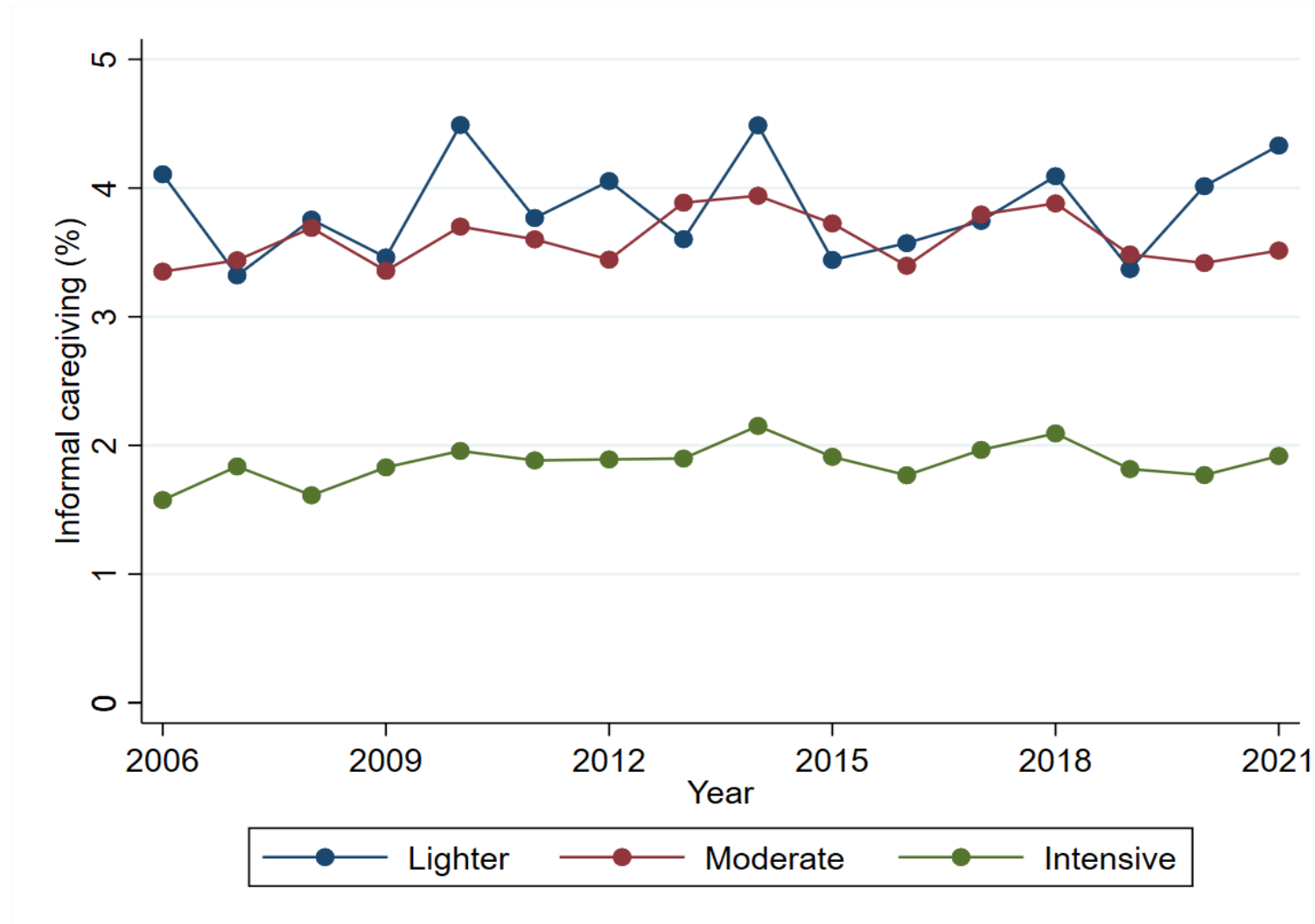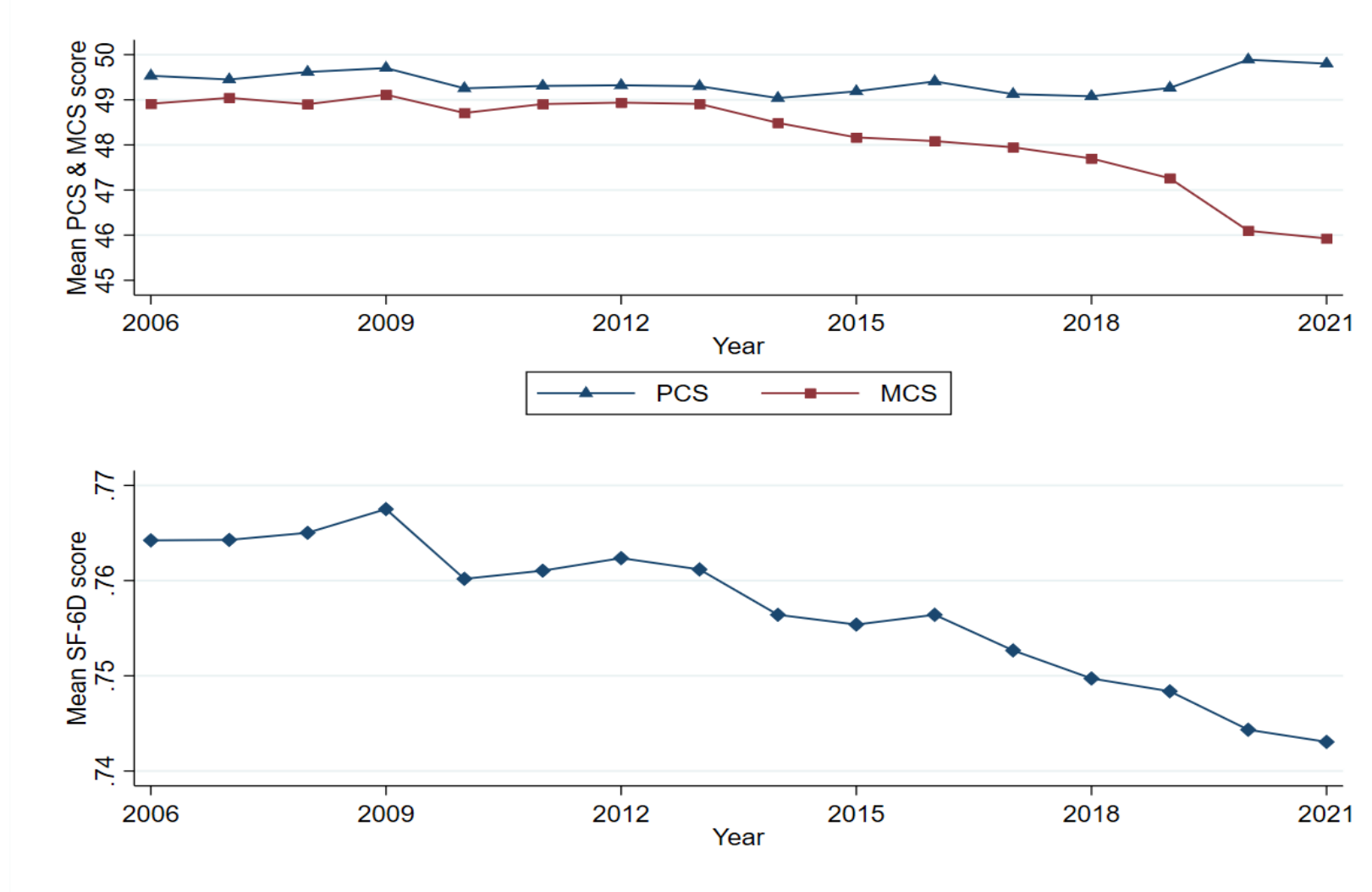Figure 1: Participants flow into the final analytic sample and missing data

Figure 2: Trend in the proportion of informal caregiving

Results (Distribution of outcome variables)
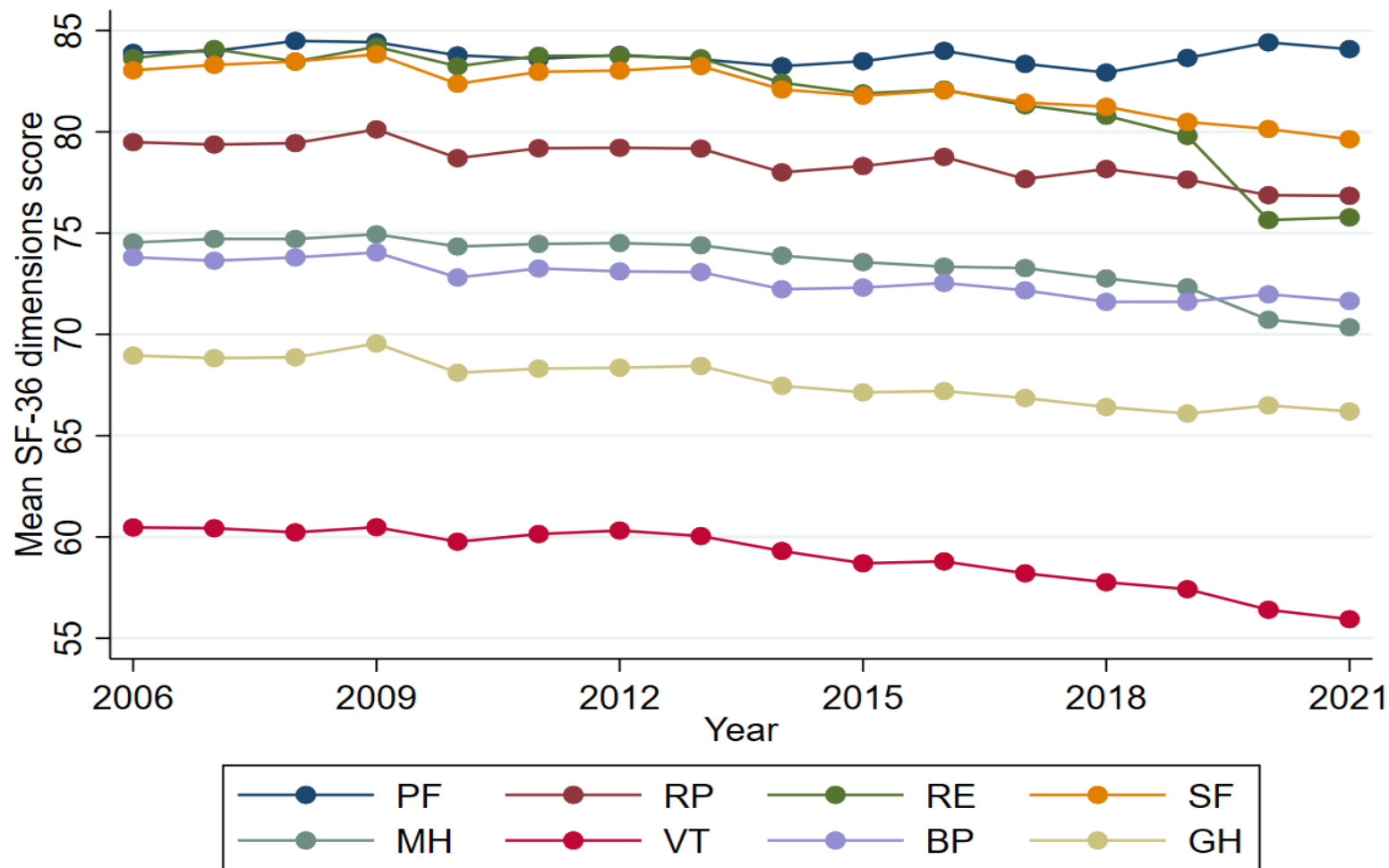
Results (Distribution of outcome variables)

Figure 3: Trend in the mean PCS, MCS, and SF-6D utility score

Notes: 1. Abbreviations: Physical functioning (PF), role physical functioning (RP), role emotional functioning (RE), social functioning (SF), mental health (MH), vitality (VT), bodily pain (BP) and general health (GH).

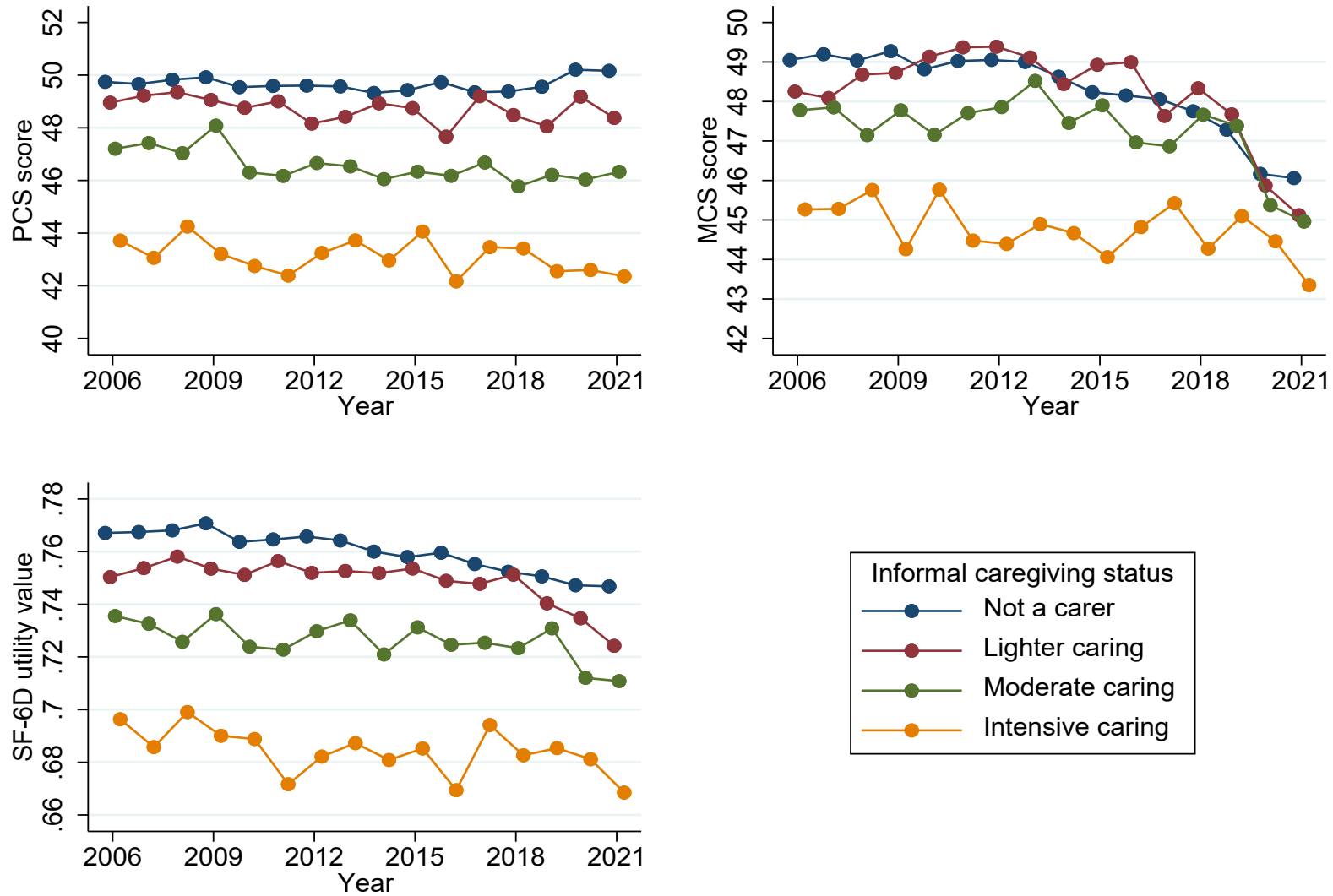# Results (PCS, MCS, and SF-6D utility scores by informal caregiving)

Figure 4: Trend in the mean PCS, MCS, and SF-6D utility score by informal caregiving

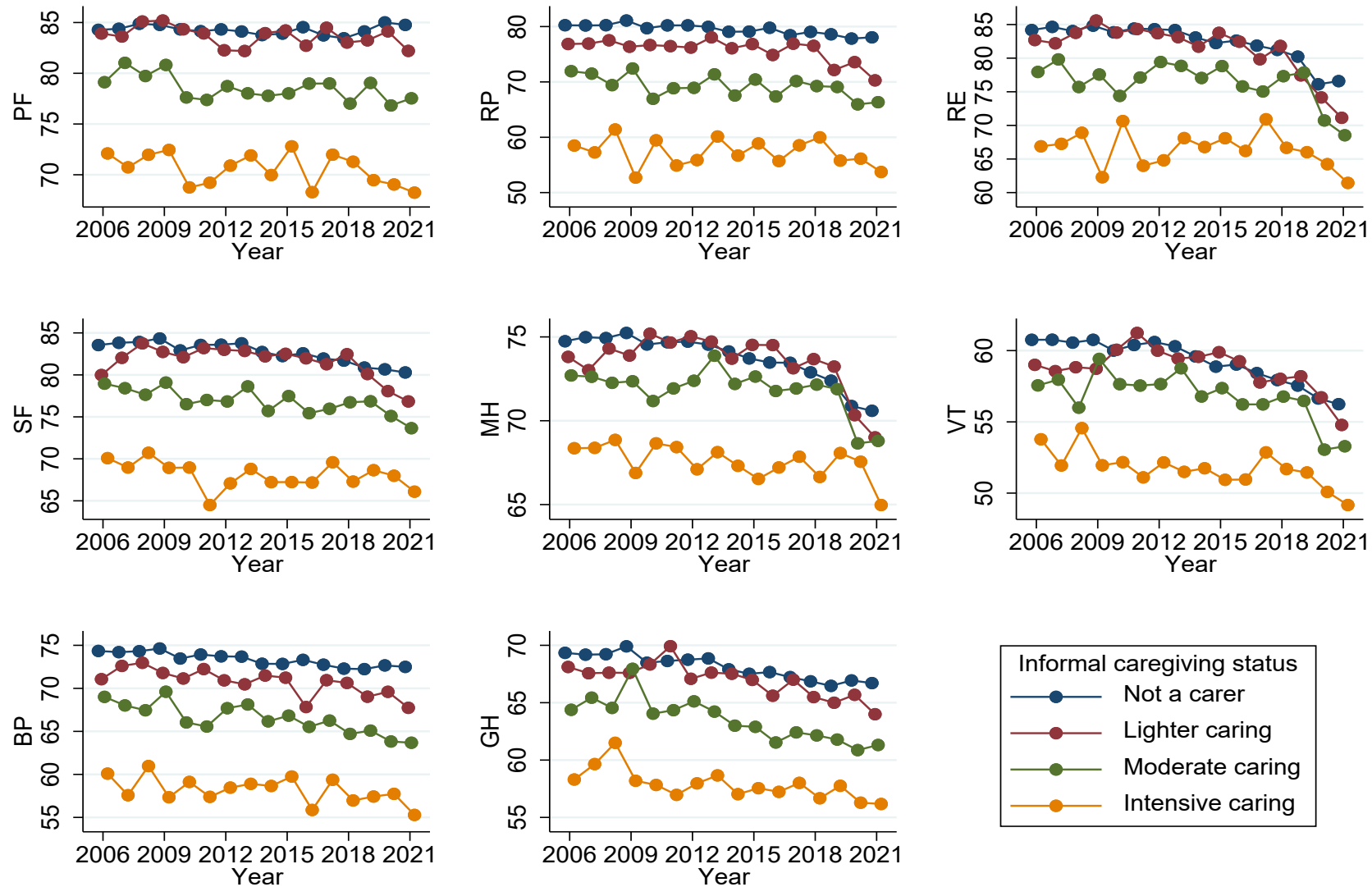# Results (Mean SF-36 dimension scores by informal caregiving)

Figure 4: Trend in the mean SF-36 dimension scores by informal caregiving

Results (Transition probabilities of informal caregiving)

Table: Estimated transition rate for each category of informal caregiving (from T to T+ 1+...+n).

Informal caregiving	Informal caregiving				Total
	Non-carer, n (%)	Lighter caring, n (%)	Moderate caring, n (%)	Intensive caring, n (%)	
Non-carer	148,855 (95.73)	3,494 (2.25)	2,379 (1.53)	761 (0.49)	155,489 (100)
Lighter caring	3,289 (49.06)	2,370 (35.35)	946 (14.11)	99 (1.48)	6,704 (100)
Moderate caring	2,238 (35.57)	845 (13.43)	2,515 (39.98)	693 (11.02)	6,279 (100)
Intensive caring	799 (25.04)	70 (2.19)	578 (18.11)	1,744 (54.65)	3,191 (100)
Total	155,181 (90.39)	6,779 (3.95)	6,418 (3.74)	3,297 (1.92)	171,675 (100)

Notes:1. T indicates the timepoint. 2. Total number of yearly observations used for calculating the transition rate is 171,675.

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Results

Table: Estimated effects of informal caregiving on the PCS, MCS, and SF-6D; fixed-effects panel regression models

Model	Outcome	Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)
Model 1	PCS	-0.05 [-0.22 - 0.12]	0.06 [-0.14 - 0.27]	**0.37* [0.03 - 0.71]**
Model 2	MCS	-0.18 [-0.39 - 0.02]	**-0.61*** [-0.86 - -0.36]**	**-1.75*** [-2.15 - -1.35]**
Model 3	SF-6D	**-0.003* [-0.005 - -0.001]**	**-0.005*** [-0.007 - -0.002]**	**-0.010*** [-0.014 - -0.006]**

Note: 1. The sample size is 26,994 unique individuals and 198,669 yearly observations. 2. All models were adjusted for age, marital status, highest education level attained, labour market status, annual household income, area of residence, BMI, disability, smoking status, alcohol drinking, physical exercise, retiring from the workforce, getting fired or made redundant, major worsening in financial situation, serious injury/illness to family member, death of spouse or child, death of close relative/family member, victim of physical violence, and personal injury or illness to self. 3. Values in bold denote statistically significant coefficients. 4. Abbreviations: ref, reference category; PCS, Physical Component Summary; MCS, Mental Component Summary; SF-6D, Short-Form Six-Dimension health index.

Results

Table: Estimated effects of informal caregiving on the dimensions of the SF-36; fixed-effects panel regression models

Model	Outcome	Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)
		SF-36 Subscales		
Model 1	PF	0.05 [-0.32 - 0.42]	0.15 [-0.25 - 0.55]	0.41 [-0.18 - 1.01]
Model 2	RP	-0.64 [-1.33 - 0.05]	-0.78* [-1.52 - -0.03]	-1.40* [-2.52 - -0.28]
Model 3	RE	-0.91* [-1.63 - -0.20]	-1.97*** [-2.74 - -1.20]	-4.97*** [-6.12 - -3.81]
Model 4	SF	-0.30 [-0.75 - 0.14]	-1.08*** [-1.57 - -0.60]	-2.83*** [-3.55 - -2.10]
Model 5	MH	-0.34* [-0.65 - -0.04]	-0.85*** [-1.18 - -0.52]	-2.19*** [-2.68 - -1.69]
Model 6	VT	0.13 [-0.21 - 0.47]	-0.33 [-0.69 - 0.04]	-1.87*** [-2.42 - -1.32]
Model 7	BP	-0.46* [-0.87 - -0.04]	-0.51* [-0.96 - -0.06]	-0.68* [-1.36 - -0.00]
Model 8	GH	-0.23 [-0.53 - 0.07]	-0.46** [-0.78 - -0.13]	-0.80** [-1.28 - -0.31]

Results (Robustness check)

Table: Estimated effects of informal caregiving on the PCS, MCS, and SF-6D; Random-effects panel regression models

Model	Outcome	Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)
Model 1	PCS	-0.11 [-0.27 - 0.06]	-0.13 [-0.33 - 0.06]	-0.09 [-0.42 - 0.23]
Model 2	MCS	-0.15 [-0.35 - 0.06]	**-0.58*** [-0.82 - -0.34]**	**-1.83*** [-2.22 - -1.45]**
Model 3	SF-6D	**-0.003** [-0.005 - -0.001]**	**-0.006*** [-0.009 - -0.004]**	**-0.014*** [-0.018 - -0.010]**

Table: Estimated effects of informal caregiving on the dimensions of the SF-36; Random-effects panel regression models

Model	Outcome	Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)
SF-36 Subscales				
Model 1	PF	0.03 [-0.32 - 0.39]	-0.15 [-0.59 - 0.29]	-0.32 [-1.06 - 0.41]
Model 2	RP	**-1.10** [-1.83 - -0.37]**	**-1.63*** [-2.46 - -0.80]**	**-3.46*** [-4.77 - -2.15]**
Model 3	RE	**-0.86* [-1.60 - -0.13]**	**-2.02*** [-2.88 - -1.17]**	**-5.66*** [-7.08 - -4.25]**
Model 4	SF	-0.38 [-0.84 - 0.07]	**-1.48*** [-2.02 - -0.94]**	**-3.90*** [-4.77 - -3.03]**
Model 5	MH	-0.30 [-0.61 - 0.02]	**-0.85*** [-1.22 - -0.48]**	**-2.40*** [-2.99 - -1.81]**
Model 6	VT	0.18 [-0.16 - 0.52]	-0.31 [-0.71 - 0.10]	**-2.09*** [-2.72 - -1.45]**
Model 7	BP	**-0.52* [-0.94 - -0.10]**	**-0.86*** [-1.34 - -0.39]**	**-1.90*** [-2.65 - -1.15]**
Model 8	GH	-0.24 [-0.55 - 0.07]	**-0.61*** [-0.96 - -0.26]**	**-1.13*** [-1.71 - -0.55]**

Results (Heterogenous Effects)

Table: Estimated effects of informal caregiving on the PCS, MCS, and SF-6D by gender; fixed-effects panel regression models

Model	Outcome	Male			Female		
		Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)	Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)
Model 1	PCS	0.07 [-0.18 - 0.33]	0.14 [-0.17 - 0.46]	0.32 [-0.25 - 0.90]	-0.12 [-0.35 - 0.12]	0.01 [-0.27 - 0.28]	0.25 [-0.17 - 0.68]
Model 2	MCS	-0.05 [-0.34 - 0.25]	-0.44* [-0.82 - -0.06]	-1.54*** [-2.21 - -0.87]	-0.27 [-0.55 - 0.01]	-0.72*** [-1.04 - -0.40]	-1.93*** [-2.43 - -1.43]
Model 3	SF-6D	-0.002 [-0.005 - 0.002]	-0.004 [-0.008 - 0.000]	-0.009* [-0.016 - -0.002]	-0.003* [-0.006 - -0.000]	-0.006*** [-0.009 - -0.002]	-0.012*** [-0.017 - -0.008]

Table: Estimated effects of informal caregiving on the dimensions of the SF-36 by gender; fixed-effects panel regression models

Model	Outcome	Male			Female		
		Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)	Lighter caregiving β (95% CI)	Moderate caregiving β (95% CI)	Intensive caregiving β (95% CI)
Model 1	PF	0.19 [-0.40 - 0.79]	0.28 [-0.40 - 0.95]	0.22 [-0.84 - 1.27]	-0.00 [-0.47 - 0.47]	0.05 [-0.44 - 0.54]	0.20 [-0.52 - 0.91]
Model 2	RP	0.07 [-0.95 - 1.09]	-0.04 [-1.21 - 1.12]	-1.40 [-3.22 - 0.42]	-1.04* [-1.98 - -0.09]	-1.27* [-2.26 - -0.28]	-2.10** [-3.54 - -0.66]
Model 3	RE	-0.17 [-1.21 - 0.87]	-1.47* [-2.65 - -0.29]	-5.91*** [-7.76 - -4.05]	-1.34** [-2.32 - -0.36]	-2.33*** [-3.35 - -1.31]	-5.07*** [-6.56 - -3.57]
Model 4	SF	-0.13 [-0.79 - 0.53]	-0.72 [-1.47 - 0.03]	-2.64*** [-3.81 - -1.46]	-0.37 [-0.97 - 0.24]	-1.34*** [-1.97 - -0.70]	-3.28*** [-4.21 - -2.35]
Model 5	MH	-0.23 [-0.69 - 0.23]	-0.73** [-1.25 - -0.21]	-1.72*** [-2.53 - -0.90]	-0.41 [-0.82 - 0.00]	-0.93*** [-1.36 - -0.50]	-2.53*** [-3.16 - -1.90]
Model 6	VT	0.56* [0.06 - 1.07]	0.10 [-0.47 - 0.67]	-0.87 [-1.77 - 0.02]	-0.19 [-0.65 - 0.27]	-0.59* [-1.07 - -0.11]	-2.39*** [-3.10 - -1.69]
Model 7	BP	-0.04 [-0.67 - 0.59]	-0.64 [-1.36 - 0.08]	-0.54 [-1.67 - 0.59]	-0.71* [-1.27 - -0.15]	-0.45 [-1.03 - 0.13]	-0.95* [-1.81 - -0.10]
Model 8	GH	-0.09 [-0.55 - 0.37]	-0.04 [-0.55 - 0.48]	-0.64 [-1.46 - 0.18]	-0.31 [-0.71 - 0.09]	-0.74*** [-1.16 - -0.33]	-1.06*** [-1.67 - -0.45]

Conclusion

- This research contributes to the current body of knowledge by pointing out the direct health burden of informal caregiving.

- Our findings will assist health technology assessment (HTA) practitioners in performing an economic evaluation of interventions given to caregivers by providing disutility of caregiving.

- The study's findings could be susceptible to bias due to the use of self-reported data on outcome and main exposure variables.

Thank you for listening

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