

Characteristics and outcomes associated with carers in Central and Eastern Sydney aged 45 years and over

*Analysis of Central and Eastern Sydney Primary
and Community Health Cohort/Resource
(CES-P&CH) data*

Characteristics and outcomes associated with carers in Central and Eastern Sydney aged 45 years and over

Project Team

A/Prof Margo Barr, CES-P&CH

AYM Alamgir Kabir, CES-P&CH

Lisa Woodland, SESLHD Priority Populations

Gurdiv Webster, SESLHD Carers Program

A/Prof Ben Harris-Roxas, SEaRCH

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The CES-P&CH brings together ten administrative datasets. These include medical and pharmaceutical data provided by Services Australia and hospital admissions, emergency department visits, cancer registry and death linked by the NSW Centre for Health Record Linkage (CHeReL).

ABOUT SEaRCH

The South Eastern Sydney Research Collaboration Hub (SEaRCH) a partnership between the UNSW Sydney Centre for Primary Health Care and Equity (CPHCE) and the South Eastern Sydney Local Health District.

CPHCE is a research centre within the Faculty of Medicine, UNSW Sydney, that has been undertake primary health care since 1996. South Eastern Sydney Local Health District is a statutory authority responsible for 8 public hospitals and a range of community-based health services covering a culturally and linguistically diverse population of over 850,000 people.

SEaRCH's role is to strengthen the planning and delivery of evidence-based primary health and integrated care. We undertake research, evaluation and capacity building activities to strengthen primary health care and address health inequities, with the aim of contributing to better, fairer health in the community.

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KEY POINTS

CONDITIONS

- When compared with non-carers, carers in Central and Eastern Sydney (CES) have higher rates of:
 - self-reported smoking
 - anxiety
 - psychological distress.

NEEDS

- Carers have higher rates of needing help with daily activities than non-carers.
- Carers have poorer self-rated physical health and poorer self-rated quality of life than non-carers.

SERVICE USE

- Carers have higher rates of GP use than non-carers.

CARERS WHO ARE NOT COPING WELL HAVE DISTINCT NEEDS

- Carers who are not coping well have higher rates of mortality than carers who are coping well.
- Carers who are not coping well have higher rates of GP use than carers who are coping well.

CARER STATUS CHANGES OVER TIME

- Over a 5-year period approximately 12% of the cohort were carers, which is close to the rate in the Australian population.
- People moved in and out of caring roles over the five years – 5% of all people in the cohort remained carers throughout; 8% became carers; and 7% moved out of a caring role.

IMPLICATIONS FOR PRACTICE

- Consider identifying carers as a priority population for tobacco control interventions.
- Consider enhancing access to psychological supports/low intensity mental health intervention for carers.
- Enhance GP monitoring of carers quality of life/coping as this is associated with higher mortality.
- Enhance carer interventions delivered by GPs.

BACKGROUND

Carers provide support to people who are frail aged, those living with lifelong disabilities, mental health conditions, alcohol or drug dependency, dementia, terminal illness, human immunodeficiency virus (HIV) or with a chronic illness. Carers may include family members who may be supporting a person in need of assistance. Often carers are spouses, parents, adult children or younger children of a person needing support. Carers may assist with activities of daily living, being a key person for transport, social support, medical appointment support or providing emotional support and assisting with decision making (adapted from SESLHD 2019).

About 42% of carers are aged between 45 and 64 years in Australia (ABS 2016). The type of care provided, and the difficulties faced by the carers are different (Fine 2012; Adair et al. 2013). As the majority of the carers in this age group are paid workers (ABS 2012), they face pressure in managing their work and caring for adult family members. So carers, specifically women carers, often need to take extended leave from work to care for their family member which causes disruptions to their employment and provisions for retirement (Adair and Temple 2012; Austen and Ong 2013; Warren 2015). In addition to that, carers might have a substantial amount of out of pocket expenses (Aggar et al. 2014; Keating et al. 2013). Jowsey et al. (2013) reported that older Australians (aged 50+ years) who care for other people were found to be associated with significantly poorer self-rated health.

THE CES PRIMARY AND COMMUNITY HEALTH COHORT/RESOURCE

The CES-P&CH is a collaboration between South Eastern Sydney Local Health District, Central and Eastern Sydney Primary Health Network, Sydney Local Health District, and the UNSW Centre for Primary Health Care and Equity. It answers health service relevant questions based on data from 30,645 45 and Up Study participants living in CES (overall n = 267,153), dating back to 2006. The Resource brings together ten NSW and national administrative datasets and more than 26 million records. These include Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Schedule (PBS) data provided by Services Australia and Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Central Cancer Registry (CCR) Mental Health Ambulatory Data Collection (MHADC) and the Death Registry (RBDM and COD) linked by the NSW Centre for Health Record Linkage (CHeReL).

Partner-led projects on integrated care, general practice (GP) follow up after hospitalisation, predictors of health service use amongst older people, the use of care plans in primary health care, and social isolation have been undertaken.

CONTEXT

This research is part of an ongoing body of work undertaken by the SESLHD Carers Program, SEaRCH and partners, to examine the needs of carers. This includes research into the information needs and technology preferences of people new to the caring role, and a current study to better understand the needs of Aboriginal carers.

This research is informed by the *SESLHD Carers Strategy 2019-2022* (SESLHD 2019) and contributes to the development and implementation of targeted strategies for carers, such as the provision of systemic information and support when they are accessing SESLHD services.

METHODS

POSSIBLE HYPOTHESIS

The overall health status of carers will be lower than that of non-carers in CES.

RESEARCH QUESTIONS

1. What are the demographic, health status and health service use characteristics of carers in CES who are 45 years or over?
2. How do carers in CES who are 45 years or over differ from non-carers?
3. What is the mortality rate for carers in CES who are 45 years or over? and How does the mortality rate for carers in differ from non-carers?
4. What are the hospitalisation rates for carers in CES who are 45 years or over? and How does the hospitalisation rate for carers in CES differ from non-carers?
5. What are the GP use rates for carers in CES who are 45 years or over? and How does the GP use rate for carers differ from non-carers?
6. What are the profiles of carers in CES, aged 45 years or over, who are coping well compared to those who are not?
7. What is the mortality rate for carers in CES, aged 45 years or over, who are not coping well? and How does the mortality rate for carers who are not coping well in CES differ from carers who are coping well?
8. What is the hospitalisation rate for carers in CES, aged 45 years or over, who are not coping well? and How does the hospitalisation rate for carers who are not coping well differ from carers who are coping well?
9. What is the GP use rate for carers in CES, aged 45 years or over, who are not coping well? and How does the GP use rate for carers in CES, aged 45 years or over, who are not coping well differ from carers who are coping well?
10. What are the profiles of people in CES, aged 45 years and over, who are transitioning to and from being a carer?

STUDY DESIGN

This research used CES-P&CH. This analysis included the 45 and Up Study questionnaire data linked to MBS, APDC, EDDC and Deaths Registry data. The cohort has been followed up twice since baseline; firstly in 2010 as part of the Social, Environment and Economic Factors (SEEF) sub-study and during the 5-year follow-up (2012-2016).

To answer these research questions, we first needed to identify who is a carer. This was done by using the 45 and Up Study baseline survey. The survey included the question, *‘Do you regularly care for a sick or disabled family member or friend?’* and *‘If Yes, about how much time each week do you usually spend caring for this person?’*

Using this we described the characteristics of carers and compared between carers and non-carers. We also looked at the impact of care giving on different health outcomes such as: self-reported quality of life or health conditions, or health service use (such as number of hospitalization or number of GP visits) as well as mortality.

ANALYSIS

Descriptive analyses were undertaken to examine the proportion of people who were/were not carers and were carers who were/were not coping well for each socio-demographic, health risk factor, health status and health service utilisation characteristic of interest. Univariate and multivariable generalised linear models with Poisson family and log link function were used to estimate crude and adjusted prevalence ratios (PR) and 95% Confidence Intervals (CI). The adjusted models were as follows:

1. Adjusted by age and sex
2. Adjusted by variables identified as potential confounders, if their inclusion in the model made a 5% change compared to the crude model
3. Adjusted for all of the variables in model 2 as well as age and sex if they were not already included.
4. Adjusted for all the variables which were significantly associated with carer status at the 5% level in the bivariate analysis.

RESULTS FOR CENTRAL AND EASTERN SYDNEY

We found at baseline, as shown in Table 1, that 11.4% of participants cared for a sick or disabled family member. As also shown in Table 1 rates had increased slightly at SEEF and follow-up.

Table 1: Summary of carers in CES

At baseline (2006-2009)
Total in CES at baseline = 29,489 Care for a sick or disabled family member or friend = 3371 (11.4%) Full time carers =1009 (30 %). Of those not full-time carers average amount of caring was 11.6 hours per week.
At SEEF (2010)
Total in CES completed SEEF = 6,377 Care for a sick or disabled family member or friend = 760 (11.9%) Full time carers =247 (33%). Of those not full-time carers average amount of caring was 7.7 hours per week.
Completed the follow-up questionnaire (2012-2016)
Total for CES completed the follow-up questionnaire = 14,969 Care for a sick or disabled family member or friend = 1889 (12.6%) Full time carers =473 (25 %). Of those not full-time carers average amount of caring was 10.1 hours per week.

RESEARCH QUESTION 1: WHAT ARE THE DEMOGRAPHIC, HEALTH STATUS AND HEALTH SERVICE USE CHARACTERISTICS OF CARERS IN CES WHO ARE 45 YEARS OR OVER?

Table 2 provides a summary of carers in CES including number and percentage by demographic and health related behaviours. It also includes Crude, Age adjusted and fully adjusted PRs and CIs for each characteristic. As shown in Table 2 we found that, in the univariate analysis for the demographic characteristics, carers compared to non-carers were more likely to be older, female, married, speak a language other than English; and less likely to have higher income, higher qualifications, or work full time.

Also as shown in table 2 the univariate analysis of carers' health-related behaviours and conditions compared with non-carers showed they were:

- more likely to
 - be a current smoker
 - have high psychological distress
 - need help with daily activities
 - have ever had high blood pressure
 - have ever had diabetes
 - have ever had depression
 - have ever had anxiety
 - have ever had heart disease
 - have ever had stroke
- and less likely to
 - consume alcohol
 - self-report good quality of health
 - self-report good quality of life.

RESEARCH QUESTION 2: HOW DO CARERS IN CES WHO ARE 45 YEARS OR OVER DIFFER FROM NON-CARERS?

As also shown in Table 2 in the fully adjusted model all of these differences remained except for needing help with daily activities was no longer more likely. Specifically, when adjusted by all of the other variables in the table, the differences between the carers and non-carers that remained were being female, married, speaking a language other than English, a current smoker, have high psychological distress, need help with daily activities, have ever had anxiety, heart disease; less likely to have a higher income, work full time, self-report good quality of life. Additionally, adequate physical activity and self-report good quality of health were more likely in carers and being aged 60-84 years (compared to 45-59 years) was less likely.

Table 2: Characteristics of carers and non-carers among 45 and Up Study participants Central and Eastern Sydney

	N	Carer n (%)	Crude PR (95% CI)	Adj (age and Sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Age at baseline					
45-59	14265	1564 (11.0)	1		1
60-74	9284	1088 (11.7)	1.07 (0.99, 1.15)		0.86 (0.77, 0.96)
75-84	4636	543 (11.7)	1.07 (0.97, 1.18)		0.81 (0.69, 0.95)
85+	1304	176 (13.5)	1.23 (1.05, 1.43)		0.92 (0.72, 1.18)
Sex					
Male	14142	1307 (9.2)	1		1
Female	15347	2064 (13.4)	1.46 (1.36, 1.56)		1.51 (1.38, 1.66)
Household income					
<\$20,000	4699	756 (16.1)	1	1	1
\$20,000-39,999	3882	492 (12.7)	0.79 (0.70, 0.88)	0.79 (0.70, 0.88)	0.90 (0.77, 1.04)
\$40,000-69,999	4945	514 (10.4)	0.65 (0.58, 0.72)	0.63 (0.56, 0.71)	0.79 (0.67, 0.92)
\$70,000 or more	10051	879 (8.7)	0.54 (0.49, 0.60)	0.53 (0.48, 0.59)	0.67 (0.57, 0.79)
Won't disclose	5912	730 (12.3)	0.77 (0.69, 0.85)	0.73 (0.66, 0.81)	0.80 (0.69, 0.92)
Highest education					
No school certificate or other qualification	2322	315 (13.6)	1	1	1
School or intermediate certificate	5089	625 (12.3)	0.91 (0.79, 1.04)	0.89 (0.77, 1.02)	0.94 (0.79, 1.12)

	N	Carer n (%)	Crude PR (95% CI)	Adj (age and Sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Higher school or leaving certificate	3306	359 (10.9)	0.80 (0.69, 0.93)	0.84 (0.72, 0.98)	0.92 (0.76, 1.12)
Trade or apprenticeship	2653	298 (11.2)	0.83 (0.71, 0.97)	0.97 (0.82, 1.14)	0.88 (0.70, 1.09)
Certificate or diploma	5604	673 (12.0)	0.89 (0.78, 1.01)	0.93 (0.81, 1.06)	1.04 (0.88, 1.25)
University degree or higher	10092	1054 (10.4)	0.77 (0.68, 0.87)	0.83 (0.73, 0.95)	1.03 (0.86, 1.22)
Work status					
Not working	12950	1722 (13.3)	1	1	1
Part time	5735	715 (12.5)	0.94 (0.86, 1.02)	0.81 (0.74, 0.90)	0.91 (0.80, 1.03)
Full time	10353	843 (8.1)	0.61 (0.56, 0.66)	0.55 (0.49, 0.61)	0.73 (0.64, 0.84)
Married					
No	8999	924 (10.3)	1	1	1
Yes	20316	2425 (11.9)	1.16 (1.08, 1.25)	1.29 (1.19, 1.39)	1.35 (1.22, 1.49)
Speaks language other than English at home					
No	23795	2559 (10.8)	1	1	1
Yes	5694	812 (14.3)	1.33 (1.22, 1.43)	1.34 (1.24, 1.45)	1.46 (1.29, 1.66)
Born in Australia					
No	10429	1138 (10.9)	1	1	1
Yes	18836	2197 (11.7)	1.07 (1.00, 1.15)	1.06 (0.98, 1.13)	1.38 (1.24, 1.55)
Current smoker					
No	27538	3107 (11.3)	1	1	1
Yes	1951	264 (13.5)	1.20 (1.06, 1.36)	1.25 (1.10, 1.41)	1.24 (1.06, 1.44)
Adequate physical activity					
No	9126	1028 (11.3)	1	1	1
Yes	20363	2343 (11.5)	1.02 (0.95, 1.10)	1.04 (0.96, 1.12)	1.15 (1.05, 1.27)

	N	Carer n (%)	Crude PR (95% CI)	Adj (age and Sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Alcohol consumption					
No	8867	1206 (13.6)	1	1	1
Yes	20019	2073 (10.4)	0.76 (0.71, 0.82)	0.82 (0.76, 0.88)	0.93 (0.85, 1.03)
Ever had high blood pressure					
No	19619	2176 (11.1)	1	1	1
Yes	9870	1195 (12.1)	1.09 (1.02, 1.17)	1.10 (1.02, 1.18)	1.04 (0.95, 1.14)
Ever had diabetes					
No	27140	3074 (11.3)	1	1	1
Yes	2349	297 (12.6)	1.12 (0.99, 1.26)	1.14 (1.01, 1.28)	0.90 (0.76, 1.06)
Ever had asthma					
No	22687	2647 (11.7)	1	1	1
Yes	3466	421 (12.1)	1.04 (0.94, 1.15)	1.02 (0.92, 1.13)	1.04 (0.91, 1.17)
Ever had depression					
No	21924	2482 (11.3)	1	1	1
Yes	3931	568 (14.4)	1.28 (1.16, 1.40)	1.23 (1.12, 1.35)	1.06 (0.93, 1.20)
Ever had anxiety					
No	23001	2605 (11.3)	1	1	1
Yes	2854	445 (15.6)	1.38 (1.24, 1.52)	1.33 (1.20, 1.47)	1.17 (1.01, 1.34)
Ever had any type of cancer					
No	19865	2227 (11.2)	1	1	1
Yes	9624	1144 (11.9)	1.06 (0.99, 1.14)	1.06 (0.98, 1.14)	1.08 (0.99, 1.19)
Ever had heart disease					
No	25907	2905 (11.2)	1	1	1
Yes	3582	466 (13.0)	1.16 (1.05, 1.28)	1.20 (1.08, 1.33)	1.19 (1.04, 1.35)
Ever had stroke					
No	28589	3246 (11.4)	1	1	1

	N	Carer n (%)	Crude PR (95% CI)	Adj (age and Sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Yes	900	125 (13.9)	1.22 (1.02, 1.46)	1.21 (1.00, 1.44)	0.99 (0.76, 1.27)
Self-reported good quality of health					
No	3866	567 (14.7)	1	1	1
Yes	25021	2727 (10.9)	0.74 (0.68, 0.81)	0.76 (0.69, 0.83)	1.18 (1.01, 1.38)
Self-reported good quality of life					
No	2993	555 (18.5)	1	1	1
Yes	25428	2669 (10.5)	0.57 (0.52, 0.62)	0.57 (0.52, 0.62)	0.60 (0.51, 0.70)
Psychological distress					
Low	24484	2576 (10.5)	1	1	1
High	2112	354 (16.8)	1.59 (1.42, 1.78)	1.56 (1.39, 1.74)	1.18 (1.02, 1.37)
Needing help with daily activity					
No	27151	3035 (11.2)	1	1	1
Yes	1469	194 (13.2)	1.18 (1.02, 1.36)	1.08 (0.93, 1.26)	0.72 (0.58, 0.89)

NOTES: ¹PRs were adjusted only for age and sex; ²PRs were adjusted for all other variables in the table; PRs bolded if significantly higher and bolded and italicised if significantly lower.

RESEARCH QUESTION 3: WHAT IS THE MORTALITY RATE FOR CARERS IN CES WHO ARE 45 YEARS OR OVER? AND HOW DOES THE MORTALITY RATE FOR CARERS DIFFER FROM NON-CARERS IN CES?

Figure 1 provides 8-year mortality by carer status. The mortality rate for carers is 14.2 per 1,000 person years. This is similar to the rate for non-carers which is 13.7 per 1,000 person years. When adjusted by demographic, risk and health conditions as shown in Table 3 there was no significant difference between carers and non-carers with regard to mortality in CES in either the crude model or when adjusted.

Figure 1: Kaplan-Meier curve: carer status and 8-year mortality from recruitment

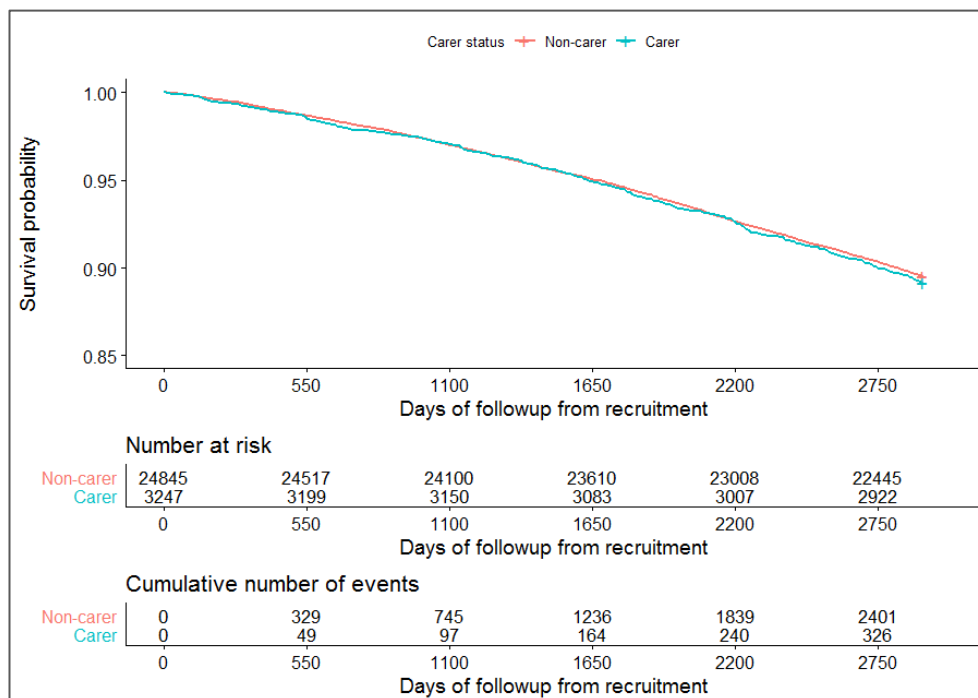


Table 3: Carer status and 8-year mortality from base line: Hazard Ratio with different models

Carer	N	Person-year	Death <=8 years of recruitment	Mortality per 1000 PY	Crude model	Adj. model1	Adj. model2	Adj. model3	Adj. model4
No	24845	189601	2601	13.72	1	1	1	1	1
Yes	3247	24745	352	14.23	1.04	0.97	1.01	0.98	0.91
					(0.93, 1.16)	(0.87, 1.09)	(0.90, 1.13)	(0.87, 1.10)	(0.78, 1.06)

NOTES: **Adj. Model 1:** Included age and sex only; **Adj. Model 2:** Included household income, age at recruitment and needing help for daily activities variables; **Adj. Model 3:** As the model 2 did not include age and sex, we forcefully included them in this model in addition to the variables included in model 2; **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoke a language other than English at home and psychological distress.

RESEARCH QUESTION 4: WHAT ARE THE HOSPITALISATION RATES FOR CARERS IN CES WHO ARE 45 YEARS OR OVER? AND HOW DOES THE HOSPITALISATION RATE FOR CARERS IN CES DIFFER FROM NON-CARERS?

Table 4.1 and 4.2 provides overnight hospitalisation +/- 1 year from the baseline survey by carer status. Just over thirty percent of carers had any overnight hospitalisation and 1.2 % had more than one hospitalisation. This is very similar to the rate for non-carers. When adjusted by demographic, risk and health conditions as shown in Table 4.1 and 4.2 there was no significant difference between carers and non-carers with regard to hospitalisations in CES.

Table 4.1: Association of carer status with any overnight hospitalisation +/- 1 year of baseline survey

Carer	N	Any overnight hosp (%)	Crude PR (95% CI)	Adj (age & sex) PR (95% CI)	Adj (model) PR (95% CI)	Adj (age, sex, model) PR (95% CI)	Adj (all covariates) PR (95% CI)
No	25772	7547 (29.3)	1	1	1	1	1
Yes	3322	1028 (30.9)	1.06 (0.99, 1.13)	1.05 (0.98, 1.12)	0.99 (0.92, 1.05)	1.02 (0.96, 1.09)	0.99 (0.91, 1.06)

NOTES: Adj. Model 1: Included age and sex only; **Adj. Model 2:** Included current working status only; **Adj. Model 3:** As the model 2 does not include age and sex, we forcefully included them in this model in addition to the variables included in model 2; **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoke a language other than English at home and psychological distress.

Table 4.2: Association of carer status with high (≥ 2) overnight hospitalisation +/- 1 year of baseline survey

Carer	N	High (≥ 2) overnight hosp N (%)	Crude PR (95% CI)	Adj (age & sex) PR (95% CI)	Adj (model*) PR (95% CI)	Adj (age, sex, model) PR (95% CI)	Adj (all covariates) PR (95% CI)
No	25772	299 (1.2)	1	1	1	1	1
Yes	3322	39 (1.2)	1.01 (0.71, 1.39)	0.97 (0.68, 1.33)	0.95 (0.66, 1.33)	0.96 (0.67, 1.34)	0.82 (0.52, 1.24)

NOTES: Adj. Model 1: Included age and sex only; **Adj. Model 2:** Included age at recruitment, current working status, needing help with daily activities and self-reported good quality of life; **Adj. Model 3:** As the model 2 does not included sex, we forcefully included sex in this model in addition to the variables included in model 2; **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoke a language other than English at home and psychological distress.

RESEARCH QUESTION 5: WHAT ARE THE GP USE RATES FOR CARERS IN CES WHO ARE 45 YEARS OR OVER? AND HOW DOES THE GP USE RATE FOR CARERS DIFFER FROM NON-CARERS?

Table 5 provides high (≥ 11) GP use during ± 1 year of baseline survey by carer status. Thirty percent of carers had high GP use. This is higher than the rate for non-carers. When adjusted by age and sex or demographic, risk and health conditions as shown in Table 5 there was a significant difference between carers and non-carers with regard to high GP use in CES [Adj. HR (95% CI): 1.21 (1.13, 1.30)].

Table 5: Association of carer status with high (≥ 11) GP use during ± 1 year of baseline survey

Carer	N	High GP use (≥ 11)	Crude PR	Adj (age & sex)	Adj (model*)	Adj (age, sex, model)	Adj (all covariates)
		N (%)	(95% CI)	PR (95% CI)	PR (95% CI)	PR (95% CI)	PR (95% CI)
No	25772	5731 (22.2)	1	1	1	1	1
Yes	3322	986 (29.7)	1.33(1.25, 1.43)	1.29(1.20, 1.38)	1.18(1.10, 1.26)	1.21(1.13, 1.30)	1.15(1.06, 1.24)

NOTES: **Adj. Model 1:** Included age and sex only; **Adj. Model 2:** Included current working status only; **Adj. Model 3:** As the model 2 does not included age and sex, we forcefully included them in this model in addition to the variables included in model 2; **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoke a language other than English at home and psychological distress.

RESEARCH QUESTION 6: WHAT ARE THE PROFILES OF CARES IN CES, AGED 45 YEARS OR OVER, WHO ARE COPING WELL COMPARED TO THOSE WHO ARE NOT?

Coping well was defined using the quality of life variable ‘*In general how would you rate your quality of life: excellent, very good, good, fair or poor*’ with excellent very good and good being rated as ‘coping well’ and fair and poor being rated as ‘not coping well’. As shown in Table 6 we found that, in the univariate analysis, carers who were coping well were more likely to: have a higher income, have higher qualifications, be working, undertake adequate physical activity, consume alcohol, self-report good quality of health; and less likely to be older, speak a language other than English, be current smokers, have high psychological distress, need help with daily activities, have ever had diabetes, depression, anxiety, stroke.

As also shown in Table 2 when the model was adjusted by age and sex all of these differences remained except for being married was significantly more likely. When adjusted by all of the other variables in the table carers who were coping well more likely self-report good quality of health, and less likely to have high psychological distress.

Table 6: Characteristics of the people who cope well (good quality of life) and who did not cope well (quality of life is not good) among carers 45 years and over in CES at baseline

	N	Not coping well	Coping well	% not coping well	Crude PR (95% CI)	Adj (age and sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Age at baseline							
45-59	1527	214	1313	14.0%	1		1
60-74	1032	180	852	17.4%	0.96 (0.88, 1.05)		1.01 (0.90, 1.14)
75-84	500	108	392	21.6%	0.91 (0.81, 1.02)		1.01 (0.85, 1.20)
85+	165	53	112	32.1%	0.79 (0.65, 0.95)		0.91 (0.67, 1.20)
Sex							
Male	1240	243	997	19.6%	1		1
Female	1984	312	1672	15.7%	1.05 (0.97, 1.13)		1.02 (0.92, 1.13)
Household income							
<\$20,000	706	231	475	32.7%	1	1	1
\$20,000-39,999	465	85	380	18.3%	1.21 (1.06, 1.39)	1.21 (1.05, 1.38)	1.04 (0.88, 1.22)
\$40,000-69,999	501	62	439	12.4%	1.30 (1.14, 1.48)	1.30 (1.13, 1.48)	1.05 (0.88, 1.24)

	N	Not coping well	Coping well	% not coping well	Crude PR (95% CI)	Adj (age and sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
\$70,000 or more	870	57	813	6.6%	1.39 (1.24, 1.56)	1.39 (1.23, 1.57)	1.09 (0.91, 1.29)
Won't disclose	682	120	562	17.6%	1.22 (1.08, 1.38)	1.21 (1.07, 1.37)	1.06 (0.90, 1.24)
Highest education							
No school certificate or other qualification	289	85	204	29.4%	1	1	1
School or intermediate certificate	598	102	496	17.1%	1.18 (1.00, 1.39)	1.16 (0.99, 1.37)	1.05 (0.86, 1.28)
Higher school or leaving certificate	338	65	273	19.2%	1.14 (0.96, 1.37)	1.13 (0.94, 1.35)	1.04 (0.84, 1.30)
Trade or apprenticeship	271	66	205	24.4%	1.07 (0.88, 1.30)	1.08 (0.89, 1.31)	1.00 (0.78, 1.29)
Certificate or diploma	657	91	566	13.9%	1.22 (1.04, 1.44)	1.19 (1.02, 1.41)	1.03 (0.85, 1.26)
University degree or higher	1033	132	901	12.8%	1.24 (1.06, 1.44)	1.21 (1.04, 1.41)	1.01 (0.83, 1.23)
Work status							
Not working	1618	392	1226	24.2%	1	1	1
Part time	700	77	623	11.0%	1.17 (1.07, 1.29)	1.18 (1.06, 1.31)	1.04 (0.91, 1.19)
Full time	826	75	751	9.1%	1.20 (1.10, 1.31)	1.22 (1.09, 1.37)	1.04 (0.90, 1.19)
Married							
No	888	198	690	22.3%	1	1	1
Yes	2315	351	1964	15.2%	1.09 (1.00, 1.19)	1.10 (1.01, 1.20)	1.03 (0.93, 1.15)
Speak a language other than English at home							
No	2463	356	2107	14.5%	1	1	1
Yes	761	199	562	26.1%	0.86 (0.79, 0.95)	0.86 (0.79, 0.95)	0.99 (0.86, 1.13)

	N	Not coping well	Coping well	% not coping well	Crude PR (95% CI)	Adj (age and sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Born in Australia							
No	1080	243	837	22.5%	1	1	1
Yes	2111	304	1807	14.4%	1.10 (1.02, 1.20)	1.10 (1.01, 1.19)	1.01 (0.90, 1.15)
Current smoker							
No	2976	480	2496	16.1%	1	1	1
Yes	248	75	173	30.2%	0.83 (0.71, 0.97)	0.81 (0.69, 0.95)	0.96 (0.80, 1.16)
Adequate physical activity							
No	949	234	715	24.7%	1	1	1
Yes	2275	321	1954	14.1%	1.14 (1.05, 1.24)	1.12 (1.03, 1.23)	1.01 (0.91, 1.12)
Alcohol consumption							
No	1134	254	880	22.4%	1	1	1
Yes	2012	273	1739	13.6%	1.11 (1.03, 1.21)	1.11 (1.03, 1.21)	1.00 (0.90, 1.10)
Ever had high blood pressure							
No	2079	314	1765	15.1%	1	1	1
Yes	1145	241	904	21.0%	0.93 (0.86, 1.01)	0.95 (0.87, 1.03)	1.00 (0.91, 1.11)
Ever had diabetes							
No	2949	465	2484	15.8%	1	1	1
Yes	275	90	185	32.7%	0.80 (0.69, 0.92)	0.81 (0.69, 0.94)	1.01 (0.82, 1.22)
Ever had asthma							
No	2518	401	2117	15.9%	1	1	1
Yes	410	98	312	23.9%	0.91 (0.80, 1.02)	0.90 (0.80, 1.01)	1.01 (0.87, 1.16)
Ever had depression							
No	2370	326	2044	13.8%	1	1	1

	N	Not coping well	Coping well	% not coping well	Crude PR (95% CI)	Adj (age and sex) PR (95% CI) ¹	Adj (all covariates) PR (95% CI) ²
Yes	542	172	370	31.7%	0.79 (0.71, 0.88)	0.78 (0.69, 0.87)	0.96 (0.83, 1.10)
Ever had anxiety							
No	2483	363	2120	14.6%	1	1	1
Yes	429	135	294	31.5%	0.80 (0.71, 0.91)	0.79 (0.70, 0.89)	0.95 (0.82, 1.11)
Ever had any type of cancer							
No	2121	360	1761	17.0%	1	1	1
Yes	1103	195	908	17.7%	0.99 (0.91, 1.07)	1.01 (0.93, 1.10)	0.99 (0.90, 1.09)
Ever had heart disease							
No	2782	444	2338	16.0%	1	1	1
Yes	442	111	331	25.1%	0.89 (0.79, 1.00)	0.92 (0.82, 1.04)	0.99 (0.85, 1.14)
Ever had stroke							
No	3106	511	2595	16.5%	1	1	1
Yes	118	44	74	37.3%	0.75 (0.59, 0.94)	0.78 (0.61, 0.98)	1.02 (0.75, 1.36)
Self-reported good quality of health							
No	542	331	211	61.1%	1	1	1
Yes	2656	213	2443	8.0%	2.36 (2.06, 2.73)	2.34 (2.04, 2.71)	1.89 (1.57, 2.30)
Psychological distress							
Low	2506	261	2245	10.4%	1	1	1
High	342	176	166	51.5%	0.54 (0.46, 0.63)	0.54 (0.46, 0.63)	0.70 (0.58, 0.85)
Need help with daily activity							
No	2934	415	2519	14.1%	1	1	1
Yes	178	111	67	62.4%	0.44 (0.34, 0.55)	0.45 (0.35, 0.57)	0.80 (0.58, 1.08)

NOTES: ¹PRs were adjusted only for age and sex; ²PRs were adjusted for all other variables in the table; PRs bolded if significantly higher and bolded and italicised if significantly lower.

RESEARCH QUESTION 7: WHAT IS THE MORTALITY RATE FOR CARERS IN CES, AGED 45 YEARS OR OVER, WHO ARE NOT COPING WELL? AND HOW DOES THE MORTALITY RATE FOR CARERS WHO ARE NOT COPING WELL IN CES DIFFER FROM CARERS WHO ARE COPING WELL?

Figure 2 provides 8-year mortality by carer coping status. The mortality rate for carers who are coping well is 11.3 per 1,000 person years. This is substantially lower than the rate for carers who are not coping well which is 25.0 per 1,000 person years. When adjusted by demographic, risk and health conditions as shown in Table 7 mortality rates in carers who were coping well were 33% lower than in carers who were not coping well in CES [Adj. HR (95% CI): 0.67 (0.51, 0.87)]

Figure 2: Kaplan-Meier curve: Survival of the carers who are/are not coping well in 8 years following recruitment

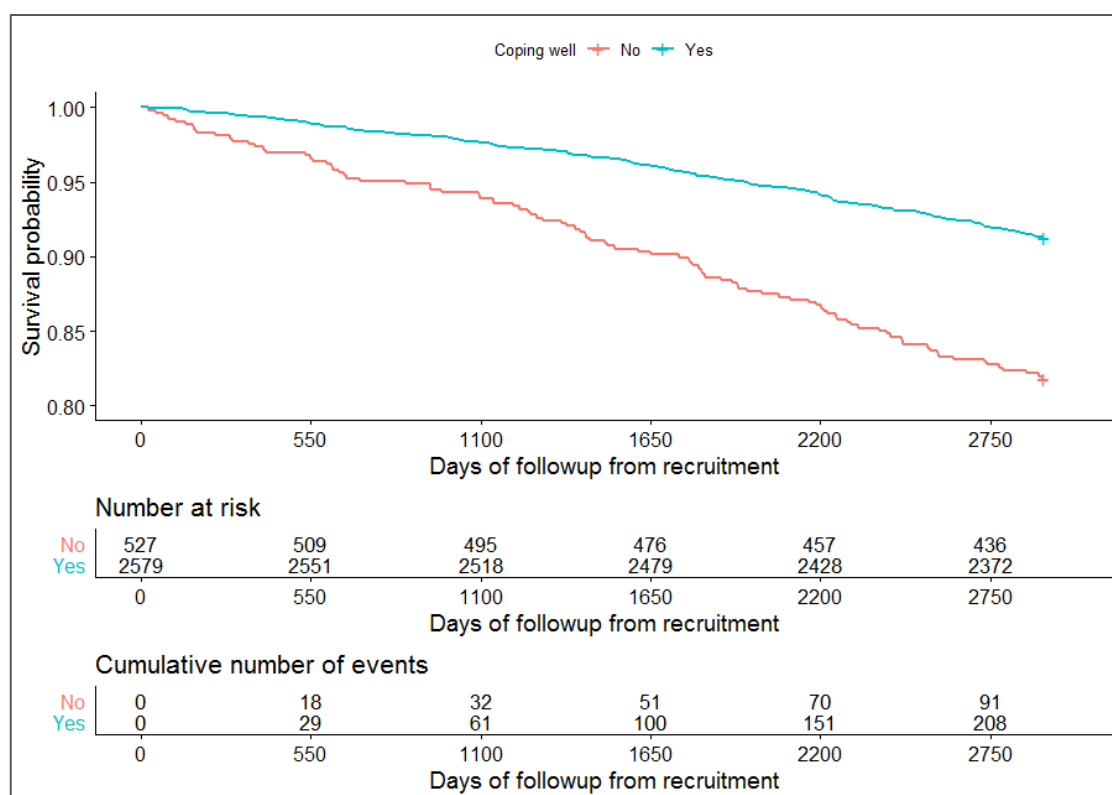


Table 7: Association of coping well among carers with 8-year of mortality from baseline

Coping well	N	Person-year, PY	Death ≤8 years of recruitment	Mortality per 100 PY	Crude model	Adj. model1	Adj. model2	Adj. model3	Adj. model4
No	527	3839	96	25.01	1	1	1	1	1
Yes	2579	19866	225	11.33	0.45	0.59	0.65	0.67	0.66
					(0.35, 0.57)	(0.47, 0.75)	(0.49, 0.86)	(0.51, 0.87)	(0.45, 0.96)

NOTES: Adj. Model 1: Included age and sex only; **Adj. Model 2:** Included current working status, needing help with daily activities, highest educational qualification and ever had depression; **Adj. Model 3:** As the model 2 does not include age and sex, we forcefully included them in this model in addition to the variables included in model 2; **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoken language other than English at home and psychological distress.

RESEARCH QUESTION 8: WHAT IS THE HOSPITALISATION RATE FOR CARERS IN CES, AGED 45 YEARS OR OVER, WHO ARE NOT COPING WELL? AND HOW DOES THE HOSPITALISATION RATE FOR CARERS WHO ARE NOT COPING WELL DIFFER FROM CARERS WHO ARE COPING WELL?

Table 8.1 and 8.2 provides hospitalisation +/- 1 year from the baseline survey by carer coping status. Around thirty percent of carers who are coping well had any hospitalisation and 1.1% had more than one hospitalisation. This is lower than the rates for carers who are not coping well. When adjusted by age and sex or by demographic, risk and health conditions as shown in Table 8.1 and 8.2 there was no significant difference between carers who are coping well and those who are not with regard to hospitalisations in CES.

Table 8.1: Association of coping well among carers with any overnight hospitalisation +/-1 year of baseline survey

Coping well	N	Any hosp n (%)	Crude model	Adj. model 1	Adj. model 2	Adj. model 3	Adj. model 4
No	535	210 (39.3)	1	1	1	1	1
Yes	2642	761 (28.8)	0.73 (0.63, 0.86)	0.82 (0.40, 1.84)	0.90 (0.76, 1.07)	0.91 (0.77, 1.08)	1.00 (0.79, 1.26)

NOTES: Adj. Model1: Included age and sex only **Adj. Model2:** Included current working status and needing help with daily activities; **Adj. Model 3:** As the model 2 did not include age and sex, we forcefully included them in this model in addition to the variables included in model 2 **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoke a language other than English at home and psychological distress.

Table 8.2: Association of coping well among carers with high (>=2) overnight hospitalisation +/-1 year of baseline survey

Coping well	N	High hosp n (%)	Crude model	Adj. model 1	Adj. model 2	Adj. model 3	Adj. model 4
No	535	9 (1.7)	1	1	1	1	1
Yes	2642	29 (1.1)	0.65 (0.32, 1.46)	0.82 (0.40, 1.84)	1.82 (0.57, 7.22)	1.82 (0.57, 7.22)	1.88 (0.54, 9.16)

NOTES: Adj. Model1: Included age and sex only; **Adj. Model2:** Included age at recruitment, sex, highest educational qualification, needing help with daily activities, psychological distress, ever had stroke and ever had anxiety; **Adj. Model 3:** Model 2 included age and sex already which came through the model selection methods. To be consistent with other tables, results were repeated in the table; **Adj. Model 4:** Included age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activities, ever had heart disease, ever had heart failure, self-reported good quality of life, spoke a language other than English at home and psychological distress.

RESEARCH QUESTION 9: WHAT IS THE GP USE RATE FOR CARERS IN CES, AGED 45 YEARS OR OVER, WHO ARE NOT COPING WELL? AND HOW DOES THE GP USE RATE FOR CARERS IN CES, AGED 45 YEARS OR OVER, WHO ARE NOT COPING WELL DIFFER FROM CARERS WHO ARE COPING WELL?

Table 9 provides high (≥ 11) GP use during ± 1 year of the baseline survey by carer coping status. Twenty five percent of carers who were coping well had high GP use. This is about 50% lower than the rate for carers who are not coping well. When adjusted by age and sex and demographic, risk and health conditions as shown in Table 9 carers who were coping well were 24% less likely to be high GP users than carers who are not coping well in CES [Adj. HR (95% CI): 0.76 (0.63, 0.94)].

Table 9: Association of coping well among carers with high (≥ 11) GP use during ± 1 year of baseline survey

Coping well	N	High GP use n (%)	Crude model	Adj. model 1	Adj. model 2	Adj. model 3	Adj. model 4
No	535	261 (48.8)	1	1	1	1	1
Yes	2642	652 (24.7)	0.51 (0.44, 0.58)	0.57 (0.49, 0.66)	0.76 (0.62, 0.93)	0.76 (0.63, 0.94)	0.87 (0.70, 1.08)

NOTES: Adj. Model 1: Included age and sex only; **Adj. Model 2:** Included variables which were identified as potential confounders, if their inclusion in to the model make a 5% change compared to the crude model. This model included household income, current working status, psychological distress and needing help with daily activities; **Adj. Model 3:** Model 2 already included age and sex which came through the model selection methods so results are the same. To be consistent with other tables, we still included this model in the table; **Adj. Model 4:** We included all the variables which were significantly associated with carer status at 5% level of significance in the bivariate analysis which included: age at recruitment, sex, household income, highest educational qualification, current working status, marital status, current smoking status, alcohol consumption, high blood pressure, ever had depression, ever had anxiety, needing help with daily activity, ever had heart disease, ever had heart failure, self reported good quality of life, spoke a language other than English at home and psychological distress.

RESEARCH QUESTION 10: WHAT ARE THE PROFILES OF PEOPLE IN CES, AGED 45 YEARS AND OVER, WHO ARE TRANSITIONING TO AND FROM BEING A CARER?

Table 10 includes information on carer status over time. Based on the participants who completed the questionnaires at each of the timepoints (baseline, SEEF and follow-up) 33% of carers were still carers at the last timepoint and 66% were no longer carers. Again, based on the participants who completed the questionnaires at each of the timepoints 15% of non-carers had been a carer at some time during the follow-up period and 75% had never been a carer.

Table 10: Dynamicity of carer status

Collection time point	n	%	Full time n(%)	Part time n(%)
2006-2009 Baseline (n=29,489)				
Non-carer	26118	88.6		
Carer	3371	11.4	1009 (29.9)	2349 (69.7)
2010 SEEF (n=6,377)				
Non-carer	5617	88.1		
Carer	760	11.9	247 (32.5)	513(67.5)
2012-2016 Follow-up (n=14,969)				
Non-carer	13080	87.4		
Carer	1889	12.6	473 (25.0)	1400 (74.1)
Baseline: SEEF (n=6,095)				
Carer: Carer	315	5.2		
Carer: non-carer	332	5.4		
Non-carer: carer	405	6.6		
Non-carer: non-carer	5043	82.7		
Baseline: follow-up (13,823)				
Carer: Carer	583	4.2		
Carer: non-carer	926	6.7		
Non-carer: carer	1146	8.3		
Non-carer: non-carer	11168	80.8		

Collection time point	n	%	Full time n(%)	Part time n(%)
Baseline: SEEF: follow-up (n=3,753)				
Carer: Carer: Carer	91	2.4		
Carer: Carer: non-Carer	91	2.4		
Carer: non-Carer: Carer	30	0.8		
Carer: non-Carer: non-carer:	158	4.2		
Non-carer: carer: carer	102	2.7		
Non-carer: carer: non-carer	156	4.2		
Non-carer: non-carer: Carer	257	6.8		
Non-carer: non-carer: non-carer	2868	76.4		

IMPLICATIONS

Further analysis is planned to look at the differences between participants who had the same carer status (i.e. carers or non-carers at both baseline and follow-up) and those where their status changed (i.e. carers to non-carers or non-carers to carers).

Implications for services that require further consideration include:

- identifying carers as a priority population for, and within, tobacco control interventions
- enhancing access to psychological supports and/or low intensity mental health intervention for carers
- enhancing GP monitoring of carers quality of life and coping as this is associated with higher mortality
- enhancing carer interventions delivered by GPs, as carers have higher levels of GP contact and use.

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