

# **Research** Article

# Characteristics and Health Service Use of a Longitudinal Cohort of Carers Aged over 45 in Central and Eastern Sydney, Australia

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Carers are a large portion of the Australian community. In 2018, 2.65 million Australians identified as carers, and almost one-third (32.6%) of this group were primary carers. There is currently a lack of understanding of the impact of being a carer on a person's health and wellbeing compared to non-carers. This research was undertaken to understand the health status, health risks, and health outcomes for carers in Central and Eastern Sydney, Australia (CES), who are 45 years of age or over. A record linkage study using data from the 45 and Up Study, Medicare Benefit Scheme claims, hospitalisations, and deaths was undertaken on participants in CES (n = 29,489). Characteristics of carers were described and outcomes over an eight-year period were also calculated. Around 12% of the cohort was carers at a given time, though most transitioned in and out of caring roles over a five-year period. Compared with non-carers, carers in CES had higher rates of self-reported smoking, anxiety, psychological distress, heart disease, and self-rated poor quality of life. Carers had higher rates of general practitioner use than non-carers (Adj. HR (95% CI): 1.21 (1.13, 1.30)). However, hospital admissions and mortality were not significantly different. This study confirms that a small proportion of carers remain in carer roles for many years. Caring often starts suddenly, and people need to quickly adapt to their new role. The finding that carers are well-engaged with GPs suggests they may play an important role in identifying carers who are struggling, and delivering interventions for carers.

#### 1. Introduction

Carers comprise a significant portion of the Australian community. In 2018, 2.65 million Australians were identified as carers, and almost one-third (31.7%) of this group were identified as primary carers [1]. In the Australian context, the definition of carers encompasses people who 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 a chronic illness [2–4].

Carers play a critical but undervalued role in Australia's systems of care [5]. Australia is a federalist system, with

social care and health services funded by both state and the federal governments [6]. There are a range of services provided for carers; however, the responsibility for these arrangements does not sit clearly with one level of government. Further, many of these services are administered by social service departments and/or agencies, rather than health ones; for example, the Carer Gateway is a service funded by the federal government and provided at a regional level by contracted social service agencies [7], whereas general practice is provided by private providers who are partly funded by the federal government primarily on a feefor-service basis, but with some support from regional Primary Heath Networks [8]. The effect of this is that (i) the role of health services in supporting carers can be unclear; and (ii) the systems that carers have to navigate, for both their own needs and the needs of the people they care for, can be complex and fragmented [9, 10].

Carers face significant challenges and pressure in their daily lives which can affect their health and wellbeing. Carers have been reported to have the lowest collective wellbeing of any group recorded using the Australian Wellbeing Index [11], and several Australian reports and studies indicate that carers experience poorer physical and mental health status than the general, non-carer population [11–13]. Carers of people with mental health issues have been found to be at particular risk of poor health [14].

Despite reporting poorer general health, carers encounter significant barriers to accessing and receiving treatment for their own health. These include a lack of time to seek treatment, issues of affordability [11], and being unable to find someone to assist them with their caring role to enable them to access services [2]. Few carers (less than 30%) report being asked about their own needs as a carer during GP appointments for the person they care for. A low uptake of carer support services among carers has also been reported [15].

The type of care provided and the difficulties encountered by carers are not uniform [9, 16–18]. Eighteen percent of the Australian population aged over 45 is carers [1]. Within the population of carers, approximately 42% of carers in Australia are aged between 45 and 64 years [1]. Most carers in this age group are paid workers [19], and consequently, they face pressure as they manage their work and their role caring for adult family members.

Carers in general, and female carers in particular, are more likely to take extended leave from work, reduce their hours of work, or exit from the labour force [20–22]. This leads to lower income levels and reduced provision for retirement [16, 23, 24]. In addition, carers experience substantial out of pocket expenses [25, 26] and social isolation [27]. Carers for people who experience mental health conditions experience distinct impacts, including the effects of stigma [28, 29].

There is some evidence that the difficulties faced by carers lead to differences in health outcomes and the use of health services. Several studies of patient-carer dyads have suggested a relationship between carer health and patient wellbeing [30, 31], which has contributed to the development of the dyadic theory of illness management [32].

The impact of caring on health and service use should not be assumed to be solely negative. A growing body of literature also suggests that caring may provide a reason to maintain one's health and may have a potentially salutogenic impact [33–35]. This link needs to be further examined.

The research described in this paper focused on an area of metropolitan Sydney that encompasses 626 square kilometres and has a population of more than 1.6 million people. The region is characterised by cultural diversity. There are 13,489 Aboriginal and/or Torres Strait Islander peoples living in the region. Forty per cent of residents were born overseas, and 38% speak a language other than English at home [36]. This study is part of an ongoing body of work aiming to examine the needs of carers in this area and contributes to the development and implementation of targeted strategies. Many of the carers in this region come from vulnerable population groups at risk of poor health and wellbeing including young and older people, Aboriginal and Torres Strait Islander Australians, people with disabilities, and people from culturally and linguistically diverse (CALD) backgrounds or who speak a language other than English at home [37]. Carers from this area have identified multiple challenges to caregiving including difficulties in accessing support in their role as carers and having insufficient time to meet their own personal needs. These factors can contribute to carers experiencing poorer physical and mental health [38].

This study aimed to identify the effect of carer status on the health status, health risks, and health service use of carers aged 45 years and over, and the association between GP use and hospitalisations for carers and non-carers.

#### 2. Methods

2.1. Study Design. This research used the Central Eastern Sydney Primary and Community Health Cohort/Resource (CES-P&CH). This resource brings together populationbased data from the Sax Institute's 45 and Up Study in New South Wales (NSW) and national administrative datasets through record linkage by the NSW Centre for Health Record Linkage [39]. The CES-P&CH resource included data from 30,645 participants living in CES from the baseline survey of the 45 and Up Study. The 45 and Up Study questionnaire data is linked deterministically to the Medicare Benefits Schedule data and probabilistically to the Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), and Deaths Registry data [40]. The 45 and Up Study was conducted in a representative population of NSW aged 45 and over. Prospective participants were randomly sampled from the Department of Human Services (formerly Medicare Australia) enrolment database, which provides near complete coverage of the population. A total of 267,153 participants joined the study by completing a baseline questionnaire (between January 2006 and December 2009) and giving signed consent for follow-up and linkage of their information to routine health databases [39, 41]. The cohort has been followed up twice since baseline, first, in 2010 as part of the Social, Environment, and Economic Factors (SEEF) substudy [42] and during the 5-year follow-up (2012-2016). Details of this study have been described elsewhere [43].

Carers were identified using a question from the 45 and Up Study baseline survey, "*do you regularly care for a sick or disabled family member or friend?*" Hospitalisations included all overnight stays which were identified from the APDC data set where admission and separation dates, mode of separation, primary and secondary diagnosis, and procedure codes are recorded. We did not count the overlapping and nested episode of hospital admissions, such as if the separation date and admission date are same for two subsequent hospitalisations, we count it as a single episode of

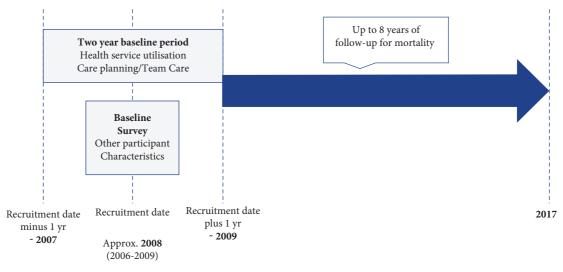


FIGURE 1: Data collection and follow-up timepoints.

hospitalisation. Then, we calculated average number of hospital admissions per year for 3 consecutive years from one year before to one year after the baseline survey. We then defined any overnight hospital stay as >0 admission per year. General practitioner (GP) visit was identified from the Medicare Benefits Schedule database using the associated item numbers, which are described in Supplementary File 1 [44].

The average number of GP visits per year was calculated for 3 consecutive years: from one year before to one year after the baseline survey. Then, the high GP use was defined as  $\geq 11$  visits per year. All-cause mortality was identified from the death registry data set. Mortality was defined if any death occurred in 8 years from baseline survey. An overview of the data collection and follow-up time points included in this study is shown in Figure 1.

Ethical approval was granted for this research project by the NSW Population and Health Services Research Ethics Committee (2016/06/642) and from the University of NSW Human Research Ethics Committee for the 45 and Up Study overall.

2.2. Data Analysis. Descriptive analyses were undertaken to examine the proportion of people who were and were not categorised as being carers for each sociodemographic, health risk factor, health status, and health service utilisation characteristic of interest. In this study, we used prevalence ratio (PR) as a measure of association [45]. PR and 95% CI were calculated using the Poisson regression model to examine which factors were related to being a carer. The adjusted PR and 95% CI were calculated by including all the covariates into the multivariable Poisson regression model. We also used PR to measure the effect of being a carer on high GP use and hospital use using the Poisson model. To measure the impact of being carer on mortality, we conducted a time-to-event analysis using the Cox proportional hazard model. The follow-up for mortality was started at baseline survey and censored at 8 years from the baseline survey. PRs and hazard ratio (HR) were initially adjusted for age and sex, and they were further adjusted for other potential confounders measured at baseline, in addition to age and sex, which were identified using the change-in-effect estimate criterion [46]. We used an *R* package, "chest" [47], to employ the change-in-estimate criterion, with a cut-off of 5%, where we put all the variables which were found to be associated with carer status at p < 0.20 in univariate analysis. We used SAS 9.4 for data management [48] and *R* version 3.5.1 for statistical analyses [49]. The variables used in the analysis are described in Supplementary File 2.

#### 3. Results

*3.1. Carer Status.* At baseline, 11.4% (3,371) of study participants were identified as carers of whom 30% (1,009) were full-time carers. For those who were not full-time carers, the average amount of caring was 12 hours per week. Table 1 presents the characteristics of carers and non-carers.

With regard to carer status, based on the participants who completed a questionnaire at baseline and follow-up, 39% of carers were still carers at the 5-year follow-up and 61% were no longer carers. Again, based on the participants who completed a questionnaire at the 5-year follow-up, 9% of non-carers had become a carer at some time during the follow-up period, and 91% had never been a carer.

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. 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.

3.2. The Demographics and Characteristics of Carers. When adjusted by all other variables in Table 1, the differences in the demographic characteristics of carers and non-carers that remained were being female and married and speaking a language other than English. Carers were also less likely to have a higher income and work full time.

				Adj. (age	Adi (all
	N	Carer, n	Crude PR	and sex)	Adj. (all
	Ν	(%)	(95% CI)	PR (95% CI) <sup>1</sup>	covariates) PR (95% CI) <sup>2</sup>
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)		0.93 (0.73, 1.19)
Sex					
Male	14142	1307 (9.2)	1		1
Female	15347	2064 (13.4)	1.46 (1.36, 1.56)		1.51 (1.37, 1.65)
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)	0.91 (0.78, 1.05)
\$40,000-69,999	4945	514 (10.4)	0.65 (0.58, 0.72)	0.63 (0.56, 0.71)	0.80 (0.68, 0.93)
\$70,000 or more	10051	879 (8.7)	0.54 (0.49, 0.60)	0.53 (0.48, 0.59)	0.68 (0.58, 0.80)
Will not disclose	5912	730 (12.3)	0.77 (0.69, 0.85)	0.73 (0.66, 0.81)	0.81 (0.70, 0.93)
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)	0.95 (0.80, 1.14)
Higher school or leaving certificate	3306	359 (10.9)	$0.80 \ (0.69, \ 0.93)$	$0.84 \ (0.72, \ 0.98)$	0.93 (0.76, 1.13)
Trade or apprenticeship Certificate or diploma	2653 5604	298 (11.2)	0.83 (0.71, 0.97)	0.97 (0.82, 1.14)  0.93 (0.81, 1.06)	0.89 (0.71, 1.10)
University degree or higher	10092	673 (12.0) 1054 (10.4)	0.89 (0.78, 1.01) 0.77 (0.68, 0.87)	0.93 (0.81, 1.00) 0.83 (0.73, 0.95)	1.06 (0.89, 1.26) 1.04 (0.87, 1.24)
, , , , , , , , , , , , , , , , , , , ,	10092	1054 (10.4)	0.77 (0.08, 0.87)	0.03 (0.75, 0.95)	1.04 (0.07, 1.24)
Work status	12050	1722 (12.2)	1	1	1
Not working Part time	12950 5735	1722 (13.3)	1     0.94 (0.86, 1.02)	$ \begin{array}{c} 1\\ 0.81 (0.74, 0.90) \end{array} $	$ \begin{array}{c} 1\\ 0.91 (0.81, 1.03) \end{array} $
Full time	10353	715 (12.5) 843 (8.1)	0.94 (0.86, 1.02) 0.61 (0.56, 0.66)	0.81 (0.74, 0.90) 0.55 (0.49, 0.61)	0.91 (0.81, 1.03) 0.73 (0.64, 0.83)
Married	10555	045 (0.1)	0.01 (0.30, 0.00)	0.35 (0.49, 0.01)	0.75 (0.04, 0.85)
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)	1.34 (1.22, 1.49)
	20510	2425 (11.7)	1.10 (1.00, 1.23)	1.29 (1.19, 1.99)	1.54 (1.22, 1.17)
Speaks language other than English at home No	23795	2559 (10.8)	1	1	1
Yes	23793 5694	812 (14.3)	1.33 (1.22, 1.43)	1.34 (1.24, 1.45)	1.44 (1.27, 1.64)
Born in Australia	5074	012 (14.5)	1.55 (1.22, 1.45)	1.54 (1.24, 1.45)	1.11 (1.27, 1.01)
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, 1.54)
Current smoker	10050	2197 (11.7)	1.07 (1.00, 1.13)	1.00 (0.96, 1.15)	1.30 (1.24, 1.34)
No	27520	2107(11.2)	1	1	1
Yes	27538 1951	3107 (11.3) 264 (13.5)	1 1.20 (1.06, 1.36)	1 1.25 (1.10, 1.41)	1.23 (1.05, 1.43)
	1751	204 (15.5)	1.20 (1.00, 1.50)	1.25 (1.10, 1.41)	1.25 (1.05, 1.45)
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)	1.16 (1.05, 1.28)
	20303	2343 (11.3)	1.02 (0.95, 1.10)	1.04 (0.90, 1.12)	1.10 (1.03, 1.20)
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, 1.02)
	20019	2073 (10.4)	0.70 (0.71, 0.82)	0.82 (0.70, 0.88)	0.95 (0.05, 1.02)
Ever had high blood pressure	10/10	217((11,1))	1	1	1
No Yes	19619 9870	2176 (11.1) 1195 (12.1)	1	1	1
	9670	1195 (12.1)	1.09 (1.02, 1.17)	1.10 (1.02, 1.18)	1.03 (0.94, 1.13)
Ever had diabetes	27140	2074(11.2)	1	1	1
No	27140	3074(11.3)	1		1
Yes	2349	297 (12.6)	1.12 (0.99, 1.26)	1.14 (1.01, 1.28)	0.89 (0.75, 1.05)
Ever had asthma	22607	2647 (11 7)	1	1	
No	22687	2647 (11.7)	1	1	1
Yes Ever had depression	3466	421 (12.1)	1.04 (0.94, 1.15)	1.02 (0.92, 1.13)	1.02 (0.90, 1.16)
Ever had depression No	21924	2482 (11.3)	1	1	1
1 3 1/	4174 <del>4</del>	2TU2 (11.J)	1	1	1

TABLE 1: Characteristics of carers and non-carers among 45 and Up Study participants, Central and Eastern Sydney.

		INDEL I. COIR	inded.		
	Ν	Carer, <i>n</i> (%)	Crude PR (95% CI)	Adj. (age and sex) PR (95% CI) <sup>1</sup>	Adj. (all covariates) PR (95% CI) <sup>2</sup>
Yes	3931	568 (14.4)	1.28 (1.16, 1.40)	1.23 (1.12, 1.35)	1.05 (0.93, 1.19)
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)	1.16 (1.01, 1.33)
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)	1.09 (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)	1.16 (1.02, 1.32)
Ever had stroke					
No	28589	3246 (11.4)	1	1	1
Yes	900	125 (13.9)	1.22 (1.02, 1.46)	1.21 (1.00, 1.44)	0.98 (0.75, 1.26)
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)	0.65 (0.57, 0.75)
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)	1.17 (1.01, 1.35)
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)	0.69 (0.55, 0.85)

TABLE 1: Continued.

*Note.* <sup>1</sup>PRs were adjusted only for age and sex. <sup>2</sup>PRs were adjusted for all other variables in the table; PRs bolded if significantly higher and italicised if significantly lower.

3.3. The Health and Well-Being of Carers. When adjusted by all of the other variables in Table 1, the health status differences between the carers and non-carers that remained were being a current smoker, having high psychological distress, needing help with daily activities, having ever had anxiety or heart disease, and a self-reporting good quality of life. In both the crude model and the model that adjusted for age and sex only, carers were less likely than non-carers to consume alcohol; however, this difference was no longer significant in the model that adjusted for all covariates. In this model, carers became more likely to self-report good quality of health and needing help with daily activities was no longer more likely. In addition, adequate physical activity and self-reporting good quality of health were more likely in carers and being aged 60-84 years (compared to 45-59 years) was less likely.

Despite some differences in health status and selfreported quality of life, as shown in Figure 2 and Table 2, there was no significant difference found between carers and non-carers in relation to 8-year mortality status in either the crude or adjusted models (14.2 per 1,000 person years and 13.7 per 1,000 person years, respectively).

3.4. The Health Service Use of Carers. The rates of overnight hospitalisation between carers and non-carers in CES were very similar, as shown in Table 3. When adjusted by the potential confounders, there was no significant difference between carers and non-carers.

However, when examining rates of GP use, as shown in Table 4, significant differences were identified between carers and non-carers. Thirty percent of carers demonstrated high GP use which was higher than the rate for non-carers. When adjusted by confounding factors, a significant difference was shown to exist between carers and non-carers (Adj. HR (95% CI): 1.21 (1.13, 1.30)).

#### 4. Discussion

This study aimed to investigate the demographic characteristics, health risks, health status, and health outcomes for carers and to describe how these differ from those of noncarers. We found that between 11.4% and 12.6% of people in Central and Eastern Sydney aged over 45 were carers at different data collection points within the study. This is similar to the proportion cited in local demographic profiles [37], but it is lower than the 18% of the population aged over 45 reported by the Australian Bureau of Statistics as carers [1]. Only 33% of carers remained carers across all three data collection points, highlighting the changing nature of caring roles. The profile of carers in this study, more likely to be females, having lower incomes and not working full-time, is consistent with previous studies [21]. We found that carers were more likely to be smokers, which is consistent with findings from elsewhere in Australia [50].

We also found that carers reported high levels of psychological distress and having ever had anxiety. This is consistent with other research that shows that psychological

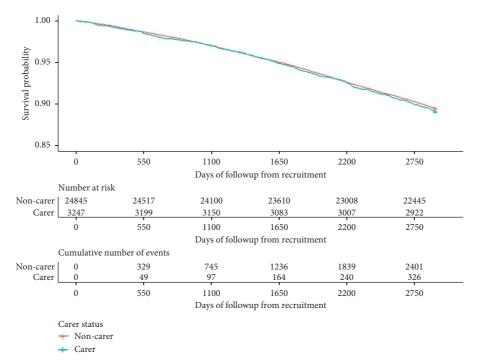


FIGURE 2: Kaplan-Meier curve: carer status and 8-year mortality from recruitment.

TABLE 2: Carer status and 8-year mortality from base line: hazard ratio with different models.
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Carer	Ν	Person-year	Death≤8 years of recruitment	Mortality per 1000 PY	Crude model	Adj. model 1	Adj. model 2
No	24845	189601	2601	13.72	1	1	1
Yes	3247	24745	352	14.23	1.04 (0.93, 1.16)	0.97 (0.87, 1.09)	0.98 (0.87, 1.10)

Notes. Adj. model 1 included age and sex only; Adj. model 2 included household income, age at recruitment, sex, and needing help for daily activity variables.

TABLE 3: Association of carer status with any overnight hospitalisation +/- 1 year of baseline survey.

Carer	Ν	Any overnight hospital (%)	Crude PR (95% CI)	Adj. 1 PR (95% CI)	Adj. 2 PR (95% CI)
No	25772	7547 (29.3)	1	1	1
Yes	3322	1028 (30.9)	1.06 (0.99, 1.13)	1.05 (0.98, 1.12)	1.02 (0.96, 1.09)

Notes. Ad. model 1 included age and sex only; Adj. model 2 included age, sex, and current working status only.

TABLE 4: Association of carer status with high ( $\geq$ 11) GP use during +/-1 year of baseline survey.

Carer	Ν	High GP use (≥11) N (%)	Crude PR (95% CI)	Adj. 1 PR (95% CI)	Adj. 2 PR (95% CI)
No	25772	5731 (22.2)	1	1	1
Yes	3322	986 (29.7)	1.33 (1.25, 1.43)	1.29 (1.20, 1.38)	1.21 (1.13, 1.30)

Notes. Adj. model 1 included age and sex only; Adj. model 2 included age, sex, and current working status.

distress may increase in response to the amount of time devoted to caregiving [35].

We found that many aspects of carers' physical health are no worse than those of non-carers. Carers' 8-year mortality was not significantly different from that of non-carers and carers were more likely to report adequate physical activity and a good quality of life. These findings point to a potential paradoxical relationship between caring and health outcomes. This aligns with an emerging body of research suggesting that aspects of carers' physical wellbeing may be better than those of noncarers [34, 35]. This finding may not account for people ceasing, or not initiating, caring roles due to poor physical health and should not be interpreted as evidence that caring itself has a positive impact on physical health.

#### Health & Social Care in the Community

It is important to note that this analysis encompasses a large, culturally and socioeconomically diverse urban population. As such the findings may have relevance to many regions and settings in Australia and internationally. However, we should be cautious about generalising the findings to populations in periurban, rural, and remote areas, given carers in these areas experience distinct needs and barriers to accessing and using health services [51].

4.1. Implications for Practice. This study's finding that carers in Central and Eastern Sydney are well-engaged with general practice suggests that general practice is an important setting to identify people in caring roles; identify carers who may be struggling in these roles; and delivering interventions for carers. This is consistent with the limited literature on the importance of general practitioners in supporting carers [52, 53]. Previous research with carers in this region of Sydney has found that many carers do not identify with terms such as carer or caregiver and often do not consider themselves as a carer until someone uses these terms to describe them [54, 55]. Given the high levels of engagement, it may often be general practitioners who are the first professionals to identify and describe people as carers and make an important contribution to carers' experience of care [56, 57]. Interventions such as recording carer identifiers within general practice record systems, carer awareness training, and better access to carer support services from within primary health care may enhance carer identification, transitions, and support [58].

The finding that carers currently smoke at a higher rate suggests that tobacco cessation and healthy lifestyle campaigns and services should be explicitly inclusive of carers. Given the higher levels of GP engagement discussed above, there may be opportunities for primary care to recognise carers as a priority population for initiating tobacco cessation discussions. Further qualitative investigation of the lived experience of barriers to tobacco cessation by carers is also required [59].

This study confirms the transitions between carer and non-carer roles and that only a proportion of carers remain in these roles for many years. Research suggests that access to good information helps carers through these transitions [60]. Caring often starts suddenly, and people need to quickly learn and adapt to their new role. Throughout their caring journey, people need information about services, resolving problems, and getting personal support.

4.2. Implications for Research. Whilst carers may experience higher levels of distress and anxiety and a low quality of life, they do not appear to have worse physical health outcomes or mortality rates. Caution should be taken in inferring any causal relationships from this, however. Deterioration in physical health may stop people from undertaking or remaining in their caring roles, leading to relatively physically healthy, but often distressed, people being able to remain carers. Further research on this point is required.

This study also found that the level of distress experienced also varied markedly between carers, which is consistent with other Australian findings that as many as a half of all carers may experience high levels of psychological distress [61]. Further research is required to understand the experience of carers who report higher levels of distress and how their characteristics and needs may differ from those of carers who are not experiencing distress. The authors plan to undertake related analysis in order to determine potential avenues for identifying and supporting this group of carers earlier within their carer journeys.

#### 5. Strengths and Limitations

This study represents a distinct contribution to the literature on carers and caregiving for four reasons. First, it is based on a large population sample of people who were recruited at ages 45 and up within the community. It did not rely on hospital settings, data, or service use, for recruitment. Second, it incorporates a range of longitudinal linked data sets along with self-reported survey data in a way that has been rarely done in carers research previously. Third, it did not rely on people identifying as carers for participation in the study, and as such, it includes people who undertake caring activities but who may not identify with a carer role or descriptor. Fourth, the comparisons between carers and non-carers have been made on the basis of adjusted models that do not assume carers and non-carers are similar groups.

However, there were some limitations with the cohort and the study. While the 45 and Up Study cohort is reasonably representative of the population from which it was drawn, nonresponse at baseline may mean that the cohort varies slightly from the population [62]. Nevertheless, comparison of these rates over time and between subgroups is still valid. A limitation of the Medicare Benefits Schedule data is the lack of any information regarding the reason for the primary care consultation. Another important limitation of this study is that the care status might change over time which might introduce some nondifferential misclassification bias, so our analysis provides a conservative estimate of the effect of the carer on the outcomes of our interest. However, carer status changes have not had an impact on the risk factor analysis.

#### 6. Translating Findings into Practice

The findings from this study have been reported to the three partner funding agencies [63], which has been hosted on a national report and grey literature clearing house [64], presented at an integrated care conference [65] and shared with carer peak bodies such as Carers NSW [66]. These dissemination activities have informed service responses to support carers, in particular through general practice. This has led to further analyses of carers' support needs, which are currently underway and a review of interventions to support carers through general practice.

### 7. Conclusions

This study showed that carers aged over 45 were more likely to smoke, need help with daily activities, experience fair or poor quality of life, and experience anxiety and psychological distress than non-carers. However, we also found that over an eight-year period, there was no difference in mortality rates between carers and non-carers. This study confirms that transitions between carer and non-carer roles occur frequently and that only a proportion of carers remain in these roles for many years. Caring roles and activities often start suddenly, and people need to quickly learn and adapt to their new roles.

Our findings suggest that carers in the Australian context seem to have ongoing contact with general practice. This suggests that general practice may be an important setting to identify people in caring roles, particularly following transitions in care arrangements. Due to the level of contact with carers, general practice could potentially play a stronger and more supportive role in identifying carers who are struggling with their caring responsibilities and also to deliver interventions for carers. Further research on (i) how to identify and support carers earlier in their carer journeys and (ii) developing effective interventions is required.

#### **Data Availability**

The data used to support the findings of this study are available from the corresponding author upon request.

# **Additional Points**

The Following Is Known about This Topic. (i) Eighteen percent of the Australian population aged over 45 is carers. Carers report low levels of wellbeing and poorer physical and mental health than non-carers. Carers report barriers to services and treatment for their own needs, distinct from those of the people they care for. This Paper Adds the Following. Carers were more likely to smoke, need help with daily activities, experience fair or poor quality of life, anxiety, and psychological distress than non-carers. Carers had significantly higher rates of general practitioner use than non-carers. There was not a significant difference in mortality rates amongst carers over an eight-year period compared with non-carers.

# **Conflicts of Interest**

The authors declare that they have no conflicts of interest.

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#### **Supplementary Materials**

Supplementary File 1: Covariate characteristics, data sources, and descriptions of MBS Groups-Codes included for GP use/GP plans. Supplementary File 2: Description of the variables used in the analysis. (*Supplementary Materials*)

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