Measuring the health status of informal and family caregivers - how, what and why

Anne Florence Stacey

BN, MMedSc

A thesis submitted for consideration of the award of Doctor of Philosophy

November 2019

Adelaide School of Medicine,

Discipline of Medicine,

Faculty of Health and Medical Sciences

The University of Adelaide, South Australia

Table of Contents

Declaration Statement

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and, where applicable, any partner institution responsible for the joint award of this degree. I acknowledge that copyright of published works contained within this thesis resides with the copyright holder(s) of those works. I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Signed	Dated
(Anne F Stacey)	24 February 2020

Acknowledgments

It has been both a privilege and a challenge to embark on my Doctor of Philosophy in later life. It represents the culmination of more than twenty-five years of interest in the wellbeing of informal carers and the desire to build on that knowledge with the goal of contributing to the healthcare of future generations of families. I could not have completed this final task without being given the opportunity and encouragement by significant others, both academic and personal.

I first wish to acknowledge Professor Anne Taylor my Principal Supervisor who, with the late Professor Graeme Hugo and members of the NOBLE (Nutrition, Obesity, Lifestyle and Environment) Study Committee made it possible for me to conduct this research. To Professor Taylor and co-supervisors, Dr Tiffany Gill and Associate Professor Kay Price, I extend my sincere thanks for their unwavering support, advice and endless patience during my PhD. In particular I wish to thank Dr Gill for her invaluable assistance in guiding me through the maze of statistical data which underpinned all the investigations. To members of the Population Research and Outcome Studies where I was based, I extend my gratitude for including me as part of their dynamic unit. Special thanks are extended to Dr Eleanora Dal Grande and Associate Professor Shi for their assistance with some additional aspects of my research. I also thank Dr Alison-Jane Hunter for her editorial advice and support during the final stages of preparing this thesis.

Of course none of my studies would have been possible without the earlier contribution of everyone involved with the three large projects in which I was able to share: namely the teams of academic researchers and members of the community who participated in the North West Adelaide Health Survey (University of Adelaide), the Health Omnibus Survey (Harrisons Health Research) and the South Australian Monitoring and Surveillance System under the auspices of S.A. Health, Government of South Australia. I also wish to acknowledge Rosemary Warmington A.O., for her long-term support of my research into the health needs of carers during her time as Executive Director (now retired) of Carers S.A.

To my own long-suffering family, I thank everyone for their unerring support and encouragement. It is to my late 100 year old Mother that I dedicate this thesis. It was she who taught me so much about the importance of family, and how to care for others.

Abbreviations/Acronyms

ABS	Australian Bureau of Statistics
ABDS	Australian Burden of Disease Study
AIHW	Australian Institute of Health and Welfare
AL	Allostatic load
APC	Age Period Cohort
BMI	Body Mass Index
BRFSS	Behavioural Risk Factor Surveillance System
CATI	Computer Assisted Telephone Interview
CDs	Collection Districts
CHD	Coronary Heart Disease
CI	Confidence interval
COPD	Chronic Obstructive Pulmonary Disease
CRP	C-Reactive Protein
CVD	Cardiovascular Disease
DALYs	Disability Adjusted Life Years
e-Sel	e-Selectin
FEV1	Forced Expiratory Volume in one second
GBD	Global Burden of Disease
Hb	Haemoglobin
HbA1c	Glycosylated haemoglobin
HBP	High Blood Pressure
HDL	High Density Lipoprotein
HILDA	Household Income and Labour Dynamics in Australia
HOS	Health Omnibus Survey
HREC	Human Research Ethics Committee
HRQoL	Health Related Quality of Life
hs-CRP	High sensitivity C-Reactive Protein
ICD-9	International Classification of Diseases, ninth revision
IL-6	Interleukin-6
IRSD	Index of Relative Socio-Economic Disadvantage
K10	Kessler 10 scale

LDL	Low Density Lipoprotein
MOS	Medical Outcomes Study. MOS 36 Item Short-Form Health Survey
MPO	Myeloperoxidase
MSK	Musculoskeletal
NATSEM	The National Centre for Social and Economic Modelling
NDIS	National Disability Insurance Scheme
NWAHS	North West Adelaide Health Study
NZ	New Zealand
OECD	Organisation for Economic Co-operation and Development
OR	Odds Ratio
PAR	Population Attributable Risk
QOL	Quality of Life
PROS	Population Research and Outcome Studies
RR	Relative Risk
REACH II	Resources for Enhancing Alzheimer’s Caregiver Health II
SF-1	Short Form 1 (Question 1)
SF-36	Short Form 36 (Questionnaire)
SPSS	Statistical Package for Social Sciences
SAMSS	South Australian Monitoring and Surveillance System
SDAC	Survey of Disability Ageing and Carers
SEIFA	Socio-Economic Indexes for Areas
TNFα	Tumor Necrosis Factor alpha
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
WHR	Waist Hip Radio
25 (OH)D	25-hydroxy vitamin D

List of Tables

List of Figures

Publications contributing to this Thesis

Paper One Citation:

Stacey AF, Gill TK, Price K, Warmington R, Taylor AW. Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects 1994–2014. PLoS ONE; 2016, 11(9): e0161994. doi:10.1371/journal.pone.0161994.

Paper Two Citation:

Stacey AF, Gill TK, Price K, Taylor AW. Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia. BMJ Open 2018;8:e020173. doi:10.1136/ bmjopen-2017-020173.

Paper Three Citation:

Stacey AF, Gill TK, Price K, Taylor AW. Biomedical health profiles of unpaid family carers in an urban population in South Australia. PLoS ONE, 2019; 14(3): e0208434. https://doi.org/10.1371/journal.pone.0208434.

Abstract

This research utilises data about adult informal family caregivers in South Australia, their prevalence over a period of two decades, and provides a review of their health and morbidity profiles between the years 2008 and 2015. The rationale for the study has come from increased epidemiological and clinical discussions on the impact of informal caregiving on the health status of family carers. The evidence suggests a proportion of carers may be at greater risk of poor health outcomes, however there are limited population-based studies that provide representative data on specific risk factors amongst carers.

The research is based on a literature review and three separate analyses, resulting in manuscripts published in international journals. The 20-year prevalence estimates are featured in the first publication using representative state-wide surveys, (total N=26,788 and n=1,504 carers aged 16 years and over). An Age-Period Cohort (APC) analysis was undertaken to examine whether there were any generational effects on the prevalence of carers.

The second publication, based on monthly state-wide surveys between 2010-2015, provided self-report data on carers' health status, risk factors and chronic illnesses (N=35,195 participants and n=2,247 carers aged 18 years and over). The population attributable risk (PAR) of being a carer was examined for selected chronic conditions.

The third paper examined carers drawn from a representative population-based longitudinal biomedical cohort study in metropolitan Adelaide (N=4056 participants

and n=191 carers aged 40 years and over). Risk factors, chronic medical conditions and biomedical, health and demographic characteristics using self-report, clinic and laboratory measured variables were assessed – including haematology, biochemistry, Vitamin D, and the inflammatory biomarkers; high sensitivity C-Reactive Protein (hs-CRP), Tumor Necrosis Factor alpha (TNFα) and Interleukin-6 (Il-6).

This South Australian profile indicates that caregiving is associated with a small to moderate increased risk of having chronic conditions, especially diabetes and asthma in female carers. Findings from blood-measured variables revealed lower serum Vitamin D and haemoglobin levels in carers from the urban cohort study. Male carers had raised diastolic blood pressure, higher blood glucose, lower haemoglobin and albumin levels and slightly elevated inflammatory biomarkers TNFα and hs-CRP.

The results of this study have provided in-depth empirical evidence of the types of medical health conditions experienced by carers, arguing the advantages of clinical assessments. Furthermore, it is proposed that the pathways of illness of both individuals within the caregiving dyad need to be assessed concurrently. Important as it is to monitor the prevalence of conditions that influence the burden of disease in the general population, it is also pertinent to monitor, measure and manage the health of the carers who provide the informal care, since they may be carrying a double burden of illness - that of the person they are looking after and their own health problems.

Chapter 1. Introduction

Informal caregiving in the twenty first century is a complex phenomenon, influenced by a range of socio-demographic, economic and public policy factors. The combination of ageing populations and increased survival, living with chronic disease and disability, have created extra demands for long-term, domestic home-based informal care. This demand has resulted in different responsibilities and challenges for family members and other close relatives or friends to provide the necessary care to meet the needs of cared-for people. However, people who take on the role of an informal carer cannot be presumed to have the physical and emotional capacity to provide the required care and support.

A review of the literature (Chapter 2) highlights that, after three decades of international research related to informal carers, there is still a lack of consistent, reproducible, detailed information on their physical health profiles. Assessment of their health has been dominated by studies of the psychological impact of caregiving, in particular those associated with care of the frail elderly and persons with dementia. There remains a gap in the knowledge of specific risk factors and chronic health conditions across informal carer groups in the population, which include biomedical health profiles. Also lacking are studies using high–level and robust methodologies, with many of the studies based on convenience samples, or biased populations, using unvalidated measures and having inconsistent reliability.

This thesis investigates the health status of adult informal carers, including demographic characteristics and morbidity (with both self-reported and biomedical assessments) using epidemiologically-sound population data collected in South Australia. The main objectives of the study were to determine prevalence estimates and trends of health-related risk factors and chronic medical conditions among informal carers.

Details of the study design and analyses of the three independent studies undertaken and published are described in Chapter 3. The first paper (Chapter 4), investigated changes in the prevalence and demographic characteristics of adult informal carers aged 15 and over, over the 20-year period from 1994, using data from an annual population survey. Paper 2 (Chapter 5), explored, using data from a risk factor surveillance system, associations between the caregiving role as a risk factor for chronic disease and the health status of informal carers. Paper 3 (Chapter 6), using the biomedical status of a subgroup of informal carers from a cohort study, addressed the differences in the biomedical profiles of informal carers compared with non-carers. Data collected included clinic and blood measured variables.

Drawing on the implications of the findings, and the strengths and limitations of those findings of the three, internationally published, peer reviewed articles, Chapter 7 provides a summary, then proposes recommendations for future work in the fields of population research, clinical practice and policy development.

Chapter 2. Literature Review

2.1 The focus of the review

Family caregiving, to care for the sick, disabled and dying, is not a new social phenomenon. However, the concept of informal caregiving that has evolved in the late twentieth century is argued as presenting greater challenges[1,2,3]. The complexity of the two-person informal caring relationship, often referred to as caregiving dyads, and the nature of specific in-home-care that may be expected to be provided,[4-7] are argued as accounting for these challenges. The added responsibilities of informal carers (different from formal or paid carers) providing assistance for persons of any age who lack the capacity to meet their own needs is acknowledged as very different from normal reciprocity amongst adults within personal relationships[8-9].

In this chapter, a review of informal carer health research from the 1980s to 2018 has determined the research direction for this thesis. In the first part of this review, the impact of epidemiological transitions of population ageing, the burden of disease, and the increasing need for informal carers within modern developed countries is explored. To identify gaps in the current research, an overview of both positive and negative aspects of caregiving and the tools for carer assessment are discussed. Research highlighting demographic, biological, behavioural and social determinants of the health of an informal carer, including biomedical and clinical aspects of their risk factors and chronic conditions, are reviewed. To contextualise these findings, relevant aged care and informal caregiving related policies influencing the lives of informal carers are examined.

2.2 Epidemiological transitions and population ageing

Global epidemiological transitions[10], for example declining mortality rates, a reduction in deaths from pandemics and changing patterns of fertility, are factors that have led to continuing population growth[10-13]. The delaying or prevention of deaths from diseases and injuries[11], and greater survival rates of people with previously life-threatening injuries and conditions, have also been attributed to public health interventions, as well as the introduction of life-saving medical, pharmacological and technological advances[2,13]. Combined with better living and social conditions, increased life expectancy and longevity, a major shift in population age distribution has led to ageing societies with increasing numbers of the population living with chronic disease, disability, dementia and other age-related conditions[10,11]. Empirical data of persons living with disability and/or dementia provide insight into this major shift in the population age distribution and the subsequent increasing need for informal carers.

2.3 Burden of disease

Between 1990 and 2015, assessment of the health of populations in 195 countries for the Global Burden of Disease Study (GBD), measured in Disability Adjusted Life Years (DALYs)[14], reported an overall improvement in health globally, with morbidity increasing with functional health loss[14]. Listed among the most prevalent diseases were Alzheimer’s disease and other dementias[15] which increased globally over this 25 year period by 7.4%[15]. There are also important risk factors that contribute to DALYs.

These are: high systolic blood pressure, smoking, high fasting plasma glucose, high body mass index (BMI), high total cholesterol, alcohol use and diets high in sodium[15].

A comparison of the burden of disease between Australia and Organisation for Economic Co-operation and Development (OECD) countries, measured in DALYs from the 2013 GBD[16], is shown in Figure 2-1.

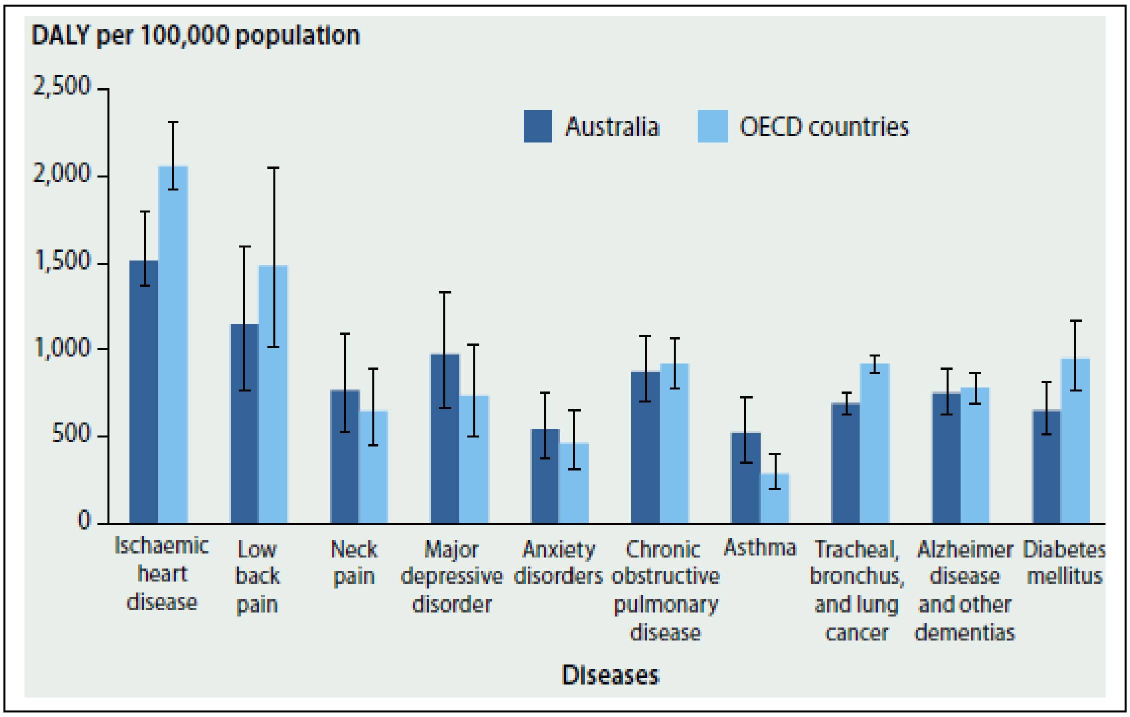


Figure 2.1 Comparison between Australia and OECD countries of the burden of disease for selected conditions, 2013

Source: AIHW Australia's Health 2016. Ch. 3 Page 60. Fig. 3.1.7.[16]

Findings showed that the burden of disease in Australia was slightly lower than OECD countries for ischemic heart disease, low back pain, chronic obstructive pulmonary disease (COPD), tracheal, bronchus and lung cancer, Alzheimer's disease and other dementias and diabetes mellitus. The burden of disease was higher in Australia than OECD countries for major depressive disorder, anxiety, asthma and neck pain[16].

Key findings from the Australian Burden of Disease Study (ABDS) in 2011[17] and again in the most recent ABDS in 2015[18] indicated that the five leading conditions causing the most burden in 2011 and 2015 were due to: cancer, cardiovascular diseases, mental health and substance use disorders, musculoskeletal conditions and injuries. Among older Australians in 2015[17], major causes of total burden were cardiovascular diseases, cancer and neurological conditions that increased with age.

In working age groups, a considerable amount of the burden was due to musculoskeletal conditions, while the main burden for young adults and children was from injuries, mental health conditions and substance abuse disorders[17]. Overall, disease-specific trends from 2015, described in the most recent AIHW Burden of Disease (2019) report, suggest a general improvement in disease burden since 2003 in Australia but the most notable increase in age-standardised burden rates was in neurological conditions[18].

Figure 2-2 illustrates the overall age specific DALY rate by age group in 2003, 2011 and 2015. These data all highlight the increases in the burden of disease as the population ages[19]. If people are living with illness for longer periods of time, they may then be susceptible to greater periods of disability due to their illness.

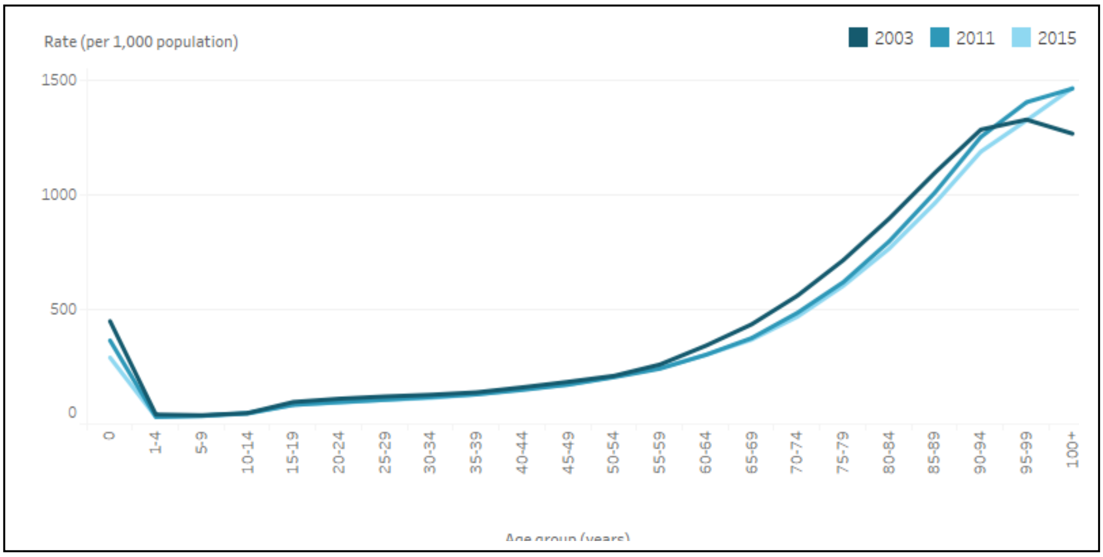


Figure 2.2 Comparison of age specific DALY rates in Australia, 2003, 2011 and 2015

Source: AIHW Australian Burden of Disease Database and Australian Burden of Disease study 2015[19]

2.4 Disability

In the World Report on Disability (WHO 2011)[20] based on 2010 global population estimates, 15% of the world's population (one billion people) were living with some form of disability. This was described in the report as impairments, activity limitations and participation restrictions[20]. In the Australian Bureau of Statistics (ABS) 2015 Survey of Disability, Ageing and Carers (SDAC)[21], a person with a disability was defined as:

> "Someone who has one or more specified types of limitations, restrictions or impairments that restrict everyday activities, and which has lasted (or is likely to last) for at least 6 months. The severity of disability is further defined by the degree of assistance or supervision required in core activities, self-care, mobility and communication and grouped for mild, moderate, severe and profound limitation"[21].

Of those Australians identified with a disability in 2015, 79% reported a physical health condition as their main long-term health problem, with the remainder (21%) reporting a mental or behavioural disorder[22].

Figure 2-3 shows the trend in overall disability in Australia in 1993 and 2013, with the likelihood of having a disability increasing with age[21]. Figure 2-4 shows the most recent data available for the Australian population with a disability and severe/profound core activity limitations[21].

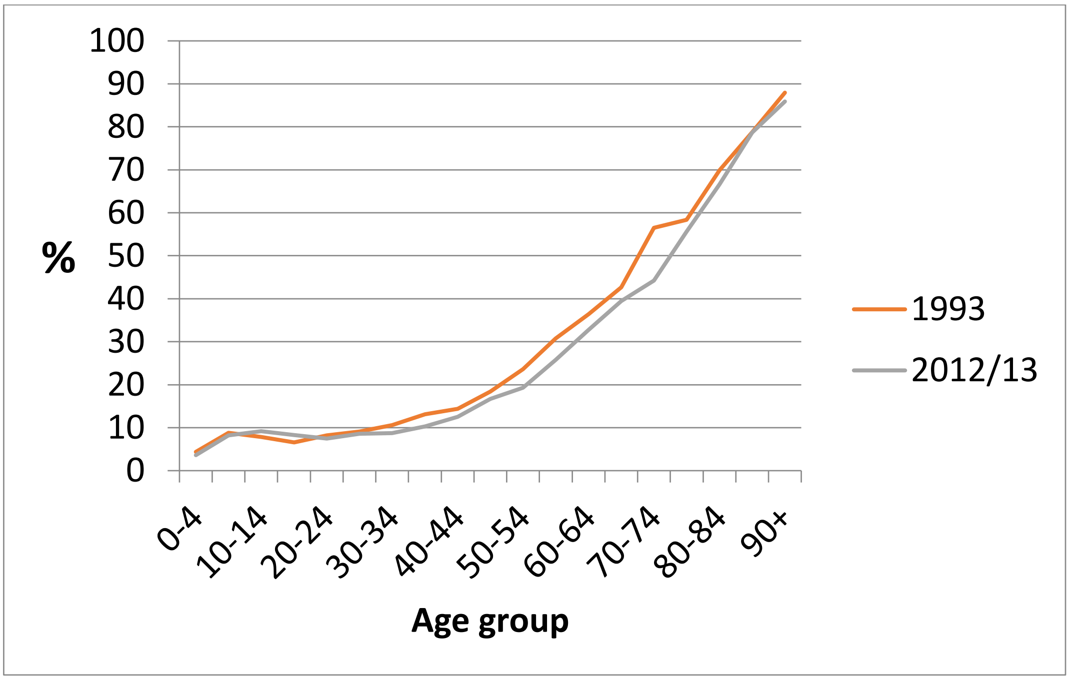


Figure 2.3 Disability prevalence by age group [1993-2013]
Source: ABS. Adapted from ABS data from Survey of Disability, Ageing and Carers 1993-2013. (Chapter 8.1)[22]

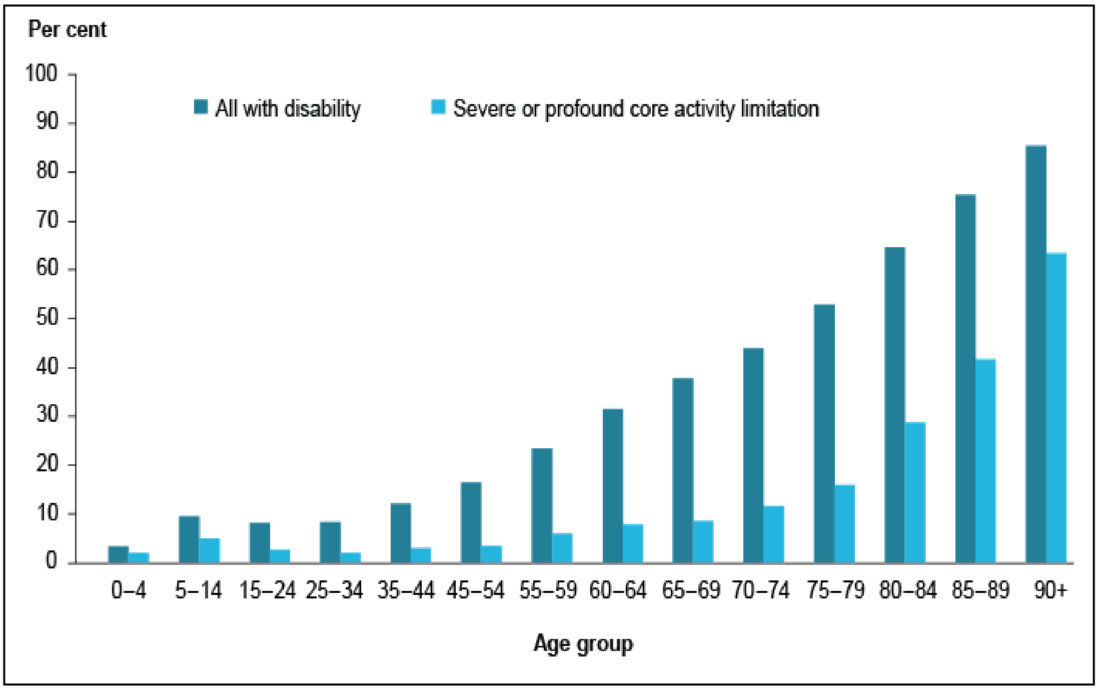


Figure 2.4 Proportion of the population with disability and severe or profound core activity limitations, by age group, 2015
Source: AIHW Australia's welfare 2017. Ch. 8.1, page 302. Figure 8.1.1 ABS 2016 [22]

In 2015, the ABS introduced a new category for inclusion in the SDAC, psychosocial disability, and collected more comprehensive data on Australians with conditions that caused restrictions in everyday activities, lasting six months or more[21]. Prior to 2015, data on this type of disability were based on narrower definitions and had been incorporated within general categories of disability. From 2015, conditions such as complications of stroke-like confusion, memory, emotional and social or behavioural problems have been featured. Other nervous, emotional or mental health conditions that restrict daily participation in education, employment, social and cultural activities were also included and accounted for almost a quarter (24.4%) of all people identified with any type of disability[21]. Overall 4.5% of the total population were found to be in this newly defined group, with males (4.3%) and females (4.7%) showing similar rates. Rates increased in older age groups, especially those aged 85 years and over[21].

In Australia, the states of Tasmania and South Australia had the highest rates of psychosocial disability due to the older age structure, however psychosocial disability was also seen in younger age groups, where boys aged up to 14 years were twice as likely to have this disability, mainly due to higher prevalence of autism[21].

Significantly, the 2015 SDAC recorded that 94.9% of persons living at home with psychosocial disability (who also may have other disabilities as well) needed assistance with daily activities, with 63.7% of them receiving care from informal carers[21]. Given that dementia is now recognised as the single greatest cause of disability in older Australians aged 65 years or over[16], information about where these people live and who cares for them provides insights into the increasing need for informal carers.

2.5 Dementia statistics in Australia

People requiring help with most aspects of daily functioning are persons living with dementia[23]. Although living with dementia is acknowledged as a major health problem in Australia, it is not a single specific disease[23]. It is an umbrella term describing a syndrome associated with more than 100 different diseases that are characterised by the impairment of brain functions including language, memory, perception, personality and cognitive skills[24]. Common types of dementia are vascular and frontotemporal dementia, Alzheimer's disease, and dementia with Lewy bodies[23]. The type and severity of symptoms and their pattern of development therefore varies with the type of dementia, which is usually progressive, of gradual onset, and irreversible[23]. Australian prevalence estimates in 2016 are displayed in Figure 2-5.

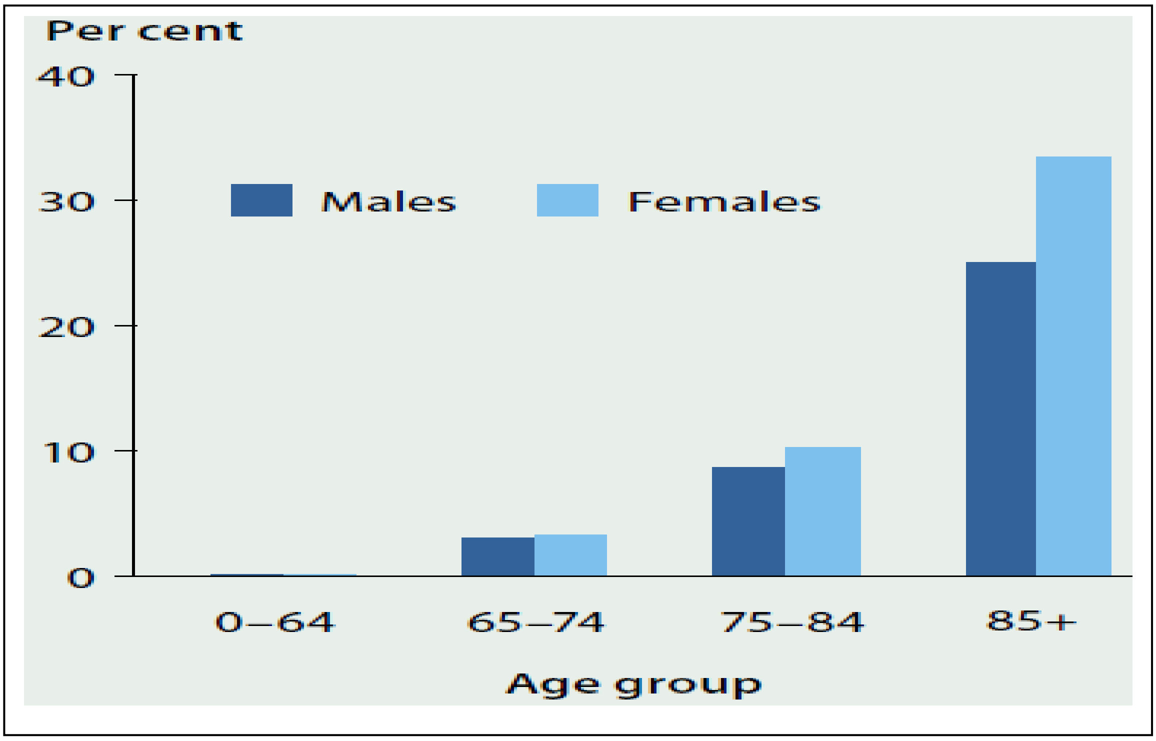


Figure 2.5 Australian prevalence estimates of people with dementia, by age group and sex, 2016.

Source: Australian Institute of Health and Welfare AIHW Australia's Health 2016. (Ch.3.12, Page 108)[16]

While previous overall prevalence estimates of dementia in Australia have been similar to the average of countries in the OECD (1.42% compared with 1.48%)[23], it was estimated in 2018 that up to 436,366 persons or 1.7% of the Australian total population live with dementia[23,25]. This figure is projected to grow to 550,000 Australians by 2030[23] and to 900,000 by 2050[23]. In 2018, an estimated 8.7% of persons aged 65 years and over lived with dementia; of these, approximately 61% were women[25]. Not only is living with dementia the single greatest cause of disability in older Australians, it was the leading cause of non-fatal burden in 2011 and the second leading cause of disability burden overall[25].

Persons with dementia are also reported to have higher than average debilitating co-morbid conditions[26] and risk factors of dementia in addition to age, genetics and family history, include vascular diseases, metabolic conditions and lifestyle-related behaviours, such as smoking and lack of physical exercise[18]. It has been reported that although chronic heart disease (CHD) is a leading cause of non-fatal burden in the 85-94 age group, dementia is currently ranked as the leading cause of fatal burden in females, and second overall in that age group[24]. By 2016, dementia had become the leading cause of death among Australian females, surpassing heart disease[18,24].

Alzheimer's disease and other dementias, therefore, not only have serious health consequences for persons with the condition but, as dependency progresses, these conditions also impact those families and friends who provide ongoing home-based informal care[25]. For persons living with dementia, this timeframe can be long term, requiring care and support for up to more than twenty years[26]. Increases in dementia prevalence are expected to place demands on a greater number of informal carers. Whether informal or formal (paid) carers, the following table (Table 2-1) highlights this increasing need for persons to care for people living with dementia in the Australian community[23,27].

Table 2-1 Projected number of carers for people with dementia in Australia by sector, 2016-2056

Year	In the Community	In cared for accommodation	Total No. of carers
2016	190,505	92,005	282,510
2026	264,620	126,231	390,851
2036	362,931	173,223	536,154
2046	448,156	214,130	662,287
2056	525,541	250,418	775,959

Source: NATSEM. Appendix 3. The Economic Cost of Dementia 2016-2056. Alzheimer's Australia 2017[27].

2.6 Informal carers. Definition, Australian prevalence estimates

During the 1990s and early 21st century, epidemiological transitions[10] have resulted in a greater need for long-term physical and psychological community-based care[28] to meet the needs and preferences of aged and disabled people[3] who decide to stay in their own homes[6,7]. This trend continues to increase globally, particularly in developed countries such as the United Kingdom (UK) and Europe, Australia, New Zealand (NZ), Canada, the United States of America (USA) and other industrialised nations[2, 29-33].

The Disability Ageing and Carer Surveys, conducted nationally by the ABS every three to five years since 1993, have collected data on persons providing informal caregiving in domestic (family) homes in all states and territories and across urban, rural and remote areas of Australia.

Definitions used for an informal carer are:

> **Carer:** A person of any age who provides any informal assistance, in terms of help or supervision, to people with disability or long-term conditions or people who are aged 60 and over. This assistance has to be ongoing, or likely to be ongoing, for at least 6 months… these carers are referred to as an "informal carer".
>
> **Primary carer:** A person is a "primary carer" if they are aged 15 and over and provide 'the most informal assistance, in terms of help or supervision, to a person with one or more disabilities or aged 60 years and over' in one or more of the core activities of self-care, mobility and communication[34].

Previous ABS population surveys of disability in 1981[35] and 1988[36] were initially focused only on the aged and persons with a handicap (as it was referred to then) and were not inclusive of informal carers as a separate, identifiable group. By 1993, informal caregiving was briefly mentioned, with just over a half a million (577,500) people identified as the '*principal'* carers of persons (approximately 3.3% of the total population and 5% of the population aged 20 years and over)[37]. Published prevalence estimates fluctuated during the 1990s with different surveys, methodologies and definitions providing varying estimates[38]. Prevalence estimates of all informal carers remained around 12% of the total population between by 2009 and 2015[21,22].

Nationally, the latest SDAC published by the ABS in 2016, (representing data collected during 2015)[21], indicated almost 2.7 million individuals, or approximately 11.6% of the Australian population aged 15 years and over, were identified as informal carers, most of whom (96%) were family members[21]. While SDAC data identify all carers, the proportion of primary carers or those who provide the most informal assistance, were examined in ABS surveys, particularly after 1998. Findings showed a steady increase of 19% to over 30% of informal carers being primary carers during the two decades from 1998[38] to 2016[26] however, initially, the increase was partly attributed to the change in definitions for the 1998 ABS survey[38].

Since 2005, informal carers have been identified separately as part of another large national survey, Household Income and Labour Dynamics in Australia (HILDA), administered by the Melbourne Institute of Applied Economic and Social Research[39]. HILDA surveys differ slightly in their terminology, referring to main carers, who are considered similar to the SDAC primary carers. Having been given specific recognition, greater understanding of the demographic profiles of persons providing care in the community has been possible.

2.6.1 Demographic characteristics of informal carers

According to demographic information from HILDA data collected between 2005 and 2011[39], women were more likely to be the main informal carer, providing the majority of home support and meeting care needs. The 50-70 age group were providing the greatest amount of informal care, with more than 10.0% caring for an elderly individual[39]. There were also consistently more females than males in the role of an informal carer (60-70%) identified in ABS surveys (Figure 2-6), with male informal carers accounting for 30-45% of all informal carers.

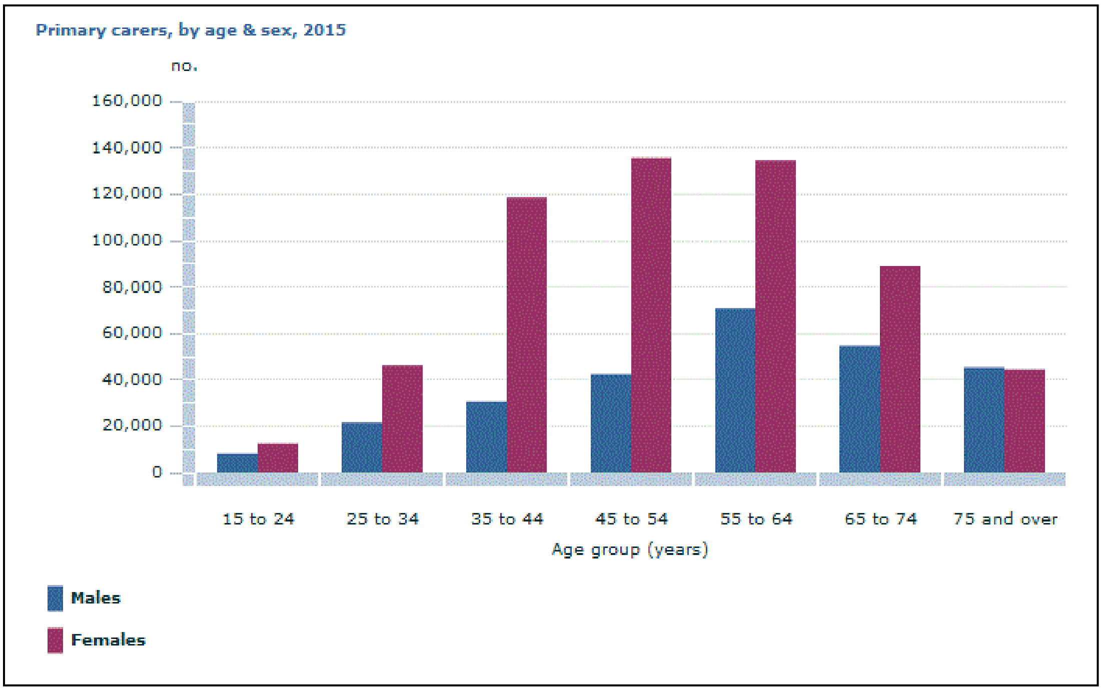


Figure 2.6 Primary Carers by age and sex, 2015. [By definition, primary carers are aged over 15 years]

Source: ABS Survey of Disability, Ageing and Carers: Summary of Findings 2015. Australian Bureau of Statistics, Commonwealth of Australia [21]

Similar gender characteristics of informal carers were reported in recent SDAC surveys[21], with significant variations according to their age, and the type and age of the cared-for person. In the 2015 SDAC survey, the average age of informal carers was 55 years[21].

The 1998 SDAC survey revealed a third (38%) of informal carers aged between 35-54, cared for partners, children and ageing parents[38]. Since the 2012 SDAC survey, with the availability of more comprehensive demographics identifying the primary informal carer, the cared for person was more likely to be a spouse or partner, but 43% had a different relationship with the care recipient[40]. Persons representing younger age groups, aged 45-65 years (14%), identified as the primary informal carer, reported looking after a co-resident parent, and 13% aged 25-44 years were caring for a child with special needs. Women were four times more likely to be the main informal carer (32.5%) compared with men (7.0%)[40]. In those instances where the person receiving the care did not live with the person identified as the primary informal carer, it was found 67% were caring for a parent[40].

Providing long term informal care has been identified as reducing employment opportunities for informal carers, particularly those persons who have a primary caring role[40]. For example, in 2009, only 54% of persons in this category were in paid work compared with 79% of the general population, even though they wanted to be in paid employment[41]. In the 2012 SDAC[40], a labour force participation rate of 63% for informal carers, compared with 69% of non-carers, was revealed. It was lower for persons in a main caring role (42%) but these differences were influenced by increased hours of informal care required in the home, as well as the presence of older age groups within the carer population who were not of working age[40]. The influence may also be due to the educational status of the adult informal carer. As reported in the 1998

SDAC, 20% of the carers had vocational qualifications and 12% had bachelor or higher degrees[40].

Gender differences between primary informal carers who work were evident from the 2012 SDAC survey[40], with over a quarter (27%) of men employed full time, in contrast with 14.6% of females. When considering part time work, fewer male carers (11%) were employed part-time than female carers (23.9%), while unemployment was higher among male informal carers (7.3%) compared with non-carers (4.8%)[40]. Providing informal care also had an association with annual household incomes[34,38,40]. For example, the 2012 SDAC survey[40] reported 65% of persons in primary informal caring roles were more likely to live in households with gross incomes in the lowest two quintiles of income. This compared with 36% of non-carer households. At the opposite end of the scale, while 23% of non-carers ranked in the highest quintile of gross household income, only 7.0% of persons in a primary informal caring role had equivalent incomes[40].

A changing demographic among persons in an informal caring role is their country of birth. Early SDAC surveys during the 1990s identified it to be more likely that informal carers were Australian or from English speaking countries[34]. However, HILDA surveys conducted between 2005 and 2011 have indicated that immigrants from English-speaking countries were less likely than persons from non-English-speaking countries to be informal primary carers[39]. Over the same period, non-English-speaking immigrants surveyed nationally accounted for 22.8% of main carers, and 16.8% were non-carers[39].

From a previous South Australian epidemiological survey of informal carers[42], demographic characteristics revealed that the carers were more likely to be female, aged 65 years and over, married or in a de facto relationship. Persons in informal caring roles were less likely to be male, aged between 15 to 34 years or never married[42]. In terms of their educational status, informal carers were more likely to have left school before the age of 15 years and less likely to have a bachelor or higher degree; a trend that is slowly changing as general educational attainment across the population is improving[42]. Carers were also more likely to earn $20,000 and be less likely to have earned $80,000 or more per year[42].

2.6.2 Influences on prevalence estimates for informal carers

Age, being a partner or spouse and being a parent have associations with being an informal carer. The AIHW (2011) reported that between 1998 and 2009, the proportion of Australians providing both informal care and aged 65 years and over, had increased from 21% to 25% of the Australian population[22]. By 2015, the most common providers of informal care were people aged over 65 years of age[22]. This represented more than 618,000 persons in an informal caring role, of whom more than one-third were the primary carer (234,100 people), with over three quarters caring for a partner. Many of these persons had been providing care long-term, with 41% having been the primary informal carer for their current recipient of care for ten years or more[22]. Based on current trends, as the Australian population ages, it is estimated 56% of informal carers will themselves be aged over 65 years by 2030[43.] Older Australians have elected to remain in their domestic home in their later years. In 2015[22], only 5.2%

were living in residential care facilities. For those needing assistance at home, 70% of that care is provided by informal carers, such as partners, parents or the spouse[22].

While a spouse or partner has been recognised as providing informal care to more than one-third (35%) of all older Australians needing assistance[22], there is a growing awareness of the role of a parent(s) as the primary informal carer of an adult child. While younger parents are known as the main informal carer of a disabled or sick dependent child, the ABS reported in 2009[22] that of the mothers and fathers who were the main informal carer for their disabled child, 6.5% were aged over 70 years[22]. From a separate 2012 report by Qu et al.[44] based on this ABS data, it was found that among persons with a severe disability who were aged over 35 years, 86% were living with one or both parents who were aged 65 years or over[44]. Many older parents caring for adult children with a disability have reported facing personal physical difficulties and anxieties associated with their capacity to continue to provide care in old age, especially when they want to retire[45,46]. They also worry about when they die their adult child surviving them will still need care[44].

In South Australia, due to population ageing, there is estimated to be a 160% increase in older people requiring informal care as well as home support and respite care by 2031, but the number of available informal carers may only increase by 57%[43]. Knowing the health status of an informal carer is necessary to ensure that they are capable of continuing their caring role.

2.7 Informal caregiving and carer health

Literature related to the provision of informal care has consistently reported persons in this role are at risk of health problems associated with the burden of caregiving[47-52]. The informal caregiving role has been aligned to the detrimental physical health of an informal carer, with associated adverse health outcomes[53-55]. Informal carers have been found to be at risk of a range of physical health conditions[56,57], including CHD[58] and hypertension[59,60]. A number of authors have further suggested that informal caregiving could be considered an independent risk factor to the health of caregivers[61-63].

An overview of the research findings related to the impact of the caregiving role on the physical health of the informal carer, however, have been mixed. In the late 1990s, Lee[64], who reviewed the caregiving burden, health, stress and coping in women in a large scale longitudinal study, concluded there was only weak evidence of increased risk of major illness and reduced physical wellbeing in informal carers. However, Lee pointed out at that time that much research overlooked social and cultural issues associated with assumptions surrounding caregiving as women's work and their coping abilities, rather than focusing on public policy aspects of informal caring. From another perspective, Pinquart and Sorensen[65], Fredman et al.[66], Vlachantoni et al.[67] and O'Reilly et al.[68] have since argued that informal carers have lower rates of mortality than non-carers. Other authors[69,70] have questioned how providing informal care is perceived and reported, challenging the persistent negativity that surrounds the role of an informal carer. For example, Roth et al.[69], and Brown and Brown[70] argued for a more balanced view and a reappraisal of informal caregiving so as to provide evidence of benefits and negatives of this role[69].

An early prospective population-based cohort study between 1993-1998 by Schulz and Beach[61], which had linked large American Nursing and Allied Health data bases, claimed a higher mortality risk for the spouse as an informal carer, with no discussion about any positives. Appraisals by several authors[69,70] of this type of published research on the health consequences of being an informal carer, were critical of inconsistent findings and an imbalance in presenting positive outcomes from the role[69]. Brown and Brown[70] believed a negative approach to informal caregiving had been so widespread it had influenced how the role was being communicated, not only in academic circles but also across government and advocacy agencies[70].

O'Reilly et al.[68] suggested that the positive aspects of informal caregiving on carer health may have been under-reported, citing results from a four-year longitudinal population-based study following the 2001 Northern Ireland Census. Findings from the Irish study indicated informal caregiving reduced mortality risk for most caregivers, and that mortality was lower in women in the role of an informal carer, in contrast with men in this role[69]. Dich et al.[71] suggested that the amount of informal caregiving required, if contained, could have a protective effect against mortality but added that, as demands intensify, the impact on the health of the informal carer also increases.

In terms of age differences in carers, Lovell et al.[72] observed that younger, healthier carers with access to support did not have to contend with the physiological challenges and declines associated with ageing. O'Reilly et al.[68] aligned the effect of the extent of the informal caregiving role and the health of an informal carer as an indicator of physical capability to maintain a significant caregiving role. Pinquart and Sorensen[65] and Vlachantoni et al.[67] discussed a healthy caregiver effect, suggesting that healthier individuals were more likely to take on the informal caring role[67,73,74]. Bertrand et al.[75] presented the argument that the healthier the person, the more likely they were to be an informal carer, further developing and proposing a 'Healthy Caregiver Hypothesis'. Roth et al.[76] found that informal caregivers had an 18% survival advantage in comparison with matched non-carers, while Brown and Brown[70] similarly referred to informal carers as possibly having a health advantage. Brown and Brown[70] however, criticised the applicability of the 'Healthy Caregiver Hypothesis' to the real world, as the Caregiver Study of Osteoporotic Fractures used by Bertrand et al.[75] was based on cognitive outcomes in a subsample of women aged mostly over 80 years old[70] and specific to the stress process model of Aneshensel et al.[77].

In a study reporting positive aspects of informal caregiving[78], informal carers described companionship, feelings of fulfilment, and satisfaction from their role as being positive outcomes. Cohen et al.[78] suggested that these positive feelings may have had a buffering effect on some of the negative consequences of the informal caregiving role and, as such, informal carers were less likely to report depression, burden or poor health. Ratcliffe et al.[79] investigated the positive impact on the quality of life experience of informal carers among a representative sample of 679 South Australian community-dwelling adults aged 65 and over. Their population-based, state-wide survey in 2009, based on face-to-face interviews, found that the quality of life of informal carers was higher than that of non-carers.

The research by Ratcliffe et al.[79] also indicated informal caregiving could have a mediating effect on negative aspects associated with the burden of informal care, especially for those carers who perceive their caring role as rewarding and providing a positive side to life. Other research of informal caregiving, based on psychometric assessments of persons in these roles, has highlighted poorer mental health outcomes[80], stress[81], distress[82], anxiety[83] and depression[80,84-86]. Depression has been reported more frequently amongst informal carers looking after adults with cognitive problems and dementias like Alzheimer's disease, severe mental illnesses such as schizophrenia[87], or autism spectrum disorders[80].

It is emphasised that the capacity of a person in an informal caregiving role to meet the needs of a cared for person is very different to the capacity required in the reciprocity expectations amongst adults within personal relationships[8,9]. Research into the impact on the health of an informal carer due to the requirements of their caregiving responsibilities, as well as the negative and positive outcomes of maintaining their role, have been varied. These understandings focus attention on how informal carer health assessments are undertaken, both at a self-reported and biological level.

2.8 Investigating informal carer health using self-reported methodologies

To critique how the physical and psychological health of an informal carer and the impact of the role of informal caregiving are measured and limitations identified, Deeken et al.[88] provide an organising structure. The sub-headings for the critique of self-reported methodologies include: 1) informal carer burden, 2) quality of life and wellbeing and 3) general health status. The review below will be presented under the same headings.

2.8.1 Informal carer burden

Informal carer burden has been described in terms of the objective demands of the caregiving role and the subjective impact of these demands on the informal carer[88]. Despite that, there is no specific definition to measure informal carer burden which, according to Mosquera et al.[89] and Bastawrous[90], has been problematic and led to different ways to measure burden and interpret the results. In their clinical review, Adelman et al.[91] commented that there was no formal classification code for caregiver burden in the International Classification of Diseases (ICD-9 or ICD-10)[91]. As well, the authors[91] identified a lack of taking into account the different thresholds for triggering burden, given the varied circumstances and tasks inherent in the role of an informal carer. Concerns have also been raised that despite the variety of 'tools' that are available to measure general burden and lifestyle changes, not all have been validated to assess caregiving[89]. In their systematic review, Mosquera et al.[89], identified 93 instruments (in English and other languages), most of which were used to measure the impact of caregiving for elders on informal carers[89].

Studies that have used large population surveys to investigate the exposure to caregiving and its impact on physical and mental health include the British Household Panel Survey from 1991-2000[82]. In this survey, it was found that informal carers who provided longer hours of care (for example between 20 and 100 hours per week) had raised levels of psychological distress; women more so than male carers. In the 2001 UK Census, Doran et al.[92] found carers of all ages were providing in excess of 50 hours of care per week. This included elderly pensioners and even the oldest carers aged over 85 years, as well as individuals at the other end of the age spectrum, with young carers, some aged under 15 years. A third of these informal carers rated their health as "not good"[92].

A UK Census-based project by Legg et al.[63] studied the association between informal care provision and self-reported health status of UK informal caregivers and the likelihood of caregiving as an independent risk factor for poor health. Rather than using a subset of the caregiver population, which was an established method, the study used data from the whole UK population in the 2001 Census. The findings identified informal care to be a complex and dynamic chronic exposure and showed there was a dose-response relationship between carers providing the highest number of hours of care (more than 20 hours/week) and reporting the worst health[63]. The study referred to carers as being exposed to physical or psychosocial stressors which could be interpreted as occupational hazards and concluded that there was an independent association between informal caregiving and self-reported health[63].

Smith et al.[93] investigated the relationship between time dedicated to informal caregiving and the mental and physical health of informal carers from an English national population survey, the Adult Psychiatric Morbidity Survey of 2007. Weekly caring hours were recorded by the sample of 1,883 carers, who were also assessed for the presence of chronic physical conditions and perceived general health status. Differences in mental health amongst those providing 10 hours or 20 hours per week were reported and distress reached abnormally high levels in those informal carers who gave the greatest number of hours, which could be 100 hours or more per week. Overall, the survey findings indicated there could be a dose-response between the amount of caregiving and informal carer health outcomes[92,93].

2.8.2 Quality of life and wellbeing

The 36-item short-form health survey instrument (SF-36)[94], with subsequent variations of the instrument, has been used to measure health-related quality of life (HRQoL) of informal carers and has been reported extensively in the literature[95-101]. More recently, the concept of wellbeing has been used as a tool for informal carer assessment[102]. However, wellbeing and similar instruments only measure limited aspects of carer health, which do not include objective physical health assessments specific to disease states or actual illnesses. As reported by Page et al.[95], of the instruments available, very few were appropriate to measure the quality of life of an informal carer specific to their caring for persons with particular neurodegenerative conditions like Parkinson’s disease, Muscular dystrophy, Motor neurone disease, Huntington’s disease, and Alzheimer’s disease[95,99]. Other research assessing the health status of cared-for persons often failed to provide equivalent or adequate appraisals of the health status of informal carers[118].

The Health and Wellbeing study of Australian informal carers, a supplement to the larger Australian Unity Wellbeing Index surveys[102] collected data on over 500 carers. It was conducted co-jointly by Carers Australia, Deakin University, and Australian Unity. When compared with the general population, informal carers were shown to have the lowest (collective) level of wellbeing scored by any group across a wide range of social indicators. The survey included five main outcome measures that scored seven aspects of personal life (for example health, personal relationships, standard of living, achieving in life, community connectedness, and safety and future security). Additional measures included assessment of anxiety, stress and depression. Informal carers were more likely to experience moderate depression, financial stress (carers' average household incomes were lower than the general population; 20% were unemployed), carry an injury and/or suffer physical pain. Many self-reported not obtaining medical care due to lack of time or were not able to afford treatment[102].

Three population surveys in European countries between 2004 and 2014 provided information relating to the social determinants of the health and wellbeing of informal carers from across a range of European countries[103-105]. Verbakel et al.[104] identified that 7.6% of the carers from the European Social Survey of 2014 were providing intensive care for a minimum of 11 hours or more per week. This group, mostly women aged 50-59, reported lower mental health and wellbeing than non-carers. An earlier longitudinal population cohort study of 7,858 European carers aged 50 years and over, who were participants of the Survey of Health, Ageing and Retirement in Europe, were followed up over eight years in three waves from 2004 to 2011[105]. Reporting on the results in 2015, Hiel et al.[105] indicated that providing informal personal care to others was found to be detrimental to physical health. There was also a decline evident in carer mental health, which was more pronounced with the advancing age of the carers.

A later survey in 2018 by Ludecke et al.[106] reported on findings from a six-country European longitudinal study, which surveyed 3,348 family carers aged 65 years or older as part of the EUROFAMCARE project. The needs of older European adults and their health outcomes were explored over one year. The findings indicated that it was the quality of the carer/care-receiver dyad (relationship) that predicted if informal carers continued to provide care, rather than the impact of the age, education, or gender of the carer. This was despite informal carers providing high levels of caring hours or having difficulties with the person's dependency and care[106]. Although informal carers in Europe were perceived as being supported to provide long term care by governments, Hiel et al.[105] concluded that policy makers needed to be aware of increasing care demands on older carers. Therefore, assessment of informal carers' support needs were important to protect the health of carers, and to avoid an extra burden on the health system[106]. Ludecke et al.[106] also emphasised that cultural, religious and policy differences emerging from the different nations, were influencing attitudes to family caregiving.

Based on self-reported data, more studies of comorbidity in carers have appeared in the caregiving literature in recent years. Kim et al.[107], using their own measure, the Morbidities Index for Caregivers of Chronic Illnesses, studied the health status of family members looking after relatives with cancer. The carers were part of the National Quality of Life Survey of Caregivers in the USA, which assessed the impact of cancer on family members' quality of life. Using additional health status indicators, Kim et al.[107] found that carers typically had four or more medical conditions. The five commonly reported morbidities were hypertension, high cholesterol, heart disease, arthritis and chronic back pain. Kim identified older age and male gender in carers as strong predictors of specific medical morbid conditions[107,108].

2.8.3 General health status

The Behavioural Risk Factor Surveillance System (BRFSS) provides on-going population surveys of informal carers across various states of the USA[109-111]. The BRFSS utilises the Caregiver Module which is a population-based snapshot of caregiving experiences, demographics and health behaviours[110]. The Module was developed specifically to evaluate attributes of adult caregivers who provide care for an individual with a chronic condition or disability, usually aged over 60 years[111]. Anderson et al.[112], describing informal caregiver characteristics in the USA in 2013 based on BRFSS data, found older carers reported lower mental distress and more satisfaction with life, compared with younger carers. However more, older, informal carers rated their health as fair or poor and experienced more physical problems than the younger group[113]. The BRFSS has been able to provide more comprehensive comparisons between caregivers of people living with dementia and carers looking after persons with cancer, heart disease, diabetes, arthritis and stroke[111,114].

Trivedi et al.[115] reported on findings from a large nationally representative survey of 438,712 adults in the USA. Of the 111,156 informal carers identified, most had good physical and mental health, but when the survey results were adjusted for gender and compared with non-carers, informal carers showed worse mental health[115]. For example, of the gender differences observed, male informal carers reported poorer overall health than non-carers while female informal carers had better overall health.
Ji et al.[116], in a prospective population-based study of 122,683 men and 161,287 women in Sweden looking after their spouses with cancer between 1987 and 2009, found an increased risk of CHD and stroke in informal carers.

Commenting on Ji et al’s study[116], which had retrieved data from multiple nationwide Swedish registers, Schneiderman et al.[117] raised the possibility of shared lifestyle factors contributing to the excess cardiovascular risk reported in Ji et al’s spouse carers. Although previous meta-analyses studies had also indicated unhealthy lifestyle behaviours such as smoking, alcohol, diet and obesity were considered as risk factors for both CVD and stroke in the spouse carers, Ji et al’s findings suggested that the psychological stress associated with caring for a person with cancer was a more plausible explanation for CVD and stroke in informal carers.

From a national health survey in Brazil, the 2012 National Health and Wellness Survey of 10,853 respondents, Laks et al.[118] found 53% of the carers were female. When compared with non-carers, the informal carers were shown to have worse co-morbid outcomes and were more often obese, smokers, reported diabetes, depressive symptoms, anxiety, pain, insomnia and hypertension.

Most studies reporting on informal carer burden, quality of life and wellbeing, and general health status results were based on self-report data. Often the methods were limited to small numbers, unrepresentative samples, or limited to specific carers (e.g. disease specific). Most significantly, there was a lack of observed and clinical data, which in some instances can reflect recall biases among the participants[87]. There is also an emerging trend for surveys to be conducted on the Internet, a weakness which, according to Gupta et al, might mean inflated numbers of younger caregivers participating, rather than older informal caregivers[87].

2.9 Investigating informal carer health using biomedical methodologies

Studies of informal carer health status conducted at the population level, which incorporate detailed clinic / blood-measured variables, have been limited. Biomedical variables featured in the caregiving research literature have predominantly included blood pressure[60], the individual's height and weight to calculate BMI[119], and, more recently, serum cholesterol[120]. There has also been an emphasis on immunological research, studying allostatic load and stress-related biomedical studies of carers, which investigated pro-inflammatory biomarkers such as Interlukin-6 (IL-6)[121,122], C-Reactive Protein (CRP)[26,123] and TNFα[26,124].

2.9.1 Inflammatory biomarkers

Longitudinal studies of biomarkers such as CRP and other markers of inflammation were conducted by Von Kanel et al. in 2012[26] and 2014[73]. In an earlier investigation in 2006, Von Kanel et al.[125] found little difference in CRP plasma levels between 116 recruited caregivers aged over 55 years of persons with Alzheimer's disease and 54 non-caregivers, control-matched for age and gender. However, in the 2012 longitudinal study, Von Kanel et al.[26] reported elevated CRP levels among their sample of recruited carers (n=118). That study did show notable increases in CRP levels of carers when examined over a five-year period, which indicated an association between CRP and a longer duration of care. Carers' CRP levels dropped when their caregiving ceased, after the death of the spouse, however the authors suggested it was not caregiver status that was associated with elevated CRP levels, but rather the number of years of caregiving[26,73]. The overall conclusions from their studies were that CRP was useful as a systemic marker of low-grade inflammation, which could indicate greater risk of atherosclerosis and CHD in carers[26,73].

Sherwood et al.[121] investigated the impact of psychological distress on inflammatory cytokines and systemic inflammation among a convenience sample of 108 carers of neuro-oncology patients over four, eight and twelve months. Informal carer participants were recruited from hospital neuro-oncology and neurosurgery clinics. Spouse carers identified with lower self-esteem and aged in their 30s were found to be 1.16 times more likely to have high levels of IL-6, but caregiving burden was not associated with raised IL-6 in carers aged 40 years and over[121]. In the same study, Sherwood et al.[121] found that elevated levels of inflammatory cytokines were evident in male carers with anxiety, but not with female informal carers, while, overall, informal carers with higher BMI also reported feeling burdened, and had higher cytokine levels[121]. Informal carers with BMIs within the normal range, although burdened, were less likely to have high cytokine levels. In this study, 10% of the informal carer participants had prior histories of diabetes, arthritis, cancer or CHD and a third had hypertension, suggesting that the presence of comorbid conditions, or the age of the carers, might have been the main factors influencing cytokine levels[121].

Studies of the physiological impacts of cumulative chronic caregiving stressors were found to be linked with downstream pathology, as investigated by Roepke et al.[126] and described in terms of stress theories and stress-related models by Vitaliano et al.[127] and Schulz and Sherwood[62]. Stress-related pathways, which feature the dysregulation of physiological systems[72] leading to health consequences and morbidity in informal carers, have been associated with immunological[72,73,76,121], metabolic[119,126,127], endocrine and neuroendocrine[128] changes. Vitaliano et al.[127] reported stress in informal carers to be linked with the metabolic syndrome and CHD. Caregiving and chronic stress have been further explored in terms of altered allostatic load (AL)[126,127], which can be an early indicator of disease risk[73, 125, 128]. AL is a construct developed by McEwen and Stellar[129] to explain the relationship between chronic stress and disease. It uses ten physiological indicators to represent cumulative damage throughout the body. The first six variables are frequently used in general biomedical studies: (1) systolic and diastolic blood pressure; (2) waist-hip ratio; (3) high-density lipoprotein (HDL); (4) cholesterol; (5) total cholesterol-HDL ratio; (6) total glycosylated haemoglobin. The remainder of the variables of allostasis are usually confined to more complex immunological stress-related research[126]. The majority of studies with informal carers who were frequently chronically stressed reported increases in these variables[73,126,129], particularly in persons providing informal care to people living with dementia[130,131]. Roepke et al.[126] suggested gender was significantly associated with AL, with male carers showing elevated AL in comparison with female carers[126].

Kiecolt-Glaser et al.[122] in a longitudinal study in 2003, and Gouin et al.[132] in 2008, investigated physiological dysfunction and chronic stress as a risk factor to the health of informal carers. Participants included both current and past informal carers (aged over 55 years) who had a spouse with dementia[122]. Based on immunological data, when informal carers were compared with non-carers, they found a four-fold overproduction of pro-inflammatory cytokines (such as IL-6)[122]. Amongst both current and former informal carers there were no significant changes in the IL-6 levels, indicating there were sustained effects on informal carers, even after the cessation of caregiving.

Von Kanel et al.[125] had reported similar findings of raised IL-6 amongst stressed older informal carers caring for persons with dementia, putting them at risk of CVD, health decline and frailty[125]. They suggested age had accounted for most of the relationship with elevated levels of IL-6. In a later study in 2012, von Kanel et al.[26] reported deleterious longer-term effects of informal carer stress based on raised CRP levels, which increased over time with the more years of caregiving, suggesting a link between caregiving and the presence of low-grade systemic inflammation[26].

2.9.2 Biomarkers to assess metabolic risk factors

As recently as 2018, a range of metabolic biomarkers were featured in representative population-based projects based on the UK Household Longitudinal Study of informal carers aged 16 years and over[120]. From a study of over 9000 participants, Lacey et al.[120] investigated links between informal caregiving and metabolic markers. The findings revealed higher total cholesterol levels in male and female informal carers, with females providing intensive informal care shown to have raised triglyceride levels and lower HDL cholesterol. Using these markers, Lacey et al.[120] argued informal caregiving to be associated with less favourable lipid profiles and therefore associated with greater risk of disease. In another study, Lacey et al.[119] reported on results of 20,700 participants from the same UK Household Longitudinal Study, showing informal caregiving also to be associated with markers of adiposity (BMI and waist circumference). They noted that among women, especially the younger female informal carers, had increased waist circumferences and BMI in comparison with non-carers. Increasing adiposity was associated with both caregiving intensity and increased hours of caregiving, suggesting greater risk of disease to carers[119].

2.9.3 Issues re biomedical and physiological studies

Research on carer morbidity, as described above, has provided valuable but mixed biomedical results. By necessity, costs can be prohibitive for conducting long term biomedical clinically-based research with large sample sizes, therefore studies are often smaller, with participants drawn from convenience samples rather than by random sampling. Problems may also arise when matching non-carers for control groups. For example, if non-carers are from socially active volunteer samples, they might not be suitable to represent (match) individuals from the informal carer sample[69]. Roepke et al.[126], Gupta et al.[87] and particularly Roth et al.[69], referred to convenience samples of informal carers who could be healthier in comparison with the wider caregiver population. This was because individuals (informal carers) who volunteer and consent for research projects were considered to be more active and healthier[87]. This may be a weakness and could influence or bias research findings based on data from those individuals.

Exclusion criteria can pose dilemmas in biomedical studies, as informal carers of different ages and types take on the caring role irrespective of their own health status[54]. Furthermore, informal carer populations include vulnerable people living with their own disabilities and major chronic illnesses. Yet by excluding them as study participants, a proportion of informal carers are being overlooked. Imposing such exclusion criteria may be preferred so as to reduce confounding but if less complex, ‘healthier’ carers are selected for investigation, findings in relation to clinic and blood measured physiological biomarkers may not reflect informal carers who are not healthy.

Additionally, due to the ongoing and changeable nature of caregiving, physiological effects of long-term caregiving can take years to manifest before changes are evident when blood parameters are measured[26]. Thus when conducting clinical research with informal carers, longitudinal or prospective studies with adequate follow-up of informal carers are recommended[26,125,133]. This is in comparison to cross sectional designs which do not provide evidence of causal relationships between caregiving status and informal carer health[74] nor do they indicate the direction of cross-sectional associations[57,74]. Although conclusions about causality cannot be drawn from the findings, Roepke et al.[126], and Brehaut et al.[45] emphasise that “regardless of the causal pathways leading to poorer caregiver health, the results have implications for health providers and policymakers”[45].

2.9.4 Investigating informal carer health using multidimensional studies

Zhang et al.[134] took a multidimensional approach to health assessments using a comprehensive range of instruments that included 25 indicators of different health dimensions. Their longitudinal study compared chronic stress of informal carers with non-carers over a period of 18 months and combined psychosocial and biomedical aspects across five domains of carer health, which included gender as a possible moderator. Their conclusions were that, although a comprehensive assessment strategy was required to adequately measure these health domains in informal carers, it was important to incorporate a broader, more modern, view of health. However, the problem highlighted by Zhang et al.[134] was that this approach might not be realistic in some research settings. Further, they concluded researchers needed to be aware of both advantages and limitations when measuring their chosen health indicators, which can be influenced by chronic stress and gender, as both have relevance to health and longevity.

Of note in the Zhang et al.[134] study was the difference by gender. Based on their multidimensional study, assessing stress in 157 adults of whom half were informal carers of a spouse with dementia, they found male informal carers reported better physical health than males who were non-carers, but male informal carers had greater physiological risk. Female informal carers reported worse psychological and physical health than female non-carers, but their physiological risk was similar[134].

Mills et al.[135] found that men who cared for their spouse were at greater risk of CVD in comparison with female spouse carers. In their study of 81 male and female carers, they examined the effects of caregiving for patients with severe dementia (Alzheimer's disease) on disturbed sleep, coagulation and inflammation in the carers. This led to a view that the gender of an informal carer appeared to have different, but subtle health responses to the caregiving experience. From an earlier meta-analysis of over 200 studies which applied multiple methods, Pinquart et al.[84], also identified gender differences between informal carers in the area of personal care, reporting females provided more hours of personal care, and also carried out more caregiving tasks. They argue this may be reflected in women as informal carers showing higher levels of burden and depression, as well as lower levels of physical health and subjective well-being than male carers.

2.10 Contextualising informal caregiving: impact of social and political change

Although this thesis is not addressing policy, important implications emerge from policy and social changes implemented over recent decades, which impact the role of an informal carer and their health status. Maintaining employment to supplement living and caring costs, policies directed at influencing aged care and social support programmes, as well as effects of mental health reform, including the deinstitutionalisation of mental health services, all have potential to impact the health status of an informal carer.

2.10.1 The changes in paid work of informal carers

Among informal carers who stay in the labour force, a quarter or more have been reported to experience a detrimental health impact[136]. However, the health outcomes of informal carers who work in paid employment have been mixed, depending upon the age and condition of the cared for person, the health status of the informal carer and the country of residence[137].

A multi-site population-based study across seven countries at 11 urban and rural sites by Prince et al.[137] investigated working carers and family demands in the low-income and middle-income countries of Cuba, the Dominican Republic, Peru, Mexico, China and India. This large investigation also provided other examples of positive and negative aspects of carer employment status, including the benefits of work activities among carers of persons with dementia. Prince et al.[137] surveyed 673 informal carer dyads across the seven low- and middle-income countries and reported that informal carers reducing or giving up paid work due to informal caring responsibilities was associated with higher levels of carer strain (economic as well as health related). This was similar to findings from European countries, as part of the Eurocare project[137].

An earlier review of employed informal carers by Edwards et al.[138], examined the role strain and depressive symptoms experienced by informal carers of older people who had cognitive impairment. The research described how holding "dual positions" of worker and carer, could lead to role strain, but that employment also provided an outlet or relief from caregiving for people with dementia. It was found that employment could compensate for reduced social contact and resources.

A large prospective cohort study by Dich et al.[71] reported that people with the highest number of demands at work and home have the highest rates of absence from work due to sickness. Referred to as the Whitehall II cohort study[71], it investigated the effects of work and family on 7,007 British civil servants, revealing that those who were informal carers with a low caregiving burden reported better health status than workers who were non-carers. However, a higher caregiving burden was associated with more hours per week providing care to an aged or physically disabled relative[95]. This was measured by AL levels to indicate any physiological dysregulation. The study argued that work-related factors could exacerbate the impact of caregiver burden, adversely affecting health behaviours in some carers, such as increased frequency of alcohol consumption and smoking. Conversely, it was reported that a proportion of informal carers were more likely to quit smoking when job demands were lower. Secondly, informal carers did not reduce their exercise, rather their caregiving role altered their free time and there was increased physical activity associated with the everyday caregiving activities.

A report about older informal carers and paid work, released in 2013 by the National Seniors Productive Ageing Centre (NSPAC), and National Seniors Australia[139], described many adverse consequences experienced by informal carers who undertake paid work, including absences from the workforce, financial stress, and poor physical and mental health. Those informal carers providing longer hours of caring were found to have a dramatically higher prevalence of mental health problems. This was similar to findings from the French Gazel cohort study which revealed greater cognitive problems among informal carers compared with non-carers[74]. In the NSPAC and National Seniors Australia report[139] it was found that among informal carers aged 45-74 years, 31% had an illness, injury or disability themselves. Almost half (47%) of informal carers had responsibilities that prevented them from working, while others reported difficulties attending work-related training, developing skills or seeking employment without flexible work hours.

Verbakel et al.[104] observed in the European Social Survey of 2014 that middle aged women in particular were “time squeezed”, as they combined the demands of informal care with paid work. The same report referred to this group of informal carers being targeted in employment policies to increase their participation in the labour market. The European studies of informal carers are therefore reflective of the important social and political changes that have been impacting on community care, aged care and other government policies during the past 10-15 years, which have influenced the wellbeing of caregivers, such as those belonging to the OECD countries[140-142].

2.10.2 Ageing-in-place, and reform strategies

Informal carers have been actively promoted as part of ageing-in-place policies but, at the same time, repositioned away from the welfare state[31,143]. Kroger and Leinonen[142] described the situation in Finland, referring to these changes as a weakening of the familiasation of family carers, where the responsibility for caring for disabled and frail elderly individuals was increasingly placed on the family. In France it is referred to as the familialist home care model[144]. Newer forms of informal care have been developed in France as part of a larger sector named “personal services to support home-based care”[144]. This complex process of formalisation of care through cash payment recognises informal care as work, although the care work is still provided predominantly by informal and semi-formal carers.

Other policy changes influencing informal carers include aged care and social support programmes in developed countries such as Canada[31,32,145], where family caregivers were, and still are, expected to take on greater responsibility for domestic home-care. Similarly, governments of Finland[142], Denmark[141] and other European countries such as the Netherlands[143] have introduced cost containment policies to circumvent anticipated shortfalls in health and community services, but to achieve this, informal caregiving has been shifted back into the home setting[142-144]. A succession of market-inspired reform strategies and social policies have continued to influence long-term care, aged care and disability support, with further decentralisation of domestic home care services[142,146].

Additional financial strain is being placed on informal carers with the introduction of cash-for-care schemes, for example in France[144], UK[146], Austria[147], Italy[148] and most recently in Australia[149]. The phasing out of collaborative State and Federal government schemes for aged care and carer support, previously for all types of informal carers, is also in progress in Australia[149]. Limited support for informal carers of persons with disabilities may be included within the National Disability Insurance Support Scheme (NDIS) but informal carer needs and supports are not yet fully incorporated into NDIS packages as funding is directed to the person with the disability[149-151].

2.10.3 Deinstitutionalisation of mental health services

Added to recent policy changes impacting aged care and disability support services, has been the ongoing effects of mental health reform in Australia and many other countries, which started during the early 1990s with the deinstitutionalisation of mental health services. This reform has moved some aspects of psychiatric support away from formal institutional care and, in turn, has impacted on family carers[152].

According to Schene et al.[152], family members have had to learn to cope with their relatives with severe mental illnesses involving dysfunctional behaviour, which was previously managed at institutional level. Although family burden has been acknowledged in studies of relatives coping with psychiatric disorders from the late 1950s[153-156], the later introduction of community psychiatry, in parallel with community care policies, was based on the market-driven concept of consumer choice[157]. Thus, with more persons living with mental illness, as well as people with physical disabilities now living in the community, by the turn of the twenty first century responsibility for long term care was increasingly shifted onto spouses, partners, parents and other unpaid familial carers[152].

In a two-country study, Boyer et al.[157] measured the quality of life levels of carers of people living with schizophrenia in both France and Chile, representing a developed and developing country respectively. Findings showed that SF-36 scales were low for both groups. In France, as psychiatric institutions discharged people with mental illnesses into the community, families had to take on many of the therapeutic roles previously carried out by psychiatric establishments before they closed. The problem with early discharge to home-based care was compounded when relatives, primarily mothers, took over responsibility for their care, as there was little or no support provided for the families. The consequences of this burden on informal carers was also reported in other literature[51,158], which confirmed the greater impact of looking after family members with psychiatric illnesses on the mental health of carers themselves[51].

In an earlier comparative study of carer burden with Dutch informal caregivers between 2001 and 2002, Hastrup et al.[158] investigated the extra burden of carers looking after individuals with a mental illness (or those with a combination of mental health and somatic conditions), and caring for people only with somatic illnesses. Their findings suggested carers of the individuals with mental illness experienced higher subjective and objective burdens (using an HRQoL measure), in contrast to caring for persons with somatic illnesses. The impact on informal carers was compounded if the cared-for person had a combination of mental and somatic illnesses, as it magnified the difficulties experienced by the carers, especially if they were co-resident with the cared for person[51,158].

2.11 Summary

From this review of informal carer health research extending from the 1980s to 2018, issues of risk to the health of informal carers associated with their caregiving roles have been described. Findings from three decades of caregiving-related research have consistently provided evidence that a proportion of informal carers do show adverse health outcomes, poorer wellbeing, lower health status and QOL than non-carers. Thus, while providing vital caregiving to other sick and dependent individuals, between a quarter and a third of the informal carers may be functioning with less than optimum health due to their own chronic medical conditions or disabilities. This highlights how informal carers themselves are subject to a similar range of illnesses, diseases, disabilities and risk factors as the general population, but it does not necessarily suggest that their morbidity is directly attributable to their caregiving role or that more carers are unwell. Those factors remain unclear.

In terms of research into the usefulness and validity of these findings, from a review of the literature, what is of importance is firstly, the lack of evidence on what are the prevailing chronic health problems, risk factors and other serious medical conditions found among informal carers: to state that informal carers have poorer health outcomes is vague and has neither practical application in the clinical setting nor for future carer policy development. Secondly, despite the collection and analysis of extensive research data since the early 1990s, there remains a lack of stable and methodologically appropriate, epidemiological-sound studies that include empirical and observed assessments of informal carers' physical health.

So, despite nearly three decades of information describing the effects of informal caregiving, comprehensive data on informal carer physical health and morbidity evidence is still lacking, particularly from an empirical perspective. Raising concerns such as these has focused attention on how research has been conducted into the health of an informal carer, which, in turn, has determined the research direction of this thesis.

The aim of this research was to explore informal carers' health status. The main objectives were to determine prevalence estimates and trends of chronic health, health-related risk factors and chronic medical conditions of carers compared with non-carers, using both self-reported and biomedical assessments. There are three main research questions.

- Investigates changes in prevalence and carer sociodemographic characteristics over the 20 year period from 1994-2014. The H_o hypothesis states: "There is no increase in the prevalence of carers in South Australia".
- Investigate the association between the caregiving role as a risk factor for chronic disease and the health status of informal/family carers. The H_o states: "There is no association between the caregiving role as a risk factor for chronic disease in carers".

- Investigate whether family informal caregivers show differences in their biomedical health profiles compared to non-carers. The H_o states, “There is no difference between biomedical profiles of informal carers and non-carers”.

The following chapter outlines the methods used to address each of these research questions and how large representative populations of South Australian informal carers were used and compared with non-carers to determine prevalence estimates, trends of health-related risk factors and chronic medical conditions among informal/family carers. Both self-report and biomedical assessments were undertaken on informal carers and non-carers, using epidemiologically-sound data collection methods.

Chapter 3. Study Design and Methods

3.1 Introduction

Central to this project has been the two-fold argument based on international evidence, firstly highlighting issues of risk to the health of family and other informal carers associated with their caregiving roles, and secondly, gaps in the assessment and measurement of carers' biomedical and physiological health status. This thesis has taken a population view of carer health, accessing data from three population data bases. The research methods of the three studies, The Health Omnibus Surveys (HOS), The South Australian Monitoring and Surveillance System (SAMSS) and The North West Adelaide Health Study (NWAHS), are detailed in this chapter. Additional details are included in each of the three manuscripts (Chapters 4, 5 and 6).

3.2 Study 1: The South Australian Health Omnibus Surveys

The HOS refers to a user-pay, population-based, cross-sectional, representative survey[159,160] developed to obtain health related data for government, academic and non-government organisations involved in the South Australian health sector. HOS enabled the collection and analysis of data on a range of health issues that could be interpreted and used for health planning and monitoring of health programmes. The surveys were state-wide and undertaken during the months of October / November annually or bi-annually in South Australia from 1990 to 2017[161-163]. HOS was administered and conducted by Harrison Health Research, a member of Quality Control Australia (ICQA), and overseen by the Population Research and Outcome Studies Unit (PROS), initially in the Strategic Planning and Policy Division of the South Australian Department of Health and subsequently with The University of

Adelaide[161]. The HOS surveys were also overseen by a quality control committee chaired by PROS epidemiologists and users of the surveys[161,162].

Data used in the research for this first study were selected from nine annual HOS surveys between 1994 and 2014, when carers were identified, namely in 1994, 1998, 2000, 2001 and 2002, 2004, 2008, 2013 and 2014. Methods were the same for each survey[161-163], except where stipulated in the text. The surveys sampled individuals from over 4,400 households each time, and face-to-face interviews were conducted with participants. Interviewers were fully trained, with ten percent of their surveys selected for validation to ensure that respondents met the selection criteria within the household and responses were consistent with the respondents' original responses. The description of the main aspects of HOS methods for data collection are featured below and apply to all the surveys carried out during the twenty-year period of this study. Analysis and interpreted of the data are presented in the first paper, Chapter 4.

3.2.1 Sampling procedure

HOS sampling was developed in 1990 and conducted by PROS using the most rigorous sampling procedures[161,162]. The sample selection was multi-stage. Using a clustered sample approach for each survey, 77% of all the individuals in the sample were selected from the Adelaide metropolitan area, with the remainder being drawn from those country areas with a population of 1000 or more. This was based on ABS Census information[164]. Within selected metropolitan and country areas, the ABS Collection Districts (CDs) were the basis of the sample frame. The Census CD is the second smallest geographic area defined in the Australian Standard Geographical Classification[164].

Stage 1 - Selection of Collection Districts

Overall, 340 CDs (out of a possible 2041) were selected in metropolitan Adelaide, and 100 (out of a possible 1010) from the country areas. A randomly selected starting point and a fixed skip interval were used to determine which CDs were chosen from the sample frame. All CDs in the sample frame were listed in numerical code order, along with the number of dwellings in that individual CD and the cumulative number of dwellings for that CD. A random number between one and the skip number was chosen as the starting point for selections and the skip interval was then used to determine which CDs were to be selected. Once the skip interval had been determined, selection of an individual CD was dependent on the number of dwellings within that CD.

Stage 2 – Selection of households

The selection of households within CDs was similar to the selection of CDs. Ten households per selected CD were chosen using a fixed skip interval from a random starting point. Hotels, motels, hospitals, nursing homes and other institutions were excluded from the survey.

Stage 3 – Selection of individuals within households

Within households, the person who was last to have a birthday (aged 15 years or over) was selected to participate in the survey. The selected persons were non-replaceable, which meant that interviews were not conducted with alternative household members.

A minimum of six visits was made to each household before the selected individual was classified as a non-contact.

Self-weighting sample

The self-weighting sampling procedure of HOS ensured that every household within each of the two strata (metropolitan Adelaide and the major country towns) had the same probability of being selected, even though different probabilities of selection existed at each stage of the sampling process. The response rate to HOS over the 20 year period of 1994 to 2014, ranged from 72.4% in 1994, 70.2% in 1998, 65.9% in 2004, 62.8% in 2008, to 54.5% by 2014, usually with a minimum of 3000 interviews per survey completed.

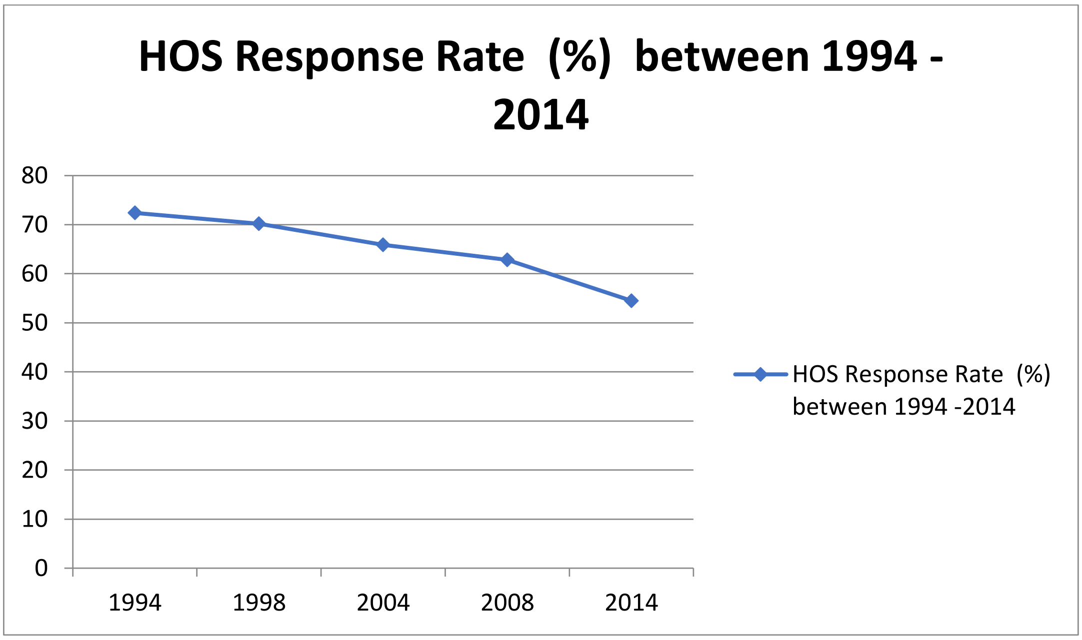


Figure 3.1 HOS Response Rates 1994-2014

3.2.2 Data Collection

HOS used a personal interview conducted by trained interviewers in each person's home. The questionnaire was designed to take approximately 30 minutes for respondents to complete. Interviewers read out the questions and, if necessary, prompt cards were used. The HOS survey data were weighted by age, gender and geographic location (metropolitan or country) to the most recent census data of South Australia or the most recent estimated residential population. Weighting corrects for any sample bias and provides estimates reflective of the South Australian population.

3.2.3 Variables

Standard demographic variables included in the surveys were gender, age group, marital status and country of birth. Socio-economic variables were the highest education level achieved; work status; and annual household income. The socio-economic disadvantage of neighbourhoods at an environmental level (using postcode) was determined using the Socio-Economic Index for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage (IRSD), from which quintiles were determined[165].

A question regarding informal family carers was not regularly included in every HOS but was added in 9 of the 20 years between 1994 and 2004. Two different questions were asked over that time in order to determine the prevalence of carers in South Australia and these are: 1994 and 1998: *"Are you a carer of a dependent person?" (A dependent person is someone who has a chronic condition that is unlikely to improve, for example frail aged, disabled etc).*

In the years 2000-2002, 2004 and 2008, 2013-2014 the question included was: "*Do you provide long-term care at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness, where long-term care is a minimum of 6 months and may extend into years*".

3.2.4 Data Analysis

Initial data analysis of the HOS cross sectional surveys was undertaken to determine trends in prevalence and changes in key carer socio-economic characteristics over the nine surveys. The crude prevalence of carers for each year, in addition to the age and sex standardised prevalences, were examined. Binary logistic regression analysis (unadjusted and adjusted) was conducted to show the association of being a carer with the various demographic variables over the three time periods, 1994, 2004 and 2014. Percentage differences were also calculated from the main socio-demographic variables for the two decades of 1994-2004 and 2004-2014. Demographic and socio-economic analysis was performed using STATA, Version 14 (StataCorp, College Station, TX, USA)[166] and Microsoft Excel.

Age Period Cohort

An age period cohort (APC) analysis was then undertaken to determine the effects of ageing, birth cohorts and time periods in relation to carer prevalence, using all nine years of data. For the APC analysis, "age" was the self-reported age of the respondents at the time of the survey interview and "cohort" was the age subtracted from the survey year. Age ranged from the oldest respondents (80 years and over) to the youngest respondents (aged 15 years). "Period" represented the total years of data collection.

Analysis of informal caregiving in South Australia was then prepared diagrammatically as line graphs representing rates (%) and rate ratios with 95% confidence intervals (CI). The estimated effects from the APC models for carers were calculated using STATA Version 14 (StataCorp, College Station, TX, USA) with the ‘apcfit’ command[166].

3.2.5 Ethical Approval

Ethics approvals for each year of the HOS were obtained from the Research Ethics Committee of The University of Adelaide (since 2010, approval number H-097-2010), and previously from the South Australian Department of Health Research Ethics Committee (approval number South Australian Health 310/07/2012). Ethical approval for access to HOS data to conduct this study was granted by the Office of Research Ethics, Compliance and Integrity, The University of Adelaide (HREC Number 19684).

3.3 Study 2: The South Australian Monitoring and Surveillance System

The South Australian Monitoring and Surveillance System (SAMSS)[167,168] was a representative state-wide population-based survey conducted using a computer assisted telephone interview (CATI). This epidemiological surveillance method was introduced in South Australia in 2002[169-170]. As well as updating prevalence estimates, socio-demographic and economic details, SAMSS was designed to provide data on key risk factors: physical and mental health variables that could be used for policy development[171]. The selection of SAMSS outcome variables were based on national and state priority areas, and related to national determinants of health. For example, the following health topics were included in the SAMSS questionnaire: arthritis / osteoporosis, asthma, COPD, CVD, diabetes, injury, depression/mental health and disability. Risk factors included cholesterol**,** blood pressure**,** height and body weight (for BMI)**,** alcohol consumption**,** nutrition, breastfeeding, food consumption, food security**,** physical activity**,** smoking and sun protection.

3.3.1 Sampling and data collection

A detailed history and description of SAMSS data collection is published elsewhere[169,170] and presented in Chapter 5. However, in brief, 600 randomly selected individuals of all ages were interviewed each month, with proxy interviews undertaken for children aged under the age of 16, where appropriate. Households were randomly selected from the Electronic White Pages and within each household the selected participant was the person last to have a birthday.

Data were collected using trained interviewers, who conducted the interview in English. CATI allowed immediate entry of data from the interviewer’s questionnaire screen to the computer database[169-171]. Over the period 2010-2015, which is the focus of this study, a total of 35,195 individuals aged 16 years and over participated. The overall response rate for SAMSS during 2010-2015 varied between 54.1% and 64.4%[170].

3.3.2 Data Weighting

Data were weighted using raking[172] by area (metropolitan/rural), age, gender, marital status, country of birth, educational attainment and dwelling status (rented property vs other) to the most recent South Australian population data and probability of selection in the household to correct for disproportionality of the sample and reflect the population of interest.

3.3.3 Covariates

Covariates included in the analysis were as follows. Respondents were asked if a doctor had ever told them they have and/or were currently receiving treatment or medication for HBP or high cholesterol. The time spent undertaking walking, moderate or vigorous physical activity over the past week was determined. The time was summed, with the time spent undertaking vigorous activity multiplied by a factor of two to account for its greater intensity. This provided an indication as to whether respondents were undertaking a sufficient level of physical activity to provide a health benefit. This is defined as 150 minutes or more of activity each week and has been categorised into insufficient inactivity (no activity, active but not sufficient) and sufficient activity[173]. BMI was derived from self-reported weight and height and classified as underweight ($<18.5 kg/m^2$), normal ($>=18.5<25.0$ kg/m^2), overweight ($>=25.0<30.0$ kg/m^2) and obese ($>=30$ kg/m^2)[174].

Data were also collected on smoking status (current, ex- or non-), short term and long-term alcohol risk (derived from the number of alcoholic drinks per day and the number of times per week alcohol was consumed)[175]. Also, participants were asked how many serves of fruit and how many serves of vegetables they ate each day, with the recommendation being at least two serves of fruit and five serves of vegetables per day[176].

Health conditions were related to national health priorities and included cardiac, respiratory, musculoskeletal and metabolic diseases[177]. Respondents were asked if a doctor had ever told them they had diabetes, CVD (heart attack, angina, heart disease and/or stroke), arthritis and/or osteoporosis. Asthma was defined as self-reported, doctor-diagnosed asthma and if the individuals and had experienced asthma symptoms in the previous twelve months. In addition, respondents were asked if they had ever been diagnosed by a doctor in the last year with depression, anxiety, or a stress related or other mental health problem.

Psychological distress was determined using the K10 scale[178] which consists of ten questions, all of which have the same response categories ‘all of the time’ (scored as a 5) and ‘none of the time’ (scored as 1). The ten items were summed to provide a score of between 10 and 50, with scores over 22 indicating levels of psychological distress. Disability was defined as physical, mental, or emotional problems or limitations that the respondent reported having in their daily life. Depression was assessed using the General Health Questionnaire[179,180].

The Short-Form-1 (SF-1) question was used as an overall health status indicator and asked participants to rate their overall health (excellent, very good, good, fair, poor)[94]. The carer question included was: "*Do you provide long-term care at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness?*".

3.3.4 Data Analysis

Frequencies and chi square tests were determined using SPSS Version 24 (IBM, Armonk, NY, USA). Univariable and multivariable regression was undertaken using the "svy" commands in STATA Version 14 (StataCorp, College Station, TX, USA)[166] to determine crude and adjusted OR. Population attributable risk was determined using STATA and the "*punaf"* add-in command to examine risk of caregiving to six chronic conditions (diabetes, asthma, CVD, arthritis, osteoporosis and mental health)[181].

For each of the chronic conditions, five models were created to determine the RR and subsequently calculate the PAR of being a carer. Model 1 was unadjusted, Model 2 adjusted for sex and age, Model 3 additionally controlled for educational attainment, income and work status, Model 4 additionally controlled for HBP and high cholesterol, and Model 5 further adjusted for sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity. The PAR analysis was undertaken overall and then stratified by males and females.

3.3.5 Ethical Approval

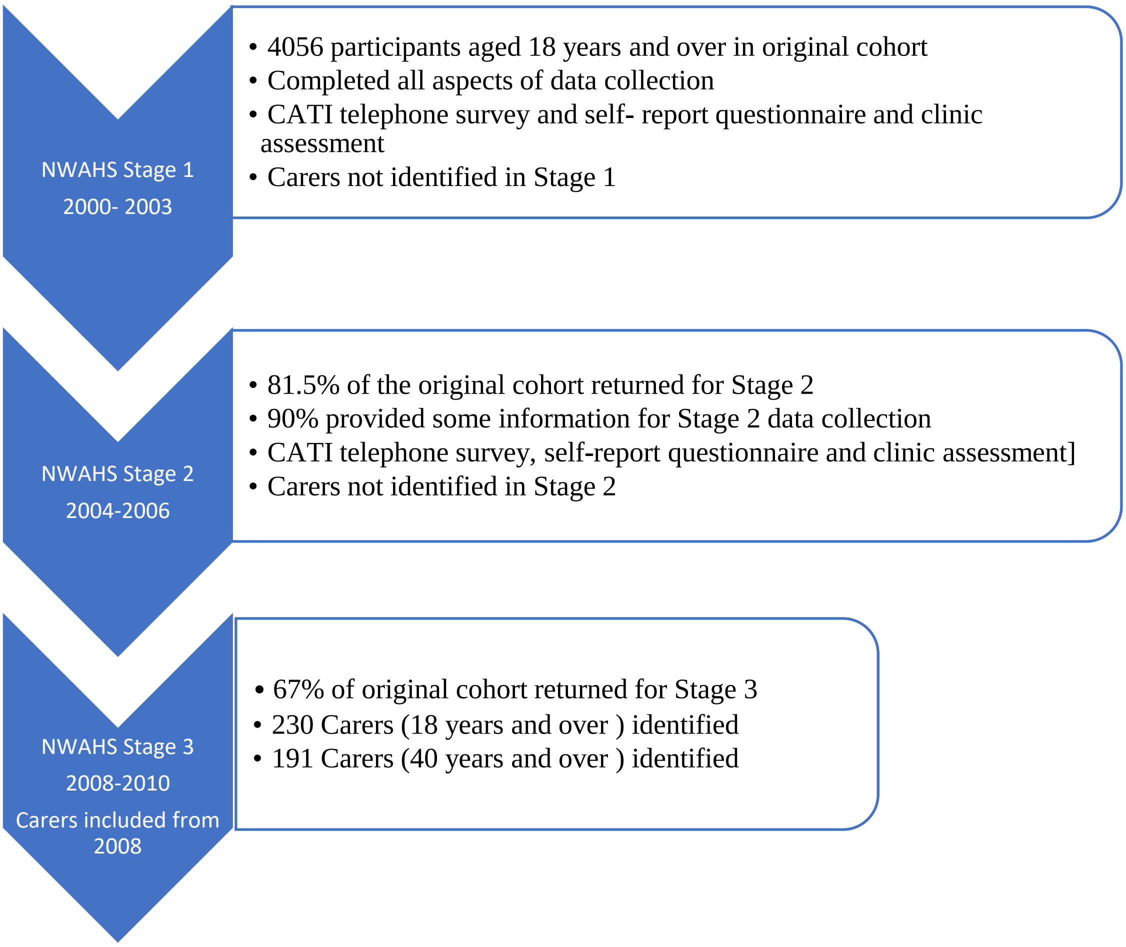
Ethics approval for SAMSS was obtained from South Australian Health Human Research Ethics Committee (project numbers 436.02.2014 and HREC/14/SAH/200). Approval for publishing the results of this study was granted by the SAMSS steering committee. Ethics approval from The University of Adelaide was granted by the Office of Research Ethics, Compliance and Integrity Research Branch (Project number 19684).

3.4 Study 3: The North West Adelaide Health Study-Stage 3

The North West Adelaide Health Study (NWAHS) is a representative population-based longitudinal cohort study in the north and western suburbs of Adelaide, the capital of South Australia[182-184]. These regions reflected the demographic profile of the state's population at the time of the initial data collection. The main objectives of the NWAHS were to investigate the prevalence of a number of chronic conditions and health-related risk factors along a continuum.

3.4.1 Study population and participants

In Stage 1, between 1999 and 2003, 4,056 participants aged 18 years were randomly selected and recruited by telephone interview. In Stage 2, (2004-6), 81.5% of the participants attended the clinic. For Stage 3 (2008-10), 67% of the original cohort attended the clinic. A diagrammatic summary of the three stages is provided in Figure 3-2.



- 4056 participants aged 18 years and over in original cohort
- Completed all aspects of data collection
- CATI telephone survey and self- report questionnaire and clinic assessment
- Carers not identified in Stage 1

- 81.5% of the original cohort returned for Stage 2
- 90% provided some information for Stage 2 data collection
- CATI telephone survey, self-report questionnaire and clinic assessment]
- Carers not identified in Stage 2

- 67% of original cohort returned for Stage 3
- 230 Carers (18 years and over) identified
- 191 Carers (40 years and over) identified

Figure 3.2 Participants in three stages of the NWAHS longitudinal cohort study 182-184

Data were collected for each stage using 1) a CATI survey, 2) self-complete questionnaire, and/or 3) a clinic assessment. Details of all methods used for the NWAHS have been described in detail and published elsewhere[182,183] although the following sections will describe the methodology relevant to this study.

3.4.2 Data collection

Questionnaire data included demographic characteristics such as age, sex, marital status, work status, educational status, annual household income, and employment status (including whether participants received government support from age, carer or disability pensions). Participants also reported if they had ever been diagnosed by a doctor, with arthritis, CVD (i.e. heart attack, stroke, angina, transient ischaemic attack), or a mental health condition (i.e. anxiety, depression, stress related problems).

Risk factors included smoking, (assessed using standard questions relating to current smoking status); and alcohol consumption was determined from questions based on the National Heart Foundation Risk Factor Prevalence Study undertaken in 1989[185]. Physical activity was determined from the amount of walking, moderate and/or vigorous activity undertaken over a one week period, which was then categorized into "No activity", "Insufficient activity" (less than 150 minutes of walking, moderate and/or vigorous activity) and "Sufficient" (150 minutes or more per week)[173]. General health was assessed using the SF-1[94].

Clinic measured variables

The presence of diabetes was derived from a self-reported doctor diagnosis of diabetes and/or a fasting plasma glucose level of greater than or equal to 7.0mmol/L. Asthma was determined using self-reported, doctor diagnosed asthma and spirometry measures following administration of salbutamol, a change in Forced Expiratory Volume in one second, (FEV1) >=12% and >200ml, or absolute change greater or equal to 400ml from baseline measurements[186,187]. Blood pressure readings, recorded in a sitting position and averaged across three readings, height and weight for calculation of BMI, and waist and hip circumference measurements to determine waist/hip ratio (WHR) using standardized measurement techniques were all determined. BMI was categorized according to the World Health Organization (WHO)[188] criteria and a high WHR was defined as > 1.0 for males and >0.85 for females[188,189].

Blood measured variables

Fasting blood samples were taken from all participants who were able to provide an adequate amount of blood sample at the clinic visit. The tests that were undertaken are listed in Table 3.1.

3.4.3 Data weighting

In Stage 1, data were weighted by region (western and northern health regions), age, sex and probability of selection in the household to the ABS 1999 Estimated Resident Population and the 2001 Census data[190,191]. Weighting was undertaken to reflect the population of interest and to correct for potential non-response bias, in which some groups of respondents may be over- or under-represented. Stage 3 was reweighted using the 2009 Estimated Resident Population for South Australia[190] and incorporated participation in the three components (CATI), self-complete questionnaire and clinic, whilst retaining the original weight from Stage 1 in the calculation.

Table 3-1 Blood Measured Variables, Carers, South Australia 1994-2014

	Blood measured variables (Fasting)
Risk factors	Albumin
	FPG (Fasting Plasma glucose)
	LDL (Low-density lipoprotein) cholesterol
	HDL (High-density lipoprotein) cholesterol
	Total cholesterol/High Density Lipoprotein Ratio
	HbA1c (Glycated haemoglobin)
	Serum 25 (OH)D (25- hydroxy vitamin D)
CBE (Haematology)	Hb (Haemoglobin)
	RBCC (Red Blood Cell Count)
	PCV (Packed Cell Volume)
	MCV (Mean Cell Volume)
	Mean Cell Haemoglobin
	Platelets
	WCC (White Cell Count)
	Neutrophils
	Lymphocytes
	Monocytes
	Eosinophils
	Basophils
MBA-20 (Biochemistry)	Na (Sodium)
	K (Potassium)
	Cl (Chloride)
	HCO_3 (Bicarbonate)
	Anion Gap
	Urea
	eGFR (Estimated Glomerular Filtration Rate)
	Urate
	Phosphate
	Ca (Total Calcium)
	Ion Calcium
	Albumin
	Globulin
	Protein
	Total Bilirubin
	GGT (Gamma glutamyl transferase)
	ALP (Alkaline phosphatase)
	ALT (Alanine aminotransferase)
	AST (Aspartate aminotransferase)
	LD (Lactate dehydrogenase)
	CK (Creatine kinase)
Inflammatory Biomarkers	hs-CRP (High sensitivity C-Reactive Protein)
	IL-6 (Interlukin-6)
	TNFα (Tumor Necrosis Factor Alpha)
	MPO (Myeloperoxidase)
	e-SEL(e-Selectin)

3.4.4 Data Analysis

Statistical analysis was conducted using SPSS version 24 (IBM, Armonk, NY, USA) and STATA version 14 (StataCorp, College Station, TX, USA). Descriptive analysis (proportions, means, and medians where applicable) were determined for all predictor variables (demographic characteristics, chronic conditions and health risk factors). Bivariable analysis using chi-square tests, including post hoc tests using the adjusted residuals, were used to determine which categories were significantly different from the other categories, between both carers and non-carers.

All continuous data were tested for normality using Kolmogorov-Smirnov and Shapiro-Wilk tests, and data that were not normally distributed were analysed using non-parametric tests (Mann-Whitney U). Generalised linear models using the binary outcome variable of carer or not a carer were used with the “svy” estimators in STATA and weighted data to determine the RR of each of the predictors, in association with the outcome variable. The models were also stratified for males and females.

3.4.5 Ethical Approval

Overall approval for all stages of the NWAHS was granted by the Queen Elizabeth Hospital Human Research Ethics Committees. The approval number for Stage 3, which has been used for this present study was 2009034. Ethical approval for this study was also granted by the Office of Research Ethics, Compliance and Integrity Research Branch, The University of Adelaide (Number 19684). As existing secondary non-identified data and no personally identifiable information was being accessed by the research team, the research was considered ‘Exempt’ from formal ethical review and did not require ethics approval. The next three chapters provide the results of each of the studies conducted using the above methodologies.

Chapter 4. Unpaid informal caregivers in South Australia: population characteristics, prevalence and Age-Period-Cohort effects 1994-2014

Statement of Authorship

Citation:

Stacey AF, Gill TK, Price K, Warmington R, Taylor AW. Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects 1994–2014. PLoS ONE, 2016; 11(9): e0161994. doi:10.1371/journal.pone.0161994.

Statement of Authorship:

Title of Paper:	Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects. 1994-2014
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	PLoSONE,11; (9):e0161994. doi:10.1371/ journal.pone.0161994 Received: April 13,2016; Accepted: August 16,2016 Published: September 20, 2016

Principal Author

Name of Principal Author (Candidate)	Anne F Stacey [AFS]		
Contribution to the Paper	My contribution to this paper was in the original idea for researching prevalence of informal caregiving in South Australia. I contributed to the drafting of the paper, wrote most of the manuscript, contributed in some of the statistical analysis and formatting of statistical tables for publication. I acted as corresponding author. Conceptualization: AFS TKG, KP, RW, AWT. Methodology: AWT RW AFS. Writing –original draft: AFS, AWT. Writing –review and editing: AFS, TKG, KP, RW, AWT		
Overall percentage (%)	60%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	30 October 2019

Co-Author Contributions

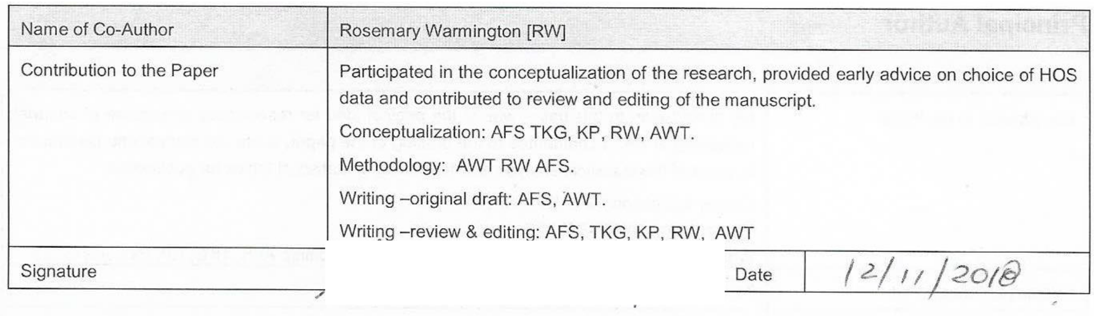
By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Anne W Taylor		
Contribution to the Paper	Participation as coordinator of all aspects of this study, contributed to overall design, drafting and methodology of the research project and edited all drafts. Conceptualization: AFS TKG, KP, RW, AWT. Methodology: AWT RW AFS. Writing –original draft: AFS, AWT. Writing –review and editing: AFS, TKG, KP, RW, AWT		
Signature		Date	30 October 2019

Name of Co-Author	Tiffany K Gill		
Contribution to the Paper	Provided advice on analyses, contributed to conceptualisation, review & editing multiple drafts of the manuscript:		
Signature		Date	30 October 2019

Name of Co-Author	Kay Price		
Contribution to the Paper	Participated in the conceptualization of the research paper, provided advice on research design and extra literature and was part of the review and editing process. Conceptualization: AFS TKG, KP, RW, AWT. Methodology: AWT RW AFS. Writing –original draft: AFS, AWT. Writing –review & editing: AFS, TKG, KP, RW, AWT		
Signature		Date	30 October 2019



Name of Co-Author	Rosemary Warmington [RW]		
Contribution to the Paper	Participated in the conceptualization of the research, provided early advice on choice of HOS data and contributed to review and editing of the manuscript. Conceptualization: AFS TKG, KP, RW, AWT. Methodology: AWT RW AFS. Writing –original draft: AFS, AWT. Writing –review & editing: AFS, TKG, KP, RW, AWT		
Signature		Date	12/11/2018

Contextual Statement

The aim of this research was to demonstrate the prevalence and demographics of adult South Australian informal carers aged 15 years and over. The availability of representative population-based carer data in South Australia has been very limited outside of information for ongoing HOS collected at face-to-face interviews since 1994. The first objective was therefore to investigate changes in carer prevalence and socio-demographic characteristics over the 20 year period to 2014.

It was further decided to conduct an analysis using Age Period Cohort (APC) to indicate any generational effects associated with carer prevalence, with particular reference to Baby Boomers and the generations expected to succeed them as carers. This to our knowledge, is the first study in South Australia and Australia to use APC in relation to informal carers.

The following chapter presents the results of both analyses of data representing two decades of prevalence, socio-demographics and APC. This provides a valuable base for understanding and predicting future characteristics and health trends of South Australian informal carers.

This manuscript was published by PLoS One on 20 September 2016. It has been re-formatted for inclusion in this thesis which follows as Chapter 4. A reprint of the paper in its published format is attached to this thesis as Appendix B.

Unpaid informal caregivers in South Australia: population characteristics, prevalence and Age-Period-Cohort effects 1994-2014

Anne F. Stacey[1], Tiffany K. Gill[1], Kay Price[2], Rosemary Warmington[3,] Anne W. Taylor[1]

1 Population Research & Outcome Studies, Discipline of Medicine, The University of Adelaide, South Australia, Australia,

2 School of Nursing and Midwifery, University of South Australia.

3 Carers South Australia. (CarersSA)

Corresponding Author: anne.stacey@adelaide.edu.au

Keywords: Informal carers, unpaid caregivers, prevalence, population-based surveys, Australia

4.1 Abstract

Background

The ongoing need for an availability of informal carers is taking on greater relevance as the global burden of disease transitions from acute fatal diseases to long term morbidity. Growing evidence suggests that extra burden on family carers may further impact on their health and ability to provide care. Important as it is to monitor the prevalence of those conditions which influence the burden of disease, it is also pertinent to monitor the prevalence and health profiles of those who provide the informal care. The aim of this study was to demonstrate the prevalence and demographics of adult carers aged 15 and over in the state of South Australia over 20 years between 1994 and 2014.

Methods

Data from nine representative, cross-sectional population surveys, conducted in South Australia, Australia were used, (total N=26,788 and n=1,504 carers). The prevalence of carers and their demographic characteristics were determined. So as to examine whether there were any generational effects on the prevalence of carers, an Age-Period Cohort (APC) analysis was undertaken.

Findings

The prevalence of carers increased during the two decades from 3.7% in 1994 to 6.7% by 2014. Large increases in the proportion of retired carers, those aged 70 years and over, those carers employed, and those with higher educational qualifications were observed. There were also larger proportions of respondents with a country of birth other than Australia, UK, Ireland and European counties. The APC analysis illustrated an increasing prevalence rate over each decade for carers aged 20 – 80 years, especially for those over the age of 60 years.

Conclusions

The results illustrate changing carer characteristics and carer prevalence estimates in South Australia as new generations of carers take on the caring role. There is a need to include questions regarding informal carers within ongoing mainstream population surveys, particularly at state levels, so as to plan for their future health care and home support.

4.2 Background

Although the concept of kinship support and filial piety has existed throughout history across most cultures, the importance of family members caring for ill or aged relatives was not adequately recognised at the level of social policy of western countries until later in the twentieth century[1-2]. Traditional expectations of family meant that the caring efforts of informal carers (unpaid caregivers) were often taken for granted[3]. Today however their pivotal role in health and social support systems are acknowledged for their significant economic contribution to containing health care costs [4-5].

Globally the ongoing need for an availability of informal carers is taking on even greater critical relevance. Firstly, as life expectancy increases and the population ages; secondly as studies of global burden of disease show a transitioning from early mortality associated with acute fatal diseases to long term morbidity dominated by chronic conditions[6-7]. Not only have these phenomena resulted in higher proportions of disability and impairment across populations but are impacting at community and individual levels[8]. For example, informal family carers of all ages provide multifaceted care for children and adults with a disability, persons who are frail and aged, chronically ill partners and friends with complex and demanding physical and mental health problems[[9].

Growing evidence suggests that the extra burden on carers can put them at risk of physical health and emotional stress and strain[10-12]. Therefore, important as it is to track the prevalence of those conditions which influence the burden of disease, (for example cancers, cardiovascular diseases, injury as well as dementias), it is also pertinent to track the prevalence, demographic profiles and health status of those who provide the informal care.

Over the past thirty years, prevalence figures of informal caregiving at the population level have emerged haphazardly across industrialised nations and more recently from developing countries[13-14]. The methodology used to identify informal caregivers still remains inconsistent, with international surveys providing estimates ranging from 15% to 39%[9,15]. However, some larger population studies do provide an overview. For example, in 2011, 12% of the British (adult) population were identified as caregivers[16]. Canadian surveys have estimated that overall 28% of adult Canadians aged 15 or over were caregivers although rates varied considerably across the provinces[17]. In the United States (US) it was estimated that up to 25-30% of the adult population were providing care and support to family and friends, but again rates varied by state[18-19]. In both the 2009 and 2012 Australian Bureau of Statistics (ABS) Disability Ageing and Carers surveys (SDAC), approximately 12% of the Australian population was identified as providing some care while approximately a third were primary carers18,22. ABS limit their definition to care provided to people with disability, long-term conditions, or care for persons who are aged 60 years and over[21]. At state levels in Australia, population-based details of carer prevalence have also mostly come from data collected by the national ABS surveys. These have been conducted approximately every five to six years since 1993. In the state of South Australia (SA), the prevalence of carers has been determined through additional separate state wide Health Omnibus Surveys (HOS) which have included carer status questions in nine of the annual surveys between 1994 and 2014.

The aim of this paper is to show changes over 20 years, between 1994 and 2014, in the prevalence and demographic characteristics of adult carers aged 15 and over in the state of South Australia. To achieve this, the trend over the past decades was analysed. Secondly, multivariable analyses were conducted to determine the demographic characteristics of those reporting that they were carers, from three time points. Thirdly, the percentage differences for demographic and socio-economic variables were analysed across the two decades from 1994 to 2014. Lastly the age-period-cohort (APC) effects were also examined. The benefits of APC analysis allow the effects of age, period and cohort to be interpreted independently whilst taking into account a plethora of individual, societal, historical and cultural aspects[22]. Age relates to the physiological processes associated with growing older, period effects relate to particular time points with the assumption that populations are all equally affected, and cohort effects relate to experiences during particular time frames.

4.3 Methods

The Health Omnibus Survey is a user-pays population-based cross-sectional, representative survey that has been undertaken annually or bi-annually in South Australia since 1990. It investigates a range of health and health service issues as requested by health-related organisations and researchers in South Australia and beyond. The research methodology used in HOS has been previously described[23] but in brief, each survey is a clustered, multi-stage, systematic, self-weighting sample selected from the Adelaide metropolitan area with the remainder being drawn from those country areas with a population of 1000 or more, based on ABS Census information. Each survey is face-to-face, and interviews are undertaken by trained interviewers.

Carer Questions

Informal carers are those who provide the main care in the home setting, are aged 15 years or older, and are giving ongoing personal care and assistance to dependent relatives and individuals with a chronic mental or physical illness or who are frail and aged. Providing this care is beyond that which is expected in a normal relationship[24-25]. Data pertaining to informal carer status was from selected years between 1994 to 2014. In 1994 and 1998, the carer question used was, *"Are you a carer of a dependent person? (A dependent person is someone who has a chronic condition that is unlikely to improve, for example frail aged, disabled etc.).* In the remaining surveys (2000-2002, 2004, 2008, 2013-2014) the carer question was,

"Do you provide long-term care at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness, where long-term care is a minimum of 6 months and may extend into years".

Demographic and socio-economic questions

Demographic variables included in the surveys are gender, age group, area of residence, country of birth and marital status. Socio-economic variables included educational attainment and work status. Details of the annual income for each household was obtained and the socio-economic disadvantage of neighbourhood at an environmental level (using postcode) was classified into the Socio-Economic Index for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage from which quintiles were determined[26].

4.3 Data Analysis

The survey data were weighted by age, gender and geographic locations so that the findings apply to the demographic profile of South Australia using either the ABS census data or the most recent estimated residential population for each year. Initially the trend in prevalence was determined using the nine years of data. Age and sex standardized prevalence estimates were also produced. For ease of interpretation data from three surveys collected ten years apart (1994, 2004 and 2014) were selected to highlight specific demographic changes. Analysis was undertaken using SPSS Statistics, Version 19 (IBM SPSS Statistics, New York, NY, USA).

For the APC analysis, the combined data from the nine years were used and an APC model was constructed using STATA Version 13 (StataCorp, College Station, TX, USA)[190] with the 'apcfit' command[27]. APC analysis was chosen so as to interpret the effects of ageing, birth cohorts and time periods in relation to carer prevalence and odds ratios. In this analysis, 'AGE' was the self-reported age of the respondents at the time of the survey interview. 'COHORT' was the age subtracted from the survey year. This ranged from the oldest respondents (80 years and over) to the youngest respondents (aged 15 years). ‘PERIOD’ represents the years of data collection (1994 to 2014).

Ethical Approval

Ethics approvals were obtained from the Research Ethics Committee of The University of Adelaide and the South Australian Department of Health. All participants gave verbal informed consent and continued participation in the face-to-face interview taken as evidence as continued willingness to participate.

4.4 Results

Overall, the total sample for the nine surveys was N=26,788 (n=1,504 were carers). The survey response rates decreased over the 20 year period from 72.4% in 1994 to 54.4% in 2014. The prevalence trend using data from nine surveys which included carer status questions is presented in Table 1 and Figure 1. In South Australia over the two decades from 1994 to 2014, there was almost a doubling of the prevalence of carers increasing from 3.7% 1994 to a peak of 7.9% in 2008 then declining to 6.7% by 2014.

Table 2 highlights the unadjusted and adjusted odds ratios of carers over three specific years; 1994, 2004 and 2014 by a range of demographic variables. Multivariable analysis shows that in 2014 carers were more likely to be female (OR 1.43; 95% CI 1.00-2.05, p=0.050), be aged 50-69 (OR 1.82; 95% CI 1.11-3.01 p=0.0.019), be born in countries other than Australia, UK or Ireland, (OR 1.82; 95% CI 1.08-3.07, p=0.02), be never married (OR 0.47; 95% CI 0.26-0.83, p=0.011), declare their work status as ‘home duties’ (OR 1.88; 95% CI 1.02-3.48, p=0.043) and have annual household incomes of $20,000-40,000 (OR 2.38; 95% CI 1.29-4.02, p=0.005).

Table 3 details the percentage increase across the two decades from 1994 to 2014 by demographic characteristics. Moderate increases across the 20 years from 1994 to 2014 were seen for females (100% increase, from 4.0% (95% CI 3.0-5.4) to 8.0% (95% CI 6.6-9.5), with an 86.2% increase in males over the same time period from 2.9% (95% CI 2.1-4.0) to 5.4% (95% CI 4.0-7.4). There was a larger 120% increase for carers aged 70 years or more, from 5.0% (95% CI 3.0-8.4) to 11.0% (95% CI 8.0-14.8). It is also noted in carers aged 15-49 years, there was a 90.9% increase from 2.2% (95% CI 1.5-3.1) to 4.2% (95% CI 3.1-5.7).

Other socio-demographic increases over the 20 years included a 108.1% increase for carers with a secondary school level or less education, from 3.7 % (95% CI 2.8-4.8) to 7.7 % (CI 95% CI 6.2-9.6), however in terms of educational attainment, there was a 112.1% increase in carers with trade qualifications, certificates and diplomas, increasing from 3.3% (95% CI 2.2-4.9) to 7.0% (95% CI 5.3-9.0).

Again, large percentage increases were recorded for work status, with a 119.0% increase for employed carers (full or part time) from 2.1% (95% CI 1.4-3.3) to 4.6% (95% CI 3.5-6.2), and a 110.9% increase in those carers nominating they were retired, from 5.5% (95% CI 3.8-7.9) to 11.6% (95% CI 9.3-14.4). Annual household income of $40,000 or more showed a 172.2% increase from 1.8% (95% CI 1.0-3.3) to 4.9% (95% CI 3.5-6.8) and a 403.3% increase for annual household income of $20-40,000 was recorded, from 3.0% (95% CI 1.9-4.8) to 15.1% (95% CI 11.5-19.6).

Other demographic percentage increases included a 163.6% increase for other country of birth, increasing from 3.3% (95% CI 1.8-5.7) to 8.7% (95% CI 5.9-12.6). Carers born in Australia showed a 93.3% percentage increase from 3.0% (95% CI 2.3-3.9) to 5.8% (95% CI 4.6-7.3), however there was a smaller 43.1% increase in carers whose country of birth was UK/Ireland, from 6.5% (95% CI 4.3-9.8) to 9.3% (95% CI 6.4-13.4).

In terms of percentage differences over the most recent decade, from 2004 to 2014, highest percentage increases were seen for annual household income of $20,000-40,000 (104.1% increase) from 7.4% (95% CI 5.4-10.1) to 15.1% (95% CI 11.5-19.6). No change in the most recent decade to 2014 was found for carers in the 18-49 age group (4.2%). The only negative percentage differences occurred in the most recent decade to 2014 was for carers born in Australia (-1.7%) and carers who were never married (-14.3%).

Figure 2 provides the results of the APC analysis. On the left axis is shown the independent effects of age (prevalence) and on the right axis the birth cohort and period effects, both using rate ratios are shown. The peak age for carers was around 80 years and showed a steady increasing rate over each decade for those aged 20 – 80 years. The graph indicates that the prevalence of being a carer increases, especially after the age of 60. In the cohort analysis the Baby Boomers born around 1951-2 are the reference point [=1] and also represent the point of acceleration of risk which for the purposes of this paper, can be interpreted as each cohort’s exposure to informal caregiving. The graph also shows a higher ratio of caring in the later cohorts born mid 1970s to 2000, suggesting that persons born around 1975 (Generation X) may be twice as likely to become carers, whereas persons born 1980s to 2000 (Generation Y) have a three-fold likelihood of becoming carers.

The Estimated Period Effect represents the specific calendar period when the sample population were surveyed. The resulting period effects of the graph show increasing prevalence from 1994, peaking at 2008 then falling into negative effects by 2014.

4.5 Discussion

The results indicate an inital increase in the prevalence of carers from 1994, a doubling of the proportion of carers by 2008 (3.7% to 7.9%), then a slight decline to 6.7% by 2014. Increases in proportions of carers across all ages were found, especially the 50-69 year old group and the 70 years and over age groups, a finding consistent with South Australia having been the state with the highest proportion of older age population in Australia [28-30]. In our surveys there was still a considerable proportion of carers whose education was secondary school or less, but there were higher prevalences of carers who had high educational attainment and tertiary training. Carers were more likely to be employed either full time or part time, but as would be expected with an ageing population, there were also more carers who had left work and retired. In terms of annual household incomes of carers which have increased over the past 20 years, much of this would be the result of inflation and many carers still remain in the low/ lowest most disadvantaged quintiles compared with the wider community.

It is well documented that women have been the traditional and dominant family caregivers in societies of all cultures[2]. Although there was a slight increase in proportions of male carers in our earlier South Australian survey of 2004, overall male percentage increases (86%) remained below the 100% increase of females. ABS national surveys across Australia amongst ‘all’ carers in 1998 showed there was some narrowing of the gender gap with just over a half of all carers being female. In the over 75 age group there were slightly more male primary carers.

Interestingly Australian disability surveys revealed that after the age of 85, carers were frequently males caring for a disabled wife[31] The implications of this changing demographic with an increasing number of male carers in this older age group raise questions about the mix and type of services needed for the future.

There is a paucity of published literature on informal caregiving in terms of surveys applying Age-Period-Cohort methods. Earlier studies include one that explored changes in attitudes towards caring for ageing parents[32]. More general research examined trends in disability in older adult cohorts using APC[33]. Other APC studies and those specific to carers using methodology comparable to this paper have not been sourced to date, except those applied to prevalence rates of chronic disease topics such as diabetes, and obesity[34].

Our APC analysis (Fig 2) illustrates the combined impact of caregiving and ageing on several birth cohorts, which range from the older carers of pre-war generations (born early 1900s to 1945), to the Baby Boomers (born 1946-1964) and Generation X, (born 1965-1980s). The prevalence of becoming a carer showed a steady increase over each decade, especially after the age of 60. Using the APC analysis, carers’ peak age was around 80 years. Again our study indicates there has been a trend for older age carers to continue caregiving into their late 70s, 80s and beyond. Other authors have observed that the onset of caregiving peaked in late middle age and older, and that informal care could span three decades or more of adult life[35]. Of concern has been the lack of data on prevalence of those much older generations who might be providing care for a spouse, relative or an adult child with a disability. Literature is more readily available on social and health impacts on those cohorts[36-38].

Our study highlights changes in carers' country of birth, an aspect that reflects sixty years of increased immigration to South Australia. Although our results show that there has been a 93% percent increase in carers born in Australia, by 2014 there were large percentage increases (over 163%) in carers born in countries other than Australia, UK, Ireland or Europe. This change from earlier carer profiles of the 1990s reflects the wider cultural characteristics of people (families) who have migrated to South Australia since the 1950s and 1960s. Australia has a rich multi-cultural heritage of people from over 200 countries. Those overseas-born persons aged 65 or over, has expanded in recent decades, doubling since 1991[39-40]. There is potential for this cultural influence to impact on carers' use of home-based care if there are inadequate culturally appropriate respite services or facilities. Further, there could be a reluctance on the part of older persons from different cultures to accept support services creating additional difficulties for the spouse or other family carers[41].

The results of our surveys show that new generations of carers have emerged with different characteristics in areas of education and employment and this can be a challenge for many to combine with their informal caring. The higher proportion of working carers in our study, (both full time and part time), takes on greater importance because of the many Baby Boomers who are the current generation of informal carers. This transition occurred as older Pre-World War II carers, (for example, ageing parents of the early Baby Boomers), became the recipients of care over the past 20 years. This coincided with a greater emphasis on community care in Australia during the past decades, which is being further developed as new government reforms and initiatives for carers and consumers[42]. For example they focus on consumer directed care packages based on ageing in place (and in the home) and in disability 'consumer choice and control' through the NDIS. Both models emphasise that they are consumer directed for home based care. Current integrated support services for carers are undergoing further development.

Younger working carers, especially parent-carers, is another group that cannot be overlooked. Carers of younger children with chronic health conditions and disabilities are more likely to be subject to employment constraints. Employment for carers can be problematic and research is emerging of the negative effects on the parents who are the informal carers[43]. In general, of those carers who also work, many do manage well without adverse health changes, but Schofield concluded that 'working carers providing high levels of care represent a vulnerable subgroup where supportive and preventive services might be focused'[44]. In our study there was a higher proportion of working carers overall, but on a global scale, Australia has had a lower percentage of employed carers (38.4%), than other countries such as Canada and USA (60%), or the UK (53%)[45-48].

While the changing prevalence of carers in our study showed an increase over time, the later decline by 2014 could have been influenced by a number of factors. For example natural attrition (deaths) amongst carers from the oldest birth cohorts would have been occuring during that time. On a national scale reduced disability rates amongst both children and adults were observed which could have resulted in slightly less demand for informal carers[20]. Other factors impacting on carer numbers may be due to younger generations choosing careers over caring roles, especially with greater labour force participation of women[49]. Also it is not uncommon for people to choose to work beyond the ages of 65 and 70 years old which would lessen their availability for complex caregiving in the home. There have also been trends towards more active retirement, especially amongst baby boomers and later generations[40]. It is conjectured that some of these socio-economic factors surrounding caregiving may have been further influenced by the Global Financial Crisis (GFC) with a general reluctance to give up paid work and income during such uncertain times. Those directly affected by the GFC may have had to actively seek employment, as a priority over any caring role.

Strengths and limitations of this study

The strengths of this study are that the results provide an analysis of carer prevalence and demographics over a twenty year period. It has used population-based data using face-to-face interviews, the gold standard of surveys, and a significant number of interviews were conducted. It is therefore more generalizable to other ageing populations and includes a number of relevant demographic covariates.

Limitations of the study include definitional issues which continue to influence all caregiving research and make comparisons of carer / caregiver prevalence figures difficult across studies[18]. Although the data were age/sex standardized no adjustment for Consumer Price Index (CPI) was undertaken, so those household income results should be assessed with caution. Due to their small numbers, non-English speaking individuals, Indigenous and those from specific cultures are included in the data collection but not in the analysis. Also, the small numbers of young carers meant that meaningful analysis could not be included in our study, however this is a limitation that does not detract from their vital roles and urgent need for further research[50-51].

In conclusion, this study demonstrates there has been an overall increase in informal caregiving in South Australia, a state which over the past two decades has shown higher proportions of people aged 65 years and over, than those in other, mainland Eastern Australian states[29]. Our research has highlighted major demographic shifts between 1994 and 2014 and it is important that policy and planning keep pace with these changes and projections. As future prevalence rates are watched with interest in South Australia, these findings may also be relevant in other specific populations with similar demographic profiles.

If we are to sustain the current model of care in the community and the informal carers in their caring role it is important to continue monitoring the prevalence, demographic and health profiles as emerging generations of informal carers with more diverse characteristics take on the caring roles. To achieve this there is an urgent need to include informal carers within ongoing mainstream population surveys, wherever appropriate, so as to provide statistics to plan for their future health care and home support. As the literature suggests, many carers themselves have health problems or suffer diminished quality of life[52-53]. Therefore carer well-being and particularly their health status needs to be considered in parallel with those persons they are caring for. Important as it is to track the prevalence of the plethora of conditions which influence the burden of disease, it is pertinent to track the prevalence, demographic profiles and health status of those who provide the informal care, as many are carrying a double burden of disease. That of the care recipient, and their own.

Acknowledgements:

Thanks to Zumin Shi, Eleonora Dal Grande, Jodie Avery, for assistance with data manipulation and analysis.

Table 4-1 Crude and age / sex standardised prevalence estimates of carers, South Australia 1994-2014

Year	HOS Total N =	Carers Total n =	SA Estimate Prevalence % (95% CI)	Age and Sex Standardised Prevalence Estimate % (95% CI)
1994	3010	104	3.4% (2.9-4.2)	3.7% (2.9-4.4)
1998	3010	127	4.5% (3.6-5.0)	4.6% (3.5-5.6)
2000	3027	141	4.7% (4.0-5.5)	4.8% (4.0-5.6)
2001	3037	170	5.6% (4.8-6.5)	5.9% (4.9-5.6)
2002	3015	154	5.0% (4.3-5.9)	5.2% (4.2-6.2)
2004	3015	177	5.9% (5.1-6.8)	5.9% (5.1-6.8)
2008	3034	239	7.9% (6.8-8.9)	7.9% (6.8-8.9)
2013	2908	218	7.5% (6.6-8.5)	7.5% (6.2-8.8)
2014	2732	174	6.4% (5.5-8.3)	6.7% (5.4-7.7)

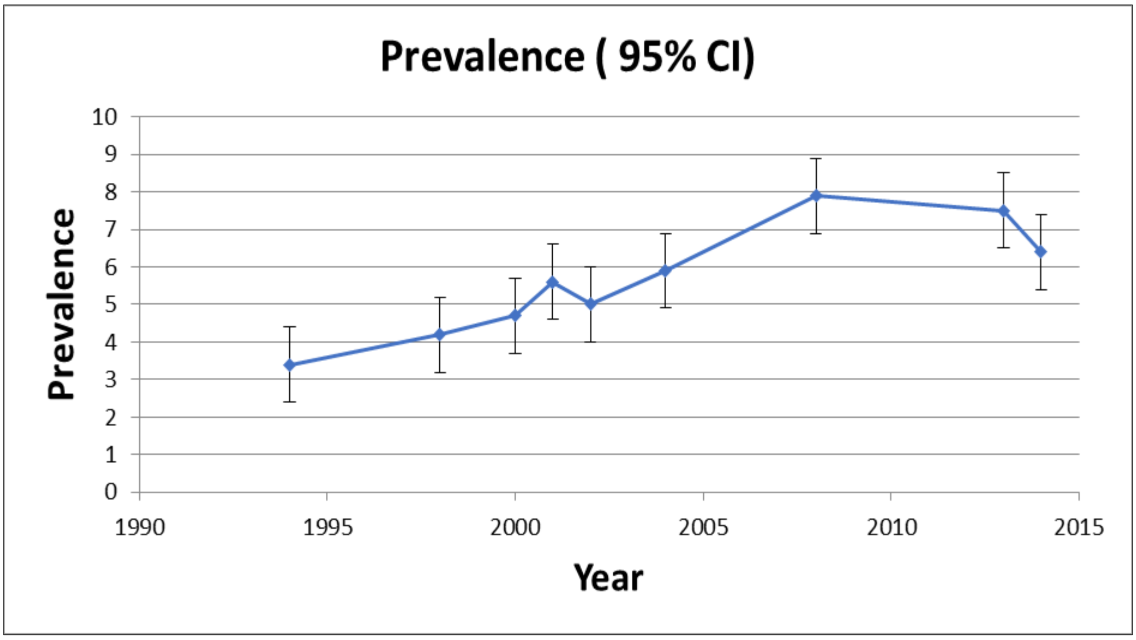


Figure 4.1 Prevalence estimates of adult carers in South Australia: 1994 to 2014

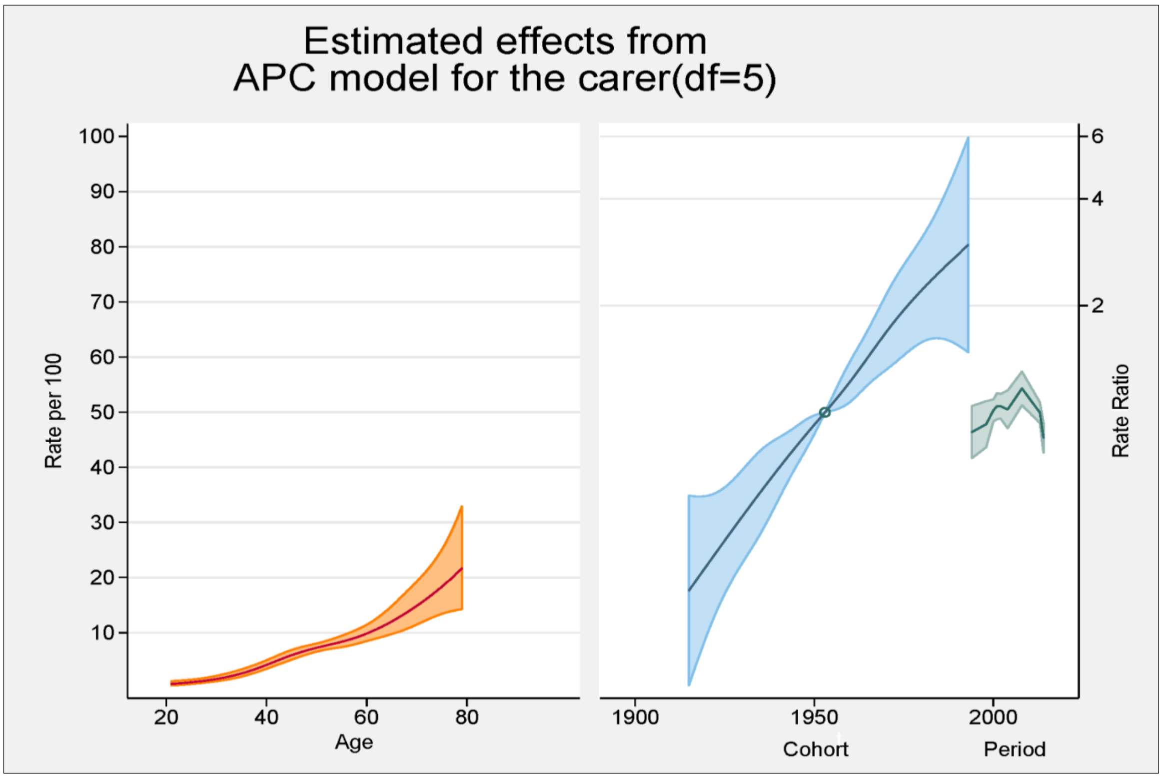


Figure 4.2 Estimated effects from APC model for adult carers (HOS)

Table 4-2 Unadjusted and adjusted odds ratios of carers over three time periods by demographic variables: Health Omnibus Survey: 1994, 2004, 2008.

	1994				2004				2014			
	Unadjusted		Adjusted		unadjusted		Adjusted		Unadjusted		Adjusted	
	odds ratio	pval	odds ratio	pval	odds ratio	pval	odds ratio	pval	odds ratio	pval	odds ratio	pval
GENDER Male	1.00		1.00		1.00		1.00		1.00		1.00	
Female	1.41 (0.90 - 2.20)	0.131	1.01 (0.56 - 1.81)	0.981	1.50 (1.04 - 2.17)	0.030	1.31 (0.87 - 1.98)	0.200	1.51 (1.06 - 2.15)	0.022	1.43 (1.00 - 2.05)	0.050
AGE GROUP 18 to 49	1.00		1.00		1.00		1.00		1.00		1.00	
50 to 69	3.10 (1.97 - 4.88)	0.000	2.08 (1.22 - 3.54)	0.007	1.90 (1.30 - 2.77)	0.001	1.48 (0.95 - 2.29)	0.084	2.34 (1.60 - 3.44)	0.000	1.82 (1.11 - 3.01)	0.019
70+	2.41 (1.18 - 4.91)	0.016	1.74 (0.69 - 4.35)	0.237	2.38 (1.52 - 3.71)	0.000	1.73 (0.93 - 3.20)	0.083	2.80 (1.73 - 4.55)	0.000	1.73 (0.79 - 3.77)	0.167
AREA Metro. Adelaide	1.00		1.00		1.00		1.00		1.00		1.00	
Country	1.19 (0.69 - 2.05)	0.521	1.07 (0.59 - 1.93)	0.829	1.24 (0.89 - 1.71)	0.197	1.13 (0.81 - 1.59)	0.471	1.19 (0.77 - 1.84)	0.427	1.14 (0.72 - 1.80)	0.580
COUNTRY OF BIRTH Australia	1.00		1.00		1.00		1.00		1.00		1.00	
UK/Ireland	2.26 (1.35 - 3.78)	0.002	1.89 (1.09 - 3.25)	0.022	1.30 (0.75 - 2.25)	0.350	1.04 (0.57 - 1.88)	0.901	1.66 (1.06 - 2.60)	0.027	1.25 (0.79 - 1.98)	0.343
Other	1.09 (0.59 - 2.02)	0.793	0.90 (0.47 - 1.74)	0.750	0.73 (0.42 - 1.27)	0.263	0.66 (0.38 - 1.16)	0.149	1.54 (0.96 - 2.46)	0.073	1.82 (1.08 - 3.07)	0.026
MARITAL STATUS #												
Married/defacto	1.00		1.00		1.00		1.00		1.00		1.00	
Separated/Divorced	1.01 (0.53 - 1.92)	0.971	1.05 (0.53 - 2.05)	0.893	0.88 (0.53 - 1.48)	0.635	0.68 (0.39 - 1.19)	0.176	1.12 (0.73 - 1.73)	0.593	0.94 (0.56 - 1.58)	0.819
Never married	0.33 (0.16 - 0.69)	0.003	0.62 (0.28 - 1.38)	0.239	0.47 (0.26 - 0.85)	0.012	0.59 (0.31 - 1.14)	0.117	0.35 (0.22 - 0.54)	0.000	0.47 (0.26 - 0.83)	0.011
EDUCATIONAL ATTAINMENT												
Up to secondary	1.00		1.00		1.00		1.00		1.00		1.00	
Trade, certificate, diploma	1.33 (0.57 - 3.09)	0.506	1.02 (0.61 - 1.69)	0.953	1.62 (0.87 - 3.00)	0.127	1.06 (0.71 - 1.60)	0.766	1.52 (0.91 - 2.56)	0.111	0.94 (0.67 - 1.32)	0.704
Degree or higher	1.49 (0.66 - 3.35)	0.337	1.19 (0.48 - 3.00)	0.706	1.86 (1.03 - 3.37)	0.040	0.81 (0.43 - 1.53)	0.512	1.70 (1.10 - 2.65)	0.018	0.70 (0.42 - 1.17)	0.169
WORK STATUS												
Employed full or part time	1.00		1.00		1.00		1.00		1.00		1.00	
Home duties	3.37 (1.96 - 5.82)	0.000	2.19 (1.13 - 4.23)	0.020	3.32 (1.99 - 5.54)	0.000	2.34 (1.34 - 4.07)	0.003	2.80 (1.50 - 5.21)	0.002	1.88 (1.02 - 3.48)	0.043
Retired	2.71 (1.47 - 4.99)	0.001	1.31 (0.58 - 2.96)	0.511	2.50 (1.66 - 3.78)	0.000	1.55 (0.92 - 2.61)	0.096	2.70 (1.80 - 4.07)	0.000	1.45 (0.84 - 2.50)	0.176
HOUSEHOLD ANNUAL INCOME												
$40,000	1.00		1.00		1.00		1.00		1.00		1.00	
$20-$40,000	1.72 (0.78 - 3.81)	0.181	1.39 (0.57 - 3.36)	0.465	1.82 (1.17 - 2.82)	0.008	1.36 (0.82 - 2.25)	0.234	3.44 (2.06 - 5.73)	0.000	2.28 (1.29 - 4.02)	0.005
<$20,000	3.14 (1.59 - 6.17)	0.001	1.99 (0.83 - 4.80)	0.124	2.35 (1.59 - 3.46)	0.000	1.71 (0.98 - 2.98)	0.060	2.03 (1.13 - 3.64)	0.018	1.55 (0.82 - 2.94)	0.174
SOCIAL DISADVANTAGE (SEIFA)												
Middle to highest	1.00		1.00		1.00		1.00		1.00		1.00	
Lowest to low	1.27 (0.81 - 2.02)	0.299	1.06 (0.65 - 1.73)	0.804	1.01 (0.74 - 1.39)	0.928	0.88 (0.62 - 1.24)	0.455	1.28 (0.90 - 1.81)	0.161	1.20 (0.85 - 1.68)	0.297

Widowed excluded

Table 4-3 Prevalence of carer status by demographic variables, by three time periods: Health Omnibus Survey: 1994, 2004, 2014

			1994			2004			2014		% diff 1994, 2014	% diff 2004, 2014
		n	**% (95% CI)**	**p value**	**n**	**% (95% CI)**	**p value**	**n**	**% (95% CI)**	**p value**		
Sex	Male	43	2.9 (2.1-4.0)	0.13	70	4.8 (3.6-6.2)	0.029	73	5.4 (4.0-7.3)	0.021	86.2	12.5
	Female	61	4.0 (3.0-5.4)		107	7.0 (5.8-8.4)		110	8.0 (6.6-9.5)		100.0	14.3
Age groups	18 to 49	43	2.2 (1.5-3.1)	<0.001	77	4.2 (3.3-5.4)	<0.001	64	4.2 (3.1-5.7)	<0.001	90.9	0.0
	50 to 69	44	6.4 (4.8-8.5)		62	7.8 (6.1-9.8)		80	9.3 (7.3-11.8)		45.3	19.2
	70+	17	5.0 (3.0-8.4)		39	9.5 (7.0-12.9)		39	11.0 (8.0-14.8)		120.0	15.8
Area	Metropolitan	68	3.3 (2.6-4.1)	0.521	117	5.5 (4.6-6.6)	0.196	131	6.4 (5.2-7.9)	0.426	93.9	16.4
	Country	36	3.9 (2.4-6.1)		61	6.7 (5.3-8.6)		52	7.5 (5.3-10.6)		92.3	11.9
Country of birth	Australia	68	3.0 (2.3-3.9)	0.005	132	5.9 (4.9-7.1)	0.29	113	5.8 (4.6-7.3)	0.046	93.3	-1.7
	UK/Ireland	23	6.5 (4.3-9.8)		28	7.5 (4.8-11.6)		24	9.3 (6.4-13.4)		43.1	24.0
	Other	13	3.3 (1.8-5.7)		18	4.4 (2.7-7.0)		47	8.7 (5.9-12.6)		163.6	97.7
Marital status #	Married/defacto	79	4.3 (3.4-5.4)	0.003	133	7.1 (6.0-8.5)	0.003	137	8.0 (6.5-9.8)	<0.001	86.0	12.7
	Separated/Divorced	11	4.3 (2.3-7.9)		16	6.3 (4.0-9.9)		20	8.9 (6.2-12.7)		107.0	41.3
	Never married	10	1.4 (0.7-2.9)		25	3.5 (2.1-5.8)		19	3.0 (2.0-4.4)		114.3	-14.3
Educational Attainment	Secondary schooling	64	3.7 (2.8-4.8)	0.628	101	6.6 (5.4-8.0)	0.16	83	7.7 (6.2-9.6)	0.092	108.1	16.7
	Trade quals, Certificate, Diploma	33	3.3 (2.2-4.9)		61	5.8 (4.4-7.6)		68	7.0 (5.3-9.0)		112.1	20.7
	Bachelor Degree	7	2.5 (1.1-5.5)		15	3.6 (2.1-6.1)		32	4.7 (3.1-7.0)		88.0	30.6
Work status #	Employed full or part time	33	2.1 (1.4-3.3)	<0.001	64	3.8 (2.9-5.1)	<0.001	71	4.6 (3.5-6.2)	<0.001	119.0	21.1
	Home duties	37	6.8 (4.8-9.4)		39	11.7 (8.2-16.4)		18	12.0 (6.8-20.1)		76.5	2.6
	Retired	27	5.5 (3.8-7.9)		51	9.1 (6.9-11.7)		65	11.6 (9.3-14.4)		110.9	27.5
Household annual income #	$40,000 or more	16	1.8 (1.0-3.3)	0.004	63	4.2 (3.2-5.5)	<0.001	68	4.9 (3.5-6.8)	<0.001	172.2	16.7
	$20-$40,000	22	3.0 (1.9-4.8)		42	7.4 (5.4-10.1)		47	15.1 (11.5-19.6)		403.3	104.1
	Less than $20,000	47	5.4 (4.0-7.1)		58	9.4 (7.4-11.8)		15	9.5 (5.8-15.2)		75.9	1.1
Index Relative Socio-disadvantage (SEIFA)												
	Middle to highest	54	3.1 (2.3-4.1)	0.492	103	5.9 (4.8-7.1)	0.928	99	6.1 (4.9-7.5)	0.161	96.8	3.4
	Lowest low	49	3.9 (2.8-5.5)		75	5.9 (4.8-7.4)		84	7.6 (5.8-10.0)		94.9	28.8
	Total	**104**	**3.4 (2.8-4.3)**		**177**	**5.9 (5.1-6.8)**		**183**	**6.7 (5.6-8.0)**		**97.1**	**13.6**

Widowed (Marital Status) : excluded; Not stated (Work Status) : excluded; Not stated (Household annual income) : excluded

References

1 Park H-J. Legislating for Filial Piety: An Indirect Approach to Promoting Family Support and Responsibility for Older People in Korea. Journal of Ageing and Society. 2015; 27:280-293.

2 Bryant L, Lim S. Australian-Chinese families caring for elderly relatives. Ageing and Society. 2013; 33:1401-1420.

3 Hirst M. Transitions to informal care in Great Britain during the1990s. Journal of Epidemiological Community Health. 2002; 56:579–587.

4 Australian Institute of Health and Welfare (AIHW). Australia's Welfare 2013. Australian Institute of Health and Welfare 2013. Australia’s welfare series no.11. Cat. no. AUS 174. Canberra: AIHW.

5 Faran-Portet M-I, Popham F, Mitchell R, Swine C, Lorant V. Caring, employment and health among adults of working age: evidence from Britain and Belgium. European Journal of Public Health, 2009; 20:(1)52–57. doi:10.1093/eurpub/ckp045

6 Australian Institute of Health and Welfare (AIHW). Australian Burden of Disease Study: fatal burden of disease 2010. Australian Burden of Disease Study series no. 1. Cat. No. BOD 1. Canberra: AIHW.

7 Australian Institute of Health and Welfare (AIHW). Australia’s Health 2014. Chapter 4. Leading types of ill health. Australian Institute of Health and Welfare. Canberra.

8 Bruhn JG, Rebach HM. The Sociology of Caregiving. Clinical Sociology and Practice. 2014. Springer; Dordrecht Heidelberg New York London. ISBN 1566-7847. DOI 10.1007/978-94-017-8857-1

9 Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Chronic Care, 2012, AARP Public Policy Institute and the United Hospital Fund: October 2012: Washington DC, USA.

10 Hastrup LH, Van Den Berg B, Gyrd-Hansen D. Do informal caregivers in mental illness feel more burdened? A comparative study of mental versus somatic illnesses. Scandinavian Journal of Public Health. 2011; 39:598-607 . DOI: 10.1177/1403494811414247

11 Prince M, Brodaty H, Uwakwe R, Acosta D, Ferri C, Guerra M et al. Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey the Public Health of Caregiving. International Journal of Geriatric Psychiatry, 2012; 27:670-682. doi: 10.1002/gps.2727.

12 Talley R, Crews JE. Framing the Public Health of Caregiving. American Journal of Public Health. 2007; 97(3):393.

13 Viana MC, Gruber MJ, Shahly V, Alhamzawi A, Alonso J. Family burden related to mental and physical disorders in the world; results from the WHO World Mental Health (WMH) surveys. Revista Brasileira de Psiquiatria. 2013; 35:115-125. doi:10.1590/1516-4446-2012-0919.

14 Colombo F, Llena-Nozal A, Mercier J, Tjadens F. Help Wanted? Providing and Paying for Long-Term Care. 2011; OECD Health Policy Studies, OECD Publishing, doi.org/10.1787/9789264097759-en+.

15 Grady P, Gullatte M. The 2014 National Nursing Research Roundtable: The science of caregiving. Nursing Outlook. 2014; 62(5):362-365.

16 Buckner L, Yeandle S. Valuing Carers 2015, The rising value of carers' support. 2015, Carers UK: London.

17 Sinha M. Portrait of Caregivers, 2012: Spotlight on Canadians: Results from the General Social Survey. 2012; Statistics Canada Catalogue no. 89-652-No. 001.

18 Anderson LA, Edwards VJ, Pearson WS, Talley RC, McGuire LC, Andresen EM. Adult Caregivers in the United States: Characteristics and Differences in Well-being, by Caregiver Age and Caregiving Status. Preventing Chronic Disease. 2013; 10:E135. doi:10.5888/pcd10.130090.

19 Trivedi R, Beaver K, Bouldin ED, Eugenio E, Zeliadt SB, Nelson K et al. Characteristics and well-being of informal caregivers: Results from a nationally-representative US survey. Chronic Illness. 2014; 10(3)167-179.

20 Australian Bureau of Statistics (ABS). Disability, Ageing and Carers, Australia. Summary of Findings, 2012. Australian Bureau of Statistics. Cat. no. 4430.0. Canberra.

21 Australian Bureau of Statistics (ABS), Disability, Ageing and Carers, Australia. Summary of Findings. 2009. Australian Bureau of Statistics. Cat. no. 4430.0. Canberra.

22 Reither EN, Hauser RM, Yang Y. Do birth cohorts matter? Age-period-cohort analyses of the obesity epidemic in the United States. Social Science and Medicine, 2009; 69:1439–1448. doi: 10.1016/j.socscimed.2009.08.040.

23 SA Health, Health Omnibus Survey. Methodology. Brief Report of the South Australian Health Omnibus Survey on the SA Health Website;http://www.dh.sa.gov.au/pehs/pros/hos.html 2002-2004.

24 Twigg, J, Atkin K. Carers Perceived. Policy and practice in informal care. 1996, Milton Keynes, UK: Open University Press.

25 Schofield H, Bloch S, Herrman H, Murphy B, Nankervis J, Singh B. (Eds). Family caregivers: disability, illness and ageing. 1998, St Leonards, NSW, Australia: Allen and Unwin in Association with VicHealth, the Victorian Health Promotion Foundation.

26 Australian Bureau of Statistics. Census of Population and Housing. Socio-economic Indexes for Areas (SEIFA). Australia, 2011 (cat. no. 2033.0.55.001).

27 Rutherford MJ, Lambert PC, Thompson JR. Age-period-cohort modelling. Stata Journal. 2010; 606-627.

28 Australian Institute of Health and Welfare (AIHW). Disability and ageing. Australian Population patterns and implications. Chapter 2: Population ageing in Australia. Disability Series. 2000. AIHW Cat. No. DIS 19; ISBN 9781 74024 0901. Canberra.

29 Borowski A, Hugo G. Demographic trends and policy implications. In Borowski A, Engel S, Ozanne E (eds.) Ageing and Social Policy in Australia. 1997:37. United Kingdom: Cambridge University Press.

30 Hugo G, Luszcz M, Carson E, Hinsliff J, Edwards P, Barton C, King P. State of Ageing in South Australia. A report to the South Australian Office for the Ageing. In Section 8: Older Carers. Carers in South Australia. 2009:233, Department for Families and communities, Government of South Australia. Adelaide. ISBN: 9781920983819

31 Australian Institute of Health and Welfare (AIHW). Australia’s welfare 2015: in brief. Cat. no. AUS 193. Canberra: AIHW. 2.4. Informal Carers.

32 Hui-Chuan Hsu, Chin-Yin Lew-Ting, Shwu-Chong Wu. Age Period, and Cohort Effects on the Attitude Toward Supporting Parents in Taiwan. The Gerontologist. 2001. 41(6):742-750.

33 Lin S-F, Beck AN, Finch BK, Hummer RA, Master RK. Trends in US Older Adult Disability: Exploring Age, Period, and Cohort Effects. American Journal of Public Health November. 2012. 102;(11)2157-2163.

34 Taylor AW, Shi Z, Montgomerie A, Dal Grande E, Campostrini S. The use of a chronic disease and risk factor surveillance system to determine the age, period and cohort effects

on the prevalence of obesity and diabetes in South Australian Adults – 2003-2013. PLos One. 2015. 10(4):e0125233. doi:10.137/journal.pone.0125233

35 Hirst M. Carer Distress: A prospective population based study. Social Science and Medicine. 2005; 61: 697-708.

36 Jowsey T, McRae I, Gillespie J, Banfield M, Yen L. Time to care? Health of informal older carers and time spent on health related activities: an Australian survey. BMC Public Health. 2013; 13:374.

37 Hosseinpoor AR, Bergen N, Chatterji S. Socio-demographic determinants of caregiving in older adults of low- and middle income countries. Age and Ageing. 2013; 42: 330–338. doi: 10.1093/ageing/afs196. Accessed 17.10 2015.

38 Lutomski .JE, Baars MAE, Schalk BWM, Boter H, Buurman BM, den Elzen, WPJ et al. The Development of the Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS): A Large-Scale Data Sharing Initiative. PLoS One. 2013; 8(12):e81673. doi: 10.1371/journal.pone.0081673.

39 Australian Bureau of Statistics (ABS). Australian Demographic Statistics, Country of Birth. 24/09/2015. March 2015. Canberra.

40 Hugo G. The Demographic Facts of Ageing in Australia. Patterns of Growth. Australian Population and Migration Centre. March/April 2014.2(2). Policy Brief. The University of Adelaide.

41 Knight BG, Sayegh P. Cultural values and caregiving: the updated sociocultural stress and coping model. Journal of Gerontology. Psychological Sciences. 2010; 65B(1):5-13.

42 Kaambwa B, Lancsar E, McCaffrey N, Chen G, Gill L, Cameron ID, Crotty M, Ratcliffe J. Investigating consumers' and informal carers' views and preferences for consumer

directed care: A discrete choice experiment. Social Science and Medicine. 2015; 140:81-94. http://dx.doi.org/10.1016/j.socscimed.2015.06.034

43 Brehaut JC, Garner RE, Miller AR, Lach LM, Kissen AF, Rosenbaum PL. Health among caregivers of children with health problems: Findings from a Canadian population-based study. American Journal of Public Health. 2009; 99(7):1254-1262.

44 Schofield D, Cunich M, Shrestha R, Passey M, Kelly S, Tanton R, Veerman L. The impact of chronic conditions of care recipients on the labour force participation in Australia: which conditions are associated with higher rates of non-participation in the labour force? BMC Public Health. 2014; 14(1):561.

45 Deloitte Access Economics: The economic value of informal care in Australia in 2015. Carers Australia, June 2015.

46 Turcotte M. Family caregiving: what are the consequences? Insights on Canadian Society, Statistics Canada. Available: http://www5.statcan.gc.ca/olc-cel/olc.action?Objld=89-652-X2013001&ObjType=46&lang=en&limit=0.

47 Public Policy Institute. Caregiving in the US, Research Report, June 2015. Available: http://www.caregiving.org/caregivig2015/. Accessed 12 May 2016.

48 Yeandle S, Bennett C, Buckner L, Fry G, PriceC. Managing Caring and Employment. CES ReportNo.2, 2007. London: Carers UK.

49 Jenkins A, Rowland F, Angus P, Hales C. The future supply of informal care, 2003 to 2013: alternative scenarios. 2003, Australian Institute of Health and Welfare: Canberra.

50 Levine C, Gibson HG, Halper D, Hart AY, Lautz J, Gould DA. Young Adult Caregivers: A First Look at an Unstudied Population. American Journal of Public Health. 2005; 95(11):2071-2075.

51 Day C. Young adult carers: a literature review informing the reconceptualisation of young adult caregiving in Australia. Journal of Youth Studies. 2015; 18(7):855-866.

52 Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish a general population. Health and Quality of Life Outcomes. 2015;13(102). doi 10.1186/s12955-015-0309-2.

53 van den Berg B, Fiebig DG, Hall J. Well-being losses due to care-giving. Journal of Health Economics. 2014; 35:123-131. doi.org/10.1016/j.jhealeco.2014.01.008

Chapter 5. Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia

Statement of Authorship

Citation

Stacey AF, Gill TK, Price K, Taylor AW. Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia. BMJ Open 2018;8:e020173. doi:10.1136/ bmjopen-2017-020173.

Statement of Authorship:

Title of Paper:	Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia.
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	BMJ Open 2018;8:e020173. doi:10.1136/ bmjopen-2017-020173 BMJ Open online (http:// dx. doi. org/ 10. 1136/ bmjopen- 2017- 020173). Received 25 October 2017 / Revised 26 May 2018 / Accepted 30 May 2018

Principal Author

Name of Principal Author (Candidate)	Anne F Stacey [AFS]		
Contribution to the Paper	My contribution to this paper was in the conceptualization of researching health profiles of informal caregivers in SA. I contributed to the drafting of the manuscript, was part of discussions on survey methodology, wrote the literature review and Discussion, interpreted the data after analysis, redrafted manuscripts and acted as the corresponding author.		
Overall percentage (%)	60%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	30 October 2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Anne W Taylor [AWT]		
Contribution to the Paper	Participation as coordinator of all aspects of this study, contributed to overall design, drafting and methodology of the research project and edited all drafts. Critically reviewed & edited the manuscripts. Contributors AFS and AWT conceptualised the study. AWT supervised the study, and AFS drafted the manuscript. TKG and AFS conducted the statistical analyses. AWT, TKG and KP contributed to writing and critical review of the manuscript. All authors read and approved the final manuscript.		
Signature		Date	30 October 2019

Name of Co-Author	Tiffany K Gill [TKG]		
Contribution to the Paper	Contributed to conceptualisation of this study, provided advice on methods and analyses, Provided statistical tables for publication, critically reviewed & edited the manuscript Contributors AFS and AWT conceptualised the study. AWT supervised the study, and AFS drafted the manuscript. TKG and AFS conducted the statistical analyses. AWT, TKG and KP contributed to writing and critical review of the manuscript. All authors read and approved the final manuscript.		
Signature		Date	30 October 2019

Name of Co-Author	Kay Price [KP]		
Contribution to the Paper	Contributed to writing, critical review and editing process of the manuscript. Read and approved the final manuscript.		
Signature		Date	30 October 2019

Contextual Statement

The research relevant to carer health issues began with this second study, building on published evidence from a review of the caregiving literature. The objective was to answer the second research question*: Is there an association between the caregiving role as a risk factor for chronic disease and the health status of informal/family carers?* The research investigated and compared carer health outcomes with non-carers in terms of major risk factors and selected chronic medical conditions.

For the initial analysis, self-report biomedical data was accessed from a second state-wide population survey, the South Australian Monitoring and Surveillance System (SAMSS). This ongoing telephone survey was conducted monthly under the auspices of the South Australian government and yielded a wider sample of heterogeneous carers who were not limited by any particular type of caregiving or care recipient condition, or gender, a common weakness of other research. For this study period, carers were identified within SAMSS from 2010 to 2015.

In view of the mixed evidence on the impact of caregiving on the health of adult carers revealed in Australian and international research, it was pertinent to ascertain if informal caregiving was associated with any increased risk to carers having chronic conditions across the South Australian population. Therefore an additional aspect of carer morbidity included within this study was to determine the population attributable risk (PAR) to indicate the level of risk caring may have on the selected major chronic conditions in this research.

The following chapter presents the results of this analysis of risk factors and chronic medical conditions associated with informal caregiving and the PAR findings.

This manuscript was published by BMJ Open on 23 July 2018 and has been re-formatted to meet the requirements of this thesis. The manuscript in its published format is included in this thesis as Appendix C.

Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia

Author Emails:

Corresponding Author: anne.stacey@adelaide.edu.au

tiffany.gill@adelaide.edu.au

Kay.Price@unisa.edu.au

anne.taylor@adelaide.edu.au

Keywords: Carer health status, family carers, informal caregivers, risk factors, chronic conditions, survey, Population Attributable Risk

SHORT TITLE: Chronic health conditions and risk factors amongst informal caregivers

5.1 Abstract

Background

There is growing discussion on the impact of informal caregiving on the health status and morbidity of family carers. Evidence suggests a proportion of carers may be at risk of poor health outcomes. However, there are limited population-based studies which provide representative data on specific risk factors amongst carers (e.g. blood pressure, cholesterol, smoking status, activity, body mass index) and major chronic conditions (e.g. asthma, diabetes, arthritis). This study aimed to redress that imbalance.

Methods

Self-reported data were from the South Australian Monitoring and Surveillance System (SAMSS) a representative cross-sectional state-wide population-based survey of 600 randomly selected persons per month. SAMSS utilises computer assisted telephone interviewing (CATI) to monitor chronic health related problems and risk factors and to assess health outcomes. In total, 2,247 family carers were identified from 35,195 participants aged 16 and older for the five-year period from 2010-2015. Logistic regression analyses examined associations of being a carer with self-reported chronic diseases and health risk factors. In addition, the population attributable risk (PAR) of being a carer was examined for selected chronic conditions.

Results

The prevalence of carers was 6.4% and peak age group for carers was 50-59 years. Adjusted odds ratios for chronic conditions in carers were significant for all chronic conditions examined. Although there is a high prevalence of self-reported risk factors and chronic conditions among carers compared to non-carers at the population level, PAR findings suggest that caregiving is associated with a small to moderate increased risk of having these chronic conditions.

Conclusions

Monitoring of carer health and morbidity particularly ‘at risk’ individuals such as female carers with diabetes, remains important and provides an ongoing baseline for future surveys. To achieve this, caregiver-based studies need to become part of mainstream biomedical research at both epidemiological and clinical levels.

Strengths and limitations of this study

- This study used PAR analysis to determine the contribution of caregiving to major chronic conditions in carers, which to our knowledge has not been undertaken using carer data on health risk factors and chronic conditions before.
- As the Study uses cross sectional data, it describes associations between carers and major chronic illnesses and risk factors.

- The sampling process was part of ongoing representative state-wide surveys over a five year period so did not limit the recruitment of carers to a specific type of caregiving or care recipient condition
- The survey using telephone and CATI protocols was not conducive to in-depth interviewing of each participant therefore limited information about the cared for persons, their diagnosis and disability or the duration or intensity of care provided.
- Questions about the carers' relationships (to the care recipient), carer lifestyles and environments, were also limited.

5.2 Background

Increasing demands for home based informal care during the closing years of the twentieth century have seen the transition of family members and close friends taking on increasingly demanding long-term physical caregiving roles in the home [1-3]. Some of these complex caring activities include tasks that medical and nursing professionals would normally perform in health care settings [4-6]. Multi-disciplinary research has stimulated discussion on the impact of informal caregiving on carers' lives, health and wellbeing, morbidity and mortality, which has been comprehensively reviewed over recent years [7-11].

International and national evidence suggests that due to the protracted periods and intensity of caring for young or older persons with severe disability, chronic illness or dementia, a proportion of carers may be at risk of negative health outcomes [12-16]. Caregiving has been shown to be a risk factor for a range of chronic physical and mental health conditions such as cardiovascular disease (CVD), coronary heart disease (CHD), psychological distress, stress and depression which have been extensively investigated throughout the caregiving literature [17-

20]. Lifestyle and health risk factors impacting on carer health have included hypertension, overweight, smoking and disturbed sleep [19,21]. Diabetes and other chronic health conditions have also been identified and investigated amongst carer populations [22].

From these many examples of negative physical and psychological health outcomes reported to be linked to informal caregiving, most relate to well-established theoretical pathways of chronic stress or conceptual models of caregiving based on a stress-coping frameworks [9,15,23,24]. Other studies have reported carer morbidity in terms of the impacts of caring for longer hours per week, the greater intensity of caring activities and more years as a carer [14]. Kenny et al.[25] also focused on the duration of caregiving which could exacerbate pre-existing (chronic) conditions in some carers. Another Australian study of older carers revealed most had a chronic illness themselves and was linked to the time they spent on caring activities [26]. This trend was not restricted to particular age groups. In a large population-based Canadian survey of caregivers of children with chronic health problems, the parent carers were shown to be twice as likely to report chronic conditions. They also had greater odds of experiencing poorer general health than carers of healthy children [27].

Despite the predominance of literature highlighting deleterious consequences of caregiving, POSITIVE outcomes have been reported, acknowledging that a proportion of informal caregivers provide ongoing care and support without any detriment to their well-being [28]. For example, some studies show that carers can experience positive benefits and maintain an adequate quality of life and health status during their caregiving [29,30]. This may be influenced by what authors have referred to as “the healthy carer effect” [7,31,32]. Focusing on mortality and the caring role, Roth et al[33]. highlighted the need for a more balanced view when reporting the impact of caregiving on carer health with greater rigor in research methodology and definition of caregivers.

Rationale, research question and study hypothesis

Many studies, particularly earlier research, are limited by non-representative samples as described by Taylor et al [34]. As such, the rationale of this study was to assess self-reported health characteristics and status of adult carers from a large, population-based, random, sample of South Australian adults. The research question for this study was: Is there an association between the caregiving role as a risk factor for chronic disease and the health status of informal/family carers. Therefore, the study objective was to compare carer health status with adults who did not identify as carers in a population, adjusting for age and sex and determining population attributable risk to ascertain the contribution of caring to major chronic conditions. The rationale for examining gender differences was considered important as research consistently shows up to two thirds more carers are females than males who may not necessarily share the same health profiles.

5.3 Methods

This representative cross-sectional study obtained data from an ongoing state-wide population-based survey (the South Australian Monitoring and Surveillance System [SAMSS]). SAMSS is an epidemiological monitoring system established in 2002 to detect and facilitate understanding of trends in the prevalence of chronic conditions, risk and protective factors, and other determinants of health within the state of South Australia (SA)[35].

Sampling frame and recruitment

SAMSS is based on self-reported data which is systematically collected from a minimum of 600 randomly selected people each month on persons of all ages in the South Australian community. This risk factor surveillance system utilises computer assisted telephone interviewing (CATI) to monitor chronic health related problems and risk factors which can assess health outcomes and provide programme and policy information[36]. All households in South Australia with a telephone number listed in the Electronic White Pages of the telephone directory are eligible for selection in the sample. Additional information is available on sampling issues in telephone surveys[37].

A letter introducing SAMSS is sent to the household of each selected telephone number. The letter informs people of the purpose of the survey and indicates that they can expect a telephone call within the time frame of the survey. Data are collected by a contracted agency and interviews are conducted in English. At least six call-backs are made to the telephone number selected to interview household members. Where a refusal is encountered, another interviewer generally (at the discretion of the supervisor) calls later, in an endeavour to obtain the interview(s). Replacement interviews for persons who cannot be contacted or interviewed are not permitted. Additional details on SAMSS methodology are available [36]. This study used aggregated data from January 2010 to December 2015. Response rates over the period of 2010-2015 varied between 54.1% and 64.4% (mean 59.8%). Family carers were identified from adults aged 16 years and over for the period 2010-2015. The question asked was ‘Do you provide long-term care at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness?’

Outcome Variables

The selection of SAMSS outcome variables related to national determinants of health, namely diet, blood pressure, cardiac, respiratory and metabolic diseases and a range of chronic conditions[36]. During interviews, all respondents were asked if a doctor had ever told them they had diabetes, Cardiovascular Disease (heart attack, angina, heart disease and/or stroke), arthritis and osteoporosis. Asthma was defined as self-reported doctor diagnosed asthma and had experienced asthma symptoms in the previous 12 months. In addition, respondents were asked if they had ever been diagnosed by a doctor in the last 12 months with depression, anxiety, a stress related or other mental health problem.

Respondents were also asked if a doctor had ever told them they have and/or were currently receiving treatment or medication for high blood pressure (HBP) or high cholesterol. They were asked to provide the time they spent undertaking walking, moderate or vigorous physical activity over the past week. The time was summed, with the time spent undertaking vigorous activity multiplied by a factor of two to account for its greater intensity. This provided an indication as to whether respondents are undertaking a sufficient level of physical activity to provide a health benefit. This is defined as 150 minutes or more of activity each week and has been categorised into insufficient inactivity (no activity, active but not sufficient) and sufficient activity[38]. Body mass index (BMI) was derived from self-reported weight and height and classified as underweight (<18.5kg/m^2), normal (>=18.5<25.0 kg/m^2), overweight (>=25.0<30.0 kg/m^2) and obese (>=30 kg/m^2) [39]. Data were also collected on smoking status (current ex or non-), short term and long-term alcohol risk (derived from the number of alcoholic drinks per day and the number of times per week alcohol was consumed) [40] and how many serves of fruit and how many serves of vegetables they ate each day with the recommendation being at least two serves of fruit and five serves of vegetables per day[41].

An indicator of overall health status, the Short Form (SF-1) was determined by asking how they would rate their overall health (excellent, very good, good, fair, poor)[42]. Psychological distress was determined using the Kessler 10 (K10) scale which consists of 10 questions, all of which have the same response categories [43]. To score the K10, ‘all of the time’ was scored as a 5 and none of the time as 1. The 10 items were summed to provide a score of between 10 and 50, with scores over 22 indicating levels of psychological distress. Disability was defined as physical, mental, or emotional problems or limitations that the respondent reported having in their daily life[44,45].

Data Analysis

Demographic variables included in the analyses were age and gender. Frequencies and chi square tests were determined using SPSS version 24. Univariable and multivariable regression was undertaken using the “svy” commands in STATA V14 to determine crude and adjusted odds ratios (OR). In the univariable analyses carer status was assessed in association with sex, age, health status, risk factors and chronic conditions variables. Multivariable logistic regression was undertaken to determine the OR associated with carer status and the range of health-related variables adjusted for age and sex.

Population attributable risk (PAR) was calculated using STATA and the “*punaf”* add-in command to examine risk of caregiving to six chronic conditions (diabetes, asthma, CVD, arthritis, osteoporosis and mental health) [46]. For each of the chronic conditions five models were created to determine the RR and subsequently calculate the PAR of being a carer. Model 1 was unadjusted, Model 2 controlled for sex and age, Model 3 additionally controlled for educational attainment, income and work status, Model 4 additionally controlled for HBP and high cholesterol, and Model 5 further adjusting for sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity. The PAR analysis was repeated for both males and females separately.

Weighting was used to correct for disproportionality of the sample with respect to the population of interest. Data were weighted using raking methodology by area (metropolitan/rural), age, gender, marital status, country of birth, educational attainment and dwelling status (rented property vs other) to the most recent SA population data and probability of selection in the household so that the results are representative of the SA population [47].

Patient and Public Involvement Statement

This population-based survey is conducted based on the health priorities identified by the South Australian Department of Health and Ageing (SA Health). The study sample is randomly selected from the population and is community based, with participants required to answer survey questions. Results are disseminated using publications and policy development, where applicable by SA Health. Information about the survey is also available on the South Australian Health website. www.sahealth.sa.gov.au

5.4 Results

Of the 35,195 participants, 6.4% (95% CI 6.0-6.8) identified as carers. Overall 64.1% of carers were female. The peak age group for carers was 50-59 with rates declining after this age.

Table 1 presents overall carer/ non-carer prevalence comparisons for health status, risk factors and chronic disease variables. The overall health status of carers was lower than non-carers, with 10.2% more carers reporting their health as only fair or poor. The prevalence for disability was 9.9% and psychological distress 5.0% higher in carers than non-carers. Comparing carer health risk factors with non-carers, the prevalence estimates for HBP and high cholesterol were higher in carers and more carers were current smokers. Carers were less likely to be at risk from alcohol related risk or injury. Carers were also more likely to have all chronic conditions except osteoporosis.

Table 2 highlights the unadjusted and adjusted OR comparing carers to non-carers on their health status, health risks and chronic conditions. After adjustment for age and sex the prevalence of fair/poor health status (SF-1), disability, psychological distress, HBP, raised cholesterol and current smoking all remained significant. Carers were less likely to have lifetime risk of alcohol related harm and risk of alcohol related injury. Adjusted odds ratios for all the selected chronic conditions in carers were significant (arthritis, asthma, COPD, CVD, diabetes, mental health, osteoarthritis, except for osteoporosis).

Table 3 presents the PAR of being a carer for six chronic conditions for each of the five different models described above. In the unadjusted model, being a carer was associated with higher RR for all the chronic conditions. After adjustment for demographic and health risk factors (Model 5) only asthma (RR=1.26) and diabetes (RR=1.19) remained statistically significant ($p<0.05$). The PAR associated with being a carer for each condition was low.

To determine if there were any differences for males and females, the PAR analysis was then stratified by sex (Tables 4 and 5). In the unadjusted model, being a male carer was associated with diabetes (RR=1.79), CVD (RR=1.87), arthritis (RR=1.69), and mental health conditions (RR=1.32). After adjustment (Model 5) all associations for male carers disappeared. In Table 5, in the unadjusted model, being a female carer was associated with all the selected chronic conditions (diabetes (RR=1.53), asthma (RR=1.42), CVD (RR=1.26), arthritis (RR=1.39), osteoporosis (RR=1.30) and mental health (RR=1.23). After adjustment (Model 5), all associations for female carers disappeared except for diabetes (RR=1.21) and asthma (RR=1.33). For both males and females, the PAR associated with being a carer in relation to the range of chronic conditions remained small.

5.5 Discussion

This representative population-based study of carer health characteristics estimated there were 6.4% (95% CI 6.0-6.8) of the SA population aged 16 years and older, who were informal carers. It shows that carers were more likely to report chronic conditions, psychological distress, disability, and to perceive their health status as poor to fair. In terms of their risk factor status, after controlling for age and sex, carers were more likely to report smoking, raised cholesterol and high blood pressure than the non-carer population. The PAR of being a carer was minimal suggesting that informal caregiving does not appear to have contributed to the proportion of chronic disease in the sampled population, indicating that if there were no carers in the population, there would only be a small reduction in the number of cases of those with the specified chronic conditions. However, in the SA sample, carers reported more chronic illness than found in other large international studies[48,49].

Despite much published literature discussing chronic illness in carers, there remains a lack of details about the specific chronic conditions amongst carers, except for cardiovascular diseases and psychological conditions like stress and depression. Our current study of self-reported carer health in SA included a range of major chronic conditions in adult carers of all ages. The presence of asthma or other respiratory conditions is rarely demonstrated in other studies, although it is acknowledged that carers in this survey are living in Australia which has one of the highest rates of asthma in the world[50]. Other chronic conditions such as diabetes have been evident in a small number of population and clinical studies about informal caregivers [22].

In the biomedical literature authors have described the link between long term informal caregiving, chronic stress, and physiological changes including the metabolic syndrome and other endocrine and immune conditions [24,51]. Some of these studies have investigated the impact of caring for a spouse with dementia or a child with a disability where carers were seen to be more at risk of serious chronic physical conditions (such as Coronary Heart Disease) or mental health conditions [52].

There are interesting similarities and contrasts between South Australian and international surveys of informal carers. For example, two large population-based surveys exploring the characteristics of informal carers have some relevance to our research [48,49]. The 2011/12 Spanish population-based national survey, although limited to informal carers in households with a disabled resident, explored associations between the carers, disease and risk factors and compare them with matched controls [48]. Variables included diabetes, HBP, cholesterol, smoking, physical activity and drinking alcohol. Results indicated there was some evidence of depression and anxiety amongst female carers, but it was gender and the caring role that was seen to mediate chronic diseases in the Spanish carers [48]. Our survey results showed carers were more likely to have diabetes, asthma and arthritis, plus major risk factors such as smoking, raised cholesterol and HBP.

A Swedish population survey collected self-reported data between 2004-2013 with the aim of analysing associations between caregiving and health outcomes. The study also investigated carer self-rated health, the presence of long-term illness in carers and their psychological well-being [49]. Comparisons with non-carers showed that carers had lower psychological wellbeing which was also reported in the Spanish Survey [48]. The self-rated perceptions of health in Swedish carers were worse than non-carers and adversely associated with carer health [49].

Psychological distress has been consistently reported in caregiver research spanning at least three decades [53,54]. A British survey found there was a progressive increase of distress in carers as the amount of caregiving increased each week [14]. There are also well documented links between psychological distress and lower perceived health status, as well as associations between distress and the presence of chronic illness [54,55]. Although it is reported that women are statistically more likely to experience high psychological distress than men, the large volume of caregiving literature showing gender associated with distress, may have more to do with the fact that more women are in caregiving roles. As two thirds of carers from our survey were female, it may explain the finding of higher distress which supports that trend. Previous research undertaken by the current authors highlighted major demographic roles in carer status[56].

The greater likelihood of carers in our sample reporting risk factors of smoking, diabetes, raised cholesterol and HBP when compared with non-carers, is interesting and highlights important issues for assessment of carer morbidity. Despite the wealth of information generated over past decades on the health impacts of smoking within various populations, discussions linking caregiving stress with smoking, are few. Like the Spanish study and to our own SAMSS surveys, some population surveys in recent years have included caregiving and smoking status in their questionnaires, for example the BRFSS state-based surveys being conducted across the USA [57]. Their results showed some similar characteristics to the South Australian survey in terms of gender and age distribution, but more of our carers reported disability or were current smokers.

In relation to smoking characteristics, studies were mostly limited to the smoking habits of caregivers of dementia and AD patients. For example, one project which was part of the REACH II study, (a randomized clinical trial conducted 2002-2004 across several states of the US), showed that 40% of caregivers smoked, which was higher than smoking in the general population (22%) [58]. Findings indicated that nearly a quarter of informal carers of persons with Alzheimer's disease, reported increased smoking over the previous month, which was linked with age, ethnicity and employment. Younger carers were more likely to be smokers, with depression the main stressor. The study suggested that the smoking increase in carers could be explained by less caregiving skills and fewer coping resources of the carers [58]. Evidence cited from other studies linked the caregiver role with higher distress and to smoking behaviours with subsequent impact on heart disease [59].

Strengths and limitations

The strengths of this study are the large sample size, the use of standardized validated instruments, and a well-established definition of carers that have not altered over the period of data collection, and also the stability of the methodology used over the research period. Our sample of carers was selected from part of a large representative state-wide surveys over a five-year period and therefore results are applicable to the wider population. The use of PAR analysis to determine the contribution of caregiving to major chronic conditions in carers, to our knowledge has not been undertaken using carer data before. Specific variables for this study included some of the major health risk factors and chronic conditions, however as data were cross sectional, only associations between carers and chronic illnesses and risk factors could be reported. The self-reported nature of the data collection is also acknowledged as a weakness of the study with the known subtleties associated with persons over-or underreporting their behaviours. For example, measurements to confirm the accuracy of each person's height and weight, blood pressure and cholesterol, were not undertaken and so these may be under-estimated [60,61].

The structure of the data base and the methodology used also limits data collected to demographic questions and health indicators that are suited to telephone and CATI protocols [62]. We acknowledge that the relationship between caregiving and physical health is complex, bi-directional and can be mediated by several factors. For example, pre-existing health problems of the carers, diagnosis of the cared for person, duration and intensity of the caregiving, type of caring role (whether more physically oriented or emotionally demanding. Questions about carer lifestyles and environments, cultural, family and social characteristics were also very limited as the survey was not conducive to in-depth interviewing of each participant. Hence it was not possible to gather additional information about the cared for persons, their diagnosis and disability or the duration or intensity of care provided. Despite that, the sampling process did allow for carer heterogeneity within the population as it did not limit the recruitment of carers to any one type of caregiving or care recipient condition. Additional information from carers on specific somatization symptoms like sleeping disorders, musculoskeletal conditions, injuries, pain and general discomfort would have been valuable but these would require a separate study. There may be opportunity for this research in the future. Lastly it is acknowledged that the scope of health issues investigated in this study was limited partly due to lack of evidence between informal caring and health status after adjustments for various variables.

Conclusion

The profiles of carer health in this study highlight several aspects of caregiving in the South Australian population. This study shows that informal carers, now recognised as the partners in care, were in terms of their own health status, reporting a range of diagnosed diseases such as asthma, diabetes, arthritis, as well as risk factors of smoking, cholesterol and blood pressure. However, although carers in this sample had higher prevalence of almost all conditions, this higher prevalence disappeared for male carers in the process of statistical adjustments. For female carers after adjustments, all associations with chronic conditions disappeared except for diabetes and asthma. Therefore, any excess prevalence of chronic conditions in the population that results from people providing care is small. The-estimation of population attributable risk associated with caregiving for these selected physical health conditions was not expected to be large, and this is indeed what was found. Overall, we concluded that our findings of small effect-size differences in physical health outcomes between carers and non–carers was associated with small to moderate risk of informal carers having these chronic conditions.

This study is novel and useful, not just for demonstrating these differences in carer health status and morbidity, but rather to show that major health disorders are present within the carer population. These findings offer more detailed information on types of chronic health problems such as asthma, diabetes, arthritis and hypertension that need more appropriate disease management strategies that are specific to carers.

Our results also provide a baseline for assessing and comparing trends across a range of chronic conditions and risk factors amongst future carers. Therefore, monitoring of carer health and morbidity, particularly 'at risk' individuals such as female carers with diabetes and asthma, is important to track trends in chronic health conditions, distress and disability in informal caregivers To achieve this, caregiver-based studies need to become part of mainstream biomedical research at both epidemiological and clinical levels.

Declarations and Acknowledgments

SAMSS is owned by Department for Health and Ageing, South Australia, Australia. All collected source data are maintained and managed by Population Research and Outcome Studies, The University of Adelaide. The opinions expressed in this work are those of the authors and may not represent the position or policy of South Australian Department for Health and Ageing.

Author details

Anne F. Stacey[1], Tiffany K. Gill[1], Kay Price[2], Anne W. Taylor[1]

1 Population Research and Outcome Studies, Discipline of Medicine, The University of Adelaide, South Australia, Australia,
2 School of Nursing and Midwifery, University of South Australia, South Australia, Australia.

Author Contributors

Anne Stacey and Anne Taylor conceptualised the study. Anne Taylor supervised the study and Anne Stacey drafted the manuscript. Tiffany Gill and Anne Stacey conducted the statistical analyses. Anne Taylor, Tiffany Gill and Kay Price contributed to writing and critical review of the manuscript. All authors read and approved the final manuscript.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethics approval was obtained from the ethics committee of the Department of Health and Ageing, South Australia (SA) (436.02.2014 and HREC/14/SAH/200).

Competing interests

All authors declare they have no competing interests.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent for publication

All authors read and approved the final manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Availability of data

The data that support the findings of this study are available from South Australian Department of Health and Ageing, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of South Australian Department of Health and Ageing.

Table 5-1 Demographic and health variable comparison between carers and non-carers

DEMOGRAPHIC VARIABLES	**Non-Carers n**	**Non-carers %**	**Carers n**	**Carers %**	**p-value χ^2 test**
GENDER					
Males	15,998	48.6	806	35.9	
Females	16,949	51.4	1,441	64.1d	<0.001
AGE GROUP					
16-39	12,758	38.7	474	21.1	
40-49	5,823	17.7	468	20.9	
50-59	5,511	16.7	513	22.8	
60-69	4,341	13.2	395	17.6	
70-79	2,766	8.4	242	10.8	
80 and over	1,746	5.3	153	6.8	<0.001
HEALTH STATUS (Short Form) SF-1					
Excellent , Very G, Good	27,466	83.4	1,644	73.2	
Fair or Poor	5,481	16.6	602	26.8	<0.001
Disability					
No	25,510	77.4	1,515	67.5	
Yes	7,437	22.6	731	32.5	<0.001
Psychological Distress (K10)					
No	29,496	90.1	1,898	85.1	
Yes	3,249	9.9	333	14.9	<0.001
HEALTH RISK FACTORS					
Alcohol Related Lifetime Risk					
Does not drink	7,562	23	657	29.4	
No risk	14,257	43.4	1,077	48.2	
Lifetime risk of harm	11,005	33.5	499	22.4	<0.001
Alcohol Related Injury					
Does not drink	7,562	23.0	657	29.4	
No risk	20,538	62.6	1,376	61.6	
Alcohol Related Injury Risk	4,725	14.4	200	9.0	<0.001
Body Mass Index (BMI)					
Underweight	621	2.1	59	2.9	
Normal	11,252	38.2	649	31.0	
Overweight	10,235	34.8	701	33.5	
Obese	7,323	24.9	381	32.6	<0.001
Fruit					
1 or less serves / day	17,238	52.3	1,158	51.5	
2 or more serves / day	14,059	42.7	965	42.9	
None /Don’t eat fruit	1,585	4.8	119	5.3	
Don’t know	64	0.2	4	0.2	0.714
Vegetables					
1 or less serves / day	7,946	24.1	444	19.8	
2-4 serves / day	21,072	64	1,488	66.2	
5 or more serves / day	3,441	10.4	272	12.1	
None /Don’t eat vegies	259	0.8	23	1.0	
Don’t know	227	0.7	18	0.8	<0.001
Physical Activity					
No activity	4,245	16.4	322	19.2	
Activity - not sufficient	7,663	29.6	591	35.3	
Sufficient Activity	14,004	54.0	761	45.5	<0.001

Table 5.1 Continued

HEALTH VARIABLES	**Non-Carers n**	**Non-carers %**	**Carers n**	**Carers %**	**p-value χ^2 test**
High Blood Pressure					
No	26,258	79.7	1600	71.2	
Yes	6,689	20.3	647	28.8	<0.001
High Cholesterol					
No	27,604	83.8	1,701	75.7	
Yes	5343	16.2	545	24.3	<0.001
Smoking Status					
Non/Ex	27,792	84.4	1,797	80.0	
Current	5,151	15.6	449	20.0	<0.001
CHRONIC CONDITIONS					
Arthritis					
No	26,279	79.8	1,542	68.7	
Yes	6.668	20.2	704	31.3	<0.001
Asthma					
Don’t Know / No	28,638	86.9	1,832	81.5	
Yes	4,309	13.1	414	18.0	<0.001
Chronic Obstructive Pulmonary Disease					
Don’t Know / No	31,543	95.7	2,093	93.2	
Yes	1,404	4.3	153	6.8	<0.001
Cardiovascular Disease					
Don’t Know / No	30,487	93.8	2,002	6.2	
Yes, CVD	2,460	7.5	245	10.9	<0.001
Diabetes					
Don’t Know / No	30,274	91.9	1,953	86.9	
Yes	2,673	8.1	294	13.1	<0.001
Osteoporosis					
Don’t Know / No	31,481	95.5	2,099	93.4	
Yes	1,467	4.5	147	6.6	<0.001
Mental Health Problems					
Don’t Know / No	27,082	82.2	1,723	76.7	
Yes	5,865	17.8	523	23.3	<0.001

Data Source: SAMSS (South Australian Monitoring and Surveillance System) 2010-2015.

Table 5-2 Unadjusted and adjusted associations between carers and health related variables.

HEALTH VARIABLES	Carer n	Carer %	Unadjusted OR	p-value	Adjusted OR	p-value
HEALTH STATUS						
(Short Form) SF-1						
Excellent/ very good / good	1644	5.7	1.00		1.00	
Fair / poor	603	9.9	1.84 (1.59-2.12)	<0.001	1.62 (1.39-1.89)	<0.001
Disability						
No/ don't know	1516	5.6	1.00		1.00	
Yes	732	9.0	1.65 (1.45-1.89)	<0.001	1.44 (1.25-1.66)	<0.001
Psychological Distress [K10]						
No	1898	6.1	1.00		1.00	
Yes	334	9.3	1.60 (1.32-1.92)	<0.001	1.63 (1.35-1.98)	<0.001
HEALTH RISK FACTORS						
Alcohol Related Lifetime Risk						
Does not drink alcohol	657	8.0	1.00		1.00	
No risk	1078	7.0	0.87 (0.75-1.00)	0.056	0.82 (0.71-0.95)	0.009
Lifetime risk of harm	499	4.3	0.52 (0.43-0.63)	<0.001	0.64 (0.52-0.78)	<0.001
Alcohol Related Injury Risk						
Does not drink alcohol	657	8.0	1.00		1.00	
No risk	1376	6.3	0.77 (0.67-0.89)	<0.001	0.77 (0.66-0.88)	<0.001
Risk of alcohol related injury	201	4.1	0.49 (0.37-0.64)	<0.001	0.71 (0.53-0.95)	0.019
Body Mass Index (BMI)						
Underweight	60	8.8	1.00		1.00	
Normal	650	5.5	0.60 (0.38-0.96)	0.033	0.60 (0.37-0.96)	0.035
Overweight	701	6.4	0.71 (0.45-1.14)	0.156	0.69 (0.43-1.12)	0.134
Obese	682	8.5	0.97 (0.60-1.54)	0.886	0.87 (0.54-1.41)	0.582
Vegetables						
1 or less	445	5.3	1.00		1.00	
2 or more	1488	6.6	1.26 (1.07-1.49)	0.005	1.17 (1.00-1.38)	0.056
5 or more	272	7.3	1.41 (1.13-1.77)	0.002	1.23 (0.99-1.54)	0.065
None	24	8.3	1.62 (0.81-3.26)	0.176	1.68 (0.82-3.42)	0.156
Don't know	19	7.6	1.47 (0.80-2.70)	0.209	1.26 (0.69-2.29)	0.456
Fruit						
1 or less	1158	6.3	1.0		1.0	
2-4	965	6.4	1.02 (0.90-1.15)	0.742	0.95 (0.84-1.08)	0.425
5 or more	119	7.0	1.12 (0.81-1.54)	0.483	1.16 (0.85-1.59)	0.349
None	5	6.5	1.03 (0.33-3.26)	0.954	0.92 (0.29-2.86)	0.880
Don't know						
Physical Activity						
No activity	322	7.1	1.00		1.00	
Activity but not sufficient	591	7.2	1.02 (0.82-1.26)	0.886	1.07 (0.86-1.33)	0.549
Sufficient Activity	762	5.2	0.72 (0.58-0.88)	0.001	0.87 (0.70-1.07)	0.176
High Blood Pressure						
No/ don't know	1600	5.7	1.00		1.00	
Yes	647	8.8	1.59 (1.40-1.79)	<0.001	1.22 (1.06-1.40)	<0.001
High Cholesterol						
No/ don't know	1702	5.8	1.00		1.00	
Yes	546	9.3	1.66 (1.46-1.88)	<0.001	1.29 (1.13-1.47)	<0.001
Smoking Status						
Non /Ex	1798	6.1	1.00		1.00	
Current	450	8.0	1.35 (1.14-1.60)	0.001	1.43 (1.20-1.71)	<0.001

Table 5-3 Unadjusted and adjusted associations between carers and health related variables

HEALTH VARIABLES	Carer n	Carer %	Unadjusted OR	p-value	Adjusted OR	p-value
CHRONIC CONDITIONS						
Arthritis						
No/ don't know	1543	5.6	1.00		1.00	
Yes	705	9.6	1.80 (1.59-2.04)	<0.001	1.34 (1.16-1.55)	<0.001
Asthma						
No/ don't know	1833	6.0	1.00		1.00	
Yes	414	8.8	1.50 (1.27-1.78)	<0.001	1.49 (1.26-1.76)	<0.001
Chronic Obstructive Pulmonary Disease						
No/ don't know	2094	6.2	1.00		1.00	
Yes	154	9.9	1.65 (1.27-2.14)	<0.001	1.40 (1.07-1.83)	0.014
Cardiovascular Disease						
No/ don't know	2002	6.2	1.00		1.00	
Yes	245	9.1	1.52 (1.28-1.80)	<0.001	1.29 (1.06-1.56)	0.009
Diabetes						
No/ don't know	1953	6.1	1.00		1.00	
Yes	294	9.9	1.71 (1.43-2.03)	<0.001	1.43 (1.19-1.72)	<0.001
Osteoporosis						
No/ don't know	2100	6.3	1.00		1.00	
Yes	148	9.1	1.51 (1.26-1.81)	<0.001	1.02 (0.84-1.23)	0.835
Mental health conditions						
No						
Yes	1724	6.0	1.00		1.00	
	523	8.2	1.40 (1.21-1.63)	<0.001	1.34 (1.15-1.56)	<0.001

Data Source: SAMSS (South Australian Monitoring and Surveillance System) 2010-2015.
OR=Odds Ratio

Table 5-4 PAR of being a carer associated with six chronic conditions, unadjusted and four multivariable models.

	Model 1: Unadjusted		**Model 2**		**Model 3**		**Model 4**		**Model 5**	
	RR *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*
Diabetes	1.61 (1.38-1.88)	3.77 (2.29-5.22)	1.32 (1.14-1.52)	2.35 (0.98-3.69)	1.23 (1.07-1.42)	1.86 (0.46-3.23)	1.19 (1.02-1.38)	1.58 (0.12-3.01)	1.19 (1.02-1.39)	1.67 (0.09-3.22)
Asthma	1.41 (1.23-1.62)	2.55 (1.37-3.72)	1.41 (1.23-1.62)	2.58 (1.38-3.77)	1.32 (1.15-1.52)	2.16 (0.94-3.36)	1.30 (1.13-1.49)	2.02 (0.84-3.18)	1.26 (1.10-1.46)	1.94 (0.64-3.22)
Cardio-vascular disease	1.46 (1.25-1.70)	2.85 (1.50-4.19)	1.13 (1.00-1.29)	1.02 (-0.10-2.12)	1.12 (0.96-1.30)	0.96 (-0.37-2.28)	1.07 (0.93-1.24)	0.61 (-0.71-1.91)	1.05 (0.91-1.22)	0.47 (-0.91-1.83)
Arthritis	1.55 (1.42-1.69)	3.39 (2.59-4.17)	1.19 (1.10-1.30)	1.55 (0.77-2.33)	1.13 (1.04-1.22)	1.07 (0.29-1.85)	1.12 (1.03-1.21)	1.00 (0.22-1.76)	1.08 (0.99-1.18)	0.71 (-0.10-1.52)
Osteoporosis	1.48 (1.25-1.75)	2.95 (1.44-4.43)	1.06 (0.90-1.24)	0.51 (-0.94-1.95)	0.99 (0.84-1.17)	-0.05 (-1.57-1.45)	0.99 (0.84-1.17)	-0.10 (-1.62-1.40)	0.98 (0.82-1.17)	-0.16 (-1.87-1.52)
Mental Health	1.31 (1.17-1.47)	1.93 (1.00-2.85)	1.25 (1.12-1.41)	1.65 (0.71-2.58)	1.10 (0.98-1.23)	0.72 (-0.23-1.67)	1.08 (0.96-1.21)	0.62 (-0.32-1.55)	1.03 (0.90-1.19)	0.28 (-0.93-1.47)

Data Source: SAMSS (South Australian Monitoring and Surveillance System) 2010-2015.

RR=Relative Risk, PAR=Population Attributable Risk. For each of the 6 chronic conditions listed above, five models were created.

Model 1: Unadjusted PAR.
Model 2: Adjusted PAR controlling for sex and age;
Model 3: Adjusted PAR controlling for age, sex, educational attainment, income and work status;
Model 4; Adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP and high cholesterol; and
Model 5: Adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP, high cholesterol, sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity.

Table 5-5 PAR of being a carer associated with six chronic conditions, unadjusted and four multivariable models, Males

	Model 1: Unadjusted		**Model 2**		**Model 3**		**Model 4**		**Model 5**	
	RR (95% CI)	*PAR % (95% CI)*	*RR (95% CI)*	*PAR % (95% CI)*	*RR (95% CI)*	*PAR % (95% CI)*	*RR (95% CI)*	*PAR % (95% CI)*	*RR (95% CI)*	*PAR % (95% CI)*
Diabetes	1.79 (1.41-2.72)	3.64 (1.71-5.53)	1.35 (1.08-1.67)	2.10 (0.36-3.82)	1.22 (0.98-1.52)	1.49 (-0.29-3.25)	1.16 (0.93-1.46)	1.17 (-0.71-3.02)	1.18 (0.93-1.50)	1.33 (-0.70-3.32)
Asthma	1.17 (0.89-1.55)	0.83 (-0.73-2.35)	1.25 (0.94-1.66)	1.11 (-0.47-2.66)	1.13 (0.86-1.50)	0.66 (-0.91-2.20)	1.13 (0.86-1.48)	0.63 (-0.91-2.14)	1.07 (0.80-1.44)	0.38 (-1.29-2.02)
Cardio-vascular Disease	1.87 (1.51-2.32)	4.01 (2.21-5.77)	1.20 (1.01-1.43)	1.36 (-0.04-2.74)	1.18 (0.96-1.45)	1.33 (-0.44-3.07)	1.10 (0.97-1.34)	0.79 (-0.97-2.52)	1.11 (0.90-1.37)	0.86 (-0.98-2.67)
Arthritis	1.69 (1.43-2.01)	3.21 (1.90-4.51)	1.20 (1.04-1.39)	1.25 (0.21-2.29)	1.15 (0.98-1.36)	1.03 (-0.26-2.31)	1.14 (0.97-1.34)	0.96 (-0.34-2.24)	1.11 (0.94-1.32)	0.79 (-0.52-2.08)
Osteoporosis	1.19 (0.75-1.89)	0.90 (-1.73-3.46)	0.83 (0.53-1.30)	-1.18 (-3.80-1.37)	0.70 (0.44-1.13)	-2.39 (-5.27-0.41)	0.69 (0.43-1.12)	-2.51 (-5.42-0.31)	0.47 (0.15-1.53)	-5.36 (-12.55-1.37)
Mental Health	1.32 (1.04-1.66)	1.50 (0.07-2.91)	1.37 (1.09-1.74)	1.70 (0.25-3.13)	1.08 (0.86-1.35)	0.44 (-0.98-1.84)	1.07 (0.86-1.34)	0.42 (-0.98-1.80)	1.01 (0.77-1.31)	0.04 (-1.70-1.74)

Data Source: SAMSS (South Australian Monitoring and Surveillance System) 2010-2015.

RR=Relative Risk, PAR=Population Attributable Risk. For each of the 6 chronic conditions listed above, five models were created.

Model 1: Unadjusted PAR.
Model 2: Adjusted PAR controlling for sex and age;
Model 3: Adjusted PAR controlling for age, sex, educational attainment, income and work status;
Model 4; Adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP and high cholesterol; and
Model 5: Adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP, high cholesterol, sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity.

Table 5-6 PAR of being a carer associated with six chronic conditions, unadjusted and four multivariable models, Females

	Model 1: Unadjusted		**Model 2**		**Model 3**		**Model 4**		**Model 5**	
	RR *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*	*RR* *(95% CI)*	*PAR %* *(95% CI)*
Diabetes	1.53 (1.25-1.87)	3.97 (1.73-6.16)	1.32 (1.09-1.59)	2.70 (0.59-4.77)	1.27 (1.04-15.4)	2.38 (0.22-4.50)	1.22 (1.01-1.47)	2.06 (-0.11-4.17)	1.21 (1.00-1.47)	2.16 (-0.16-4.43)
Asthma	1.42 (1.22-1.66)	3.21 (1.56-4.83)	1.46 (1.24-1.71)	3.39 (1.71-5.04)	1.38 (1.18-1.63)	3.00 (1.30-4.68)	1.36 (1.16-1.59)	2.83 (1.17-4.46)	1.33 (1.13-1.56)	2.84 (1.02-4.63)
Cardio vascular Disease	1.26 (1.02-1.55)	1.97 (-0.03-3.94)	1.09 (0.90-1.31)	0.75 (-1.04-2.51)	1.09 (0.88-1.34)	0.78 (-1.25-2.77)	1.05 (0.86-1.29)	0.48 (-1.52-2.44)	1.01 (0.82-1.24)	0.12 (-1.96-2.15)
Arthritis	1.39 (1.26-1.53)	2.96 (1.95-3.96)	1.15 (1.05-1.26)	1.39 (0.42-2.34)	1.11 (1.02-1.22)	1.09 (0.12-2.05)	1.10 (1.01-1.21)	1.00 (0.04-1.95)	1.06 (0.97-1.17)	0.65 (-0.39-1.67)
Osteoporosis	1.30 (1.09-1.55)	2.29 (0.53-4.01)	1.09 (0.93-1.29)	0.86 (-0.73-2.42)	1.05 (0.88-1.26)	0.51 (-1.24-2.23)	1.05 (0.88-1.25)	0.48 (-1.28-2.20)	1..01 (0.70-1.46)	0.17 (-4.59-4.71)
Mental Health	1.23 (1.07-1.40)	1.74 (0.51-2.95)	1.22 (1.06-1.39)	1.68 (0.44-2.91)	1.11 (0.97-1.27)	0.92 (-0.34-2.17)	1.09 (0.95-1.24)	0.77 (-0.48-1.99)	1.05 (0.89-1.23)	0.43 (-1.18-2.02)

Data Source: SAMSS (South Australian Monitoring and Surveillance System) 2010-2015. RR=Relative Risk, PAR=Population Attributable Risk. For each of the 6 chronic conditions listed above, five models were created.

Model 1: Unadjusted PAR.
Model 2: Adjusted PAR controlling for sex and age

References

1. Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Donelan K. When the caregiver needs care: The plight of vulnerable Caregivers. Am J Public Health. 2002; 92(3):409-413.
2. Viana MC, Gruber MJ, Shahly V, Alhamzawi A, Alonso J. Family burden related to mental and physical disorders in the world; results from the WHO World Mental Health (WMH) surveys. Rev Bras Psiquiatr. 2013;35:115-125. doi:10.1590/1516-4446-2012-0919. PMID: 23904015.
3. Cummins R, Hughes J, Tomyn A, Gibson A, Woerner J, Lai L. Australian Unity Wellbeing Index Survey:17.1. The wellbeing of Australians: Carer health and wellbeing. (Special Report). 2007. Melbourne: Deakin University. Carers Australia and Australian Unity. Available at: http://www.acqol.com.au/reports/auwbi.php.
4. Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Chronic Care. AARP Public Policy Institute and the United Hospital Fund. October 2012. Available at: www.aarp.org/family/caregiving/info-10-2012.
5. McDonald J, McKinlay E, Keeling S, Levack W. How family carers engage with technical health procedures in the home: a grounded theory study. BMJOpen 2015, 5:e007761. doi:10.1136/bmjopen-2015-007761.
6. Stajduhar KI, Funk L, Toye C, Grande GE, Todd CJ. Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). Palliative Medicine. 2010, 24(6):573-593. doi:10.1177/0269216310371412.
7. Pinquart M, Sörensen S. Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. J Gerontol B Psychol Sci Soc Sci. 2007;62B (2):P126-P137.

8. Saria MG, Nyamathi A, Phillips LR, *et al.* The Hidden Morbidity of Cancer: Burden in Caregivers of Patients with Brain Metastases. Nurs Clin North Am 2017;52:159–78.
9. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one’s physical health? A meta-analysis. Psychol Bull. 2003;129(6): 946–972. doi.org/10.1037/0033-2909.129.6.946.
10. Vitaliano PP, Young HM, Zhang J. Is Caregiving a Risk Factor for Illness? Curr Dir Psychol Sci 2004;13:13–16.
11. van den Berg B, Fiebig DG, Hall J. Well-being losses due to care-giving. J Health Econ. 2014;35:123–131. doi: 10.1016/j.jhealeco.2014.01.008 PMID: 24662888.
12. Richardson TJ , Lee SJ, Berg-Weger M, Grossberg GT. Caregiver health: Health of caregivers of Alzheimer’s and other dementia patients. Curr Psychiatry Rep. 2013;15:367. doi: 10.1007/s11920-013-0367-2.
13. Edwards B, Higgins DJ. Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia. Med J Aust. 2009;190: S61-S65.
14. Smith L, Onwumere J, Craig T, McManus S, Bebbington P, Kuipers E. Mental and physical illness in caregivers: results from an English national survey sample. Br J Psychiatry. 2014;205: 197-203. doi: 10.1192/bjp.bp.112.125369.
15. Schulz R, Sherwood PR. Physical and Mental Health Effects of Family Caregiving. Physical and Mental Health Effects of Family Caregiving. Am J Nurs. 2008;108(9 Supplement): 23-27 doi:10.1097/01.NAJ.0000336406.45248.4c.
16. Legg L, Weir CJ, Langhorne P, Smith LN, Stott DJ. Is informal caregiving independently associated with poor health? A population-based study. J Epidemiol Community Health. 2013;67: 95–97. doi: 10.1136/jech-2012-201652.
17. Miyawaki A, Tomio J, Kobayashi Y, Yakahashi H, Noguchi H, Tamiya N. Impact of long-hours family caregiving on non-fatal coronary heart disease risk in middle-aged

people: Results from a longitudinal nationwide survey in Japan. Geriatrics Gerontology International. 2017, doi:10.1111/ggi.13061.

18. Phillips, A. C., Gallagher, S., Hunt, K., Der, G. and Carroll, D. (2009), Symptoms of depression in non-routine caregivers: The role of caregiver strain and burden. British Journal of Clinical Psychology, 48: 335–346. doi: 10.1348/014466508X397142.
19. Laks J, Goren A, Duenas H, Novick D, KAHLE-Wrobleski K. Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. International Journal of Geriatric Psychiatry. 2016, 31:176-185. doi:10.1002/gps.4309.
20. Hussain R, Wark S, Dillon G, Ryan P. Self-reported physical and mental health of Australian carers: a cross-sectional study. BMJ Open 2016;6:e011417. doi:10.1136/bmjopen-2016-011417.
21. Capistrant BD, Moon JR, Glymour MM. Spousal Caregiving and Incident Hypertension. Am J Hypertens. 2012;25(4):437-443. doi:10.1038/ajh.2011.232.
22. Lebrec J, Ascher-Svanum H, Chen YF, Reed C, Kahle-Wrobleski K, Hake AM, Raskin J, Naderali E, Schuster D, Heine RJ, Kendall DM. Effect of diabetes on caregiver burden in an observational study of individuals with Alzheimer's disease. BMC Geriatr. 2013;16(1):93. doi: 10.1186/s12877-016-0264-8.
23. Luecken LJ, Lemery KS. Early caregiving and physiological stress responses. Clin Psychol Rev 2004;24:171–91.
24. Vitaliano PP, Scanlan JM, Zhang J, et al. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. Psychosom Med 2002;64:418–35.
25. Kenny PK, King MT, Hall J. The physical functioning and mental health of informal carers: evidence of care-giving impacts from an Australian population-based cohort. Health Soc Care Community. 2014;22(6):646-659. doi: 10.1111/hsc.12136.

26. Jowsey T, McRae I, Gillespie J, Banfield M, Yen L. Time to care? Health of informal older carers and time spent on health related activities: an Australian Survey. BMC Public Health. 2013;13:374. http://www.biomedcentral.com/1471-2458/13/374.
27. Brehaut JC, Kohen DE, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL. Health Among Caregivers of Children With Health Problems: Findings From a Canadian Population-Based Study. Am J Public Health. 2009;99:1254-1262. doi:10.2105/AJPH.2007,129817.
28. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. Int J Geriatr Psychiatry. 2002;17: 184-188. doi:10.1002/gps.561.
29. Ratcliffe J, Lester LH, Couzner L, Crotty M. An assessment of the relationship between informal caring and quality of life in older community-dwelling adults – more positives than negatives? Health Soc Care Community 2013;21(1):35–46.
30. O'Reilly D, Rosato M, Maguire A, Wright D. Caregiving reduces mortality risk for most caregivers: a census-based record linkage study. Int J Epidemiol, 2015;1959–1969 doi: 10.1093/ije/dyv172.
31. Vlachantoni A, Evandrou M, Falkingham J, Robards J. Informal care health and mortality. 2013; Maturitas 74:114-118. doi.org/10.1016/j.maturitas.2012.10.013.
32. Buyck JF, Bonnaud S, Bourmendi A, Andrieu S, Bonenfant S, Goldberg M, Zins M, Ankri J. Informal caregiving and self-reported mental and physical health: results from the Gazel Cohort Study. Am J Public Health. 2011;101(10): 1971-9. doi: 10.2105/AJPH.2010.300044.
33. Roth DL, Fredman L, Haley WE. Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies. Gerontologist, 2015;55(2): 309–319. doi:10.1093/geront/gnu177.

34. Taylor R, Ford G, Dunbar M. The Effects of caring on health: A community-based longitudinal study. Soc Sci Med. 1995;40(10): 1407-1415.
35. SAMSS Brief Report. No. 2002-20. 2002. Adelaide: Department of Health. Available from: http://www.health.sa.gov.au/ pros.
36. SAMSS Technical Paper 1 – Method. Population Research and Outcomes Studies Unit. South Australian Monitoring and Surveillance System (SAMSS). Survey Methodology. SAMSS Technical Paper Series No.1/04, August 2004. Adelaide: Department of Health.
37. Dal Grande E, Taylor AW. Sampling and coverage issues of telephone surveys used for collecting health information in Australia: results from a face-to-face survey from 1999 to 2008. BMC Med Res Methodol 2010;10:77.
38. BeActive Australia. Commonwealth of Australia May 1999. National Physical Activity Guidelines for Adults, Department of Health and Aged Care. Canberra. Reprinted 2005. Available at http://www.beactive.com.au/downloads/National%20Guidelines/Adult%20Brochure%20Final.pdf.
39. World Health Organization (WHO). (2010). BMI classification. Geneva, Switzerland: World Health Organization, [updated 30/04/2013 Accessed 29/04/2013]; Available from: http://apps.who.int/bmi/index.jsp?introPage=intro_3.html.
40. National Health and Medical Research Council. (NHMRC). Australian Guidelines to Reduce Health Risks from Drinking Alcohol, Canberra, Australia: National Health and Medical Research Council; 2009.
41. National Health and Medical Research Council). (NHMRC). Food for health, dietary guidelines for Australians: a guide to healthy eating. 2005; Australian Government, Canberra (2005) Available from: http://www.nhmrc.gov.au/publications/synopses/_files/n31.pdf [22.09.08]

42. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). 1. Conceptual Framework and Item Selection. Med Care. 1992;30(6):473–483.
43. Kessler RC, Mroczek DK. Final versions of our non-specific psychological distress scale. University of Michigan, Ann Arbor: Survey Research Centre of the Institute for Social Research; 1994.
44. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. Psychol Med. 1979;9(1): 139-45.
45. Goldney RD, Dal Grande E, Fisher LJ, et al. Population attributable risk of major depression for suicidal ideation in a random and representative community sample. J Affect Disord. 2003;74(3): 267-272.
46. Rockhill B, Newman B, Weinberg C. Use and misuse of population attributable fractions. Am J Public Health. 1998;88:15-19.
47. Dal Grande E, Chittleborough CR, Campostrini S, Tucker G, Taylor AW. Health Estimates Using Survey Raked-Weighting Techniques in an Australian Population Health Surveillance System. Am J Epidemiol. 2015; 182(6):544-556. doi: 10.1093/aje/kwv080.
48. Gonzalez-de Paz L, Real J, Borrás-Santos A, Martínez-Sánchez JM, Rodrigo-Baños V, Dolores Navarro-Rubio M. Associations between informal care, disease and risk factors: A Spanish country-wide population-based study. J Public Health Policy. 2016;37(2):173-89. doi:10.1057/jphp.2016.3. Epub 2016 Feb 11.
49. Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish general population. Health Qual Life Outcomes. 2015;13:109.
50. To T, Stanojevic S, Moores G, Gershon AS, Bateman ED, Cruz AA, Boulet L-P. Global asthma prevalence in adults: findings from the cross- sectional world health survey. BMC Public Health. 2012;12:204. http://www.biomedcentral.com/1471-2458/12/204.

51. Roepke SK, Mausbach BT, Patterson TL, von Känel R, Ancoli-Israel S, Harmell AL, Dimsdale JE, Aschbacher K, Mills PJ, Ziegler MG, Allison M, Grant I. Effects of Alzheimer caregiving on allostatic load. J Health Psychol. 2011;16(1): 58–69. doi:10.1177/1359105310369188.
52. Lovell B, Moss M, Wetherell M. The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD. Psychoneuroendocrinology. 2012;37: 534-542.
53. Vitaliano PP, Schulz R, Kiecolt-Glaser J, Grant I. Research on physiological and physical concommitants of caregiving:Where do we go from here ? Annals of Behavioural Medicine. 1997;19(2):117-123.
54. Hirst M, Carer distress: A prospective, population-based study. Soc Sci Med. 2005;61:697-708. doi:10.1016/j.socscimed.2005.01.001.
55. Price K, Gill T, Winefield H, Koster C, Chittleborough C, Taylor A, Hornibrook L, Administrative Assistant. Determinants of Psychological Distress – A Literature Review. The Assessment of the Determinants and Epidemiology of Psychological Distress (ADEPD) Study. Discipline of Psychiatry, University of Adelaide. December 2008.
56. Stacey AF, Gill TK, Price K, Warmington R, Taylor AW. Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period Cohort Effects 1994– 2014. PLoSONE. 2016;11(9): e0161994.doi:10.1371/ journal.pone.0161994.
57. Crawford A, DeFries E, Brumback B, Andresen E. Characteristics of caregivers and care recipients: Results from 2007 Kansas Behavioral Risk Factor Surveillance System. Kansas Department of Health and Environment Office of Health Promotion. 2009. Accessed from www.kdheks.gov/brfss/PDF/ BRFSS_2007_CaregiverModule_Rpt.pdf.

58. Salgado-Garcia FI, Zuber JK, Graney MJ, Nichols LO, Martindale-Adams JL, Andrasik F. Smoking and Smoking Increase in Caregivers of Alzheimer’s Patients. Gerontologist. 2015;55(5):790-792. doi:10.1093/geront/gnt149.
59. Von Kanel R, Mausbach BT, Patterson TL, Dimsdale JE, Aschbacher K, Mills PJ, Ziegler MG, Ancoli-Israel S, Grant I. Increased Framingham coronary heart disease risk score in dementia caregivers relative to non-caregiving controls. Gerontology. 2008;54:131-137. doi: 10.1159/000113649.
60. Taylor AW, Dal Grande E, Gill TK, Chittleborough CR, Wilson DH, Adams RA, Grant JF, Phillips P, Appleton S, Ruffin RE. How valid are self-reported height and weight? A comparison between CATI self-report and clinic measurements using a large cohort study. Aust N Z J Public Health 2006;30:238–46.
61. Taylor A, Dal Grande, Gill, T, Pickering S, Grant J, Adams R., Phillips P. Comparing self-reported and measured high blood pressure and high cholesterol status using data from a large representative cohort study Aust N Z J Public Health. 2010;34(4):394-400.
62. Dal Grande, E.; Fullerton S, Taylor, A. Reliability of self-reported health risk factors and chronic conditions questions collected using the telephone in South Australia, Australia BMC Med Res Methodol. 2012; 12(1):1-10.

Chapter 6. Biomedical health profiles of unpaid family carers in an urban population in South Australia.

Statement of Authorship

Citation

Stacey AF, Gill TK, Price K, Taylor AW. Biomedical health profiles of unpaid family carers in an urban population in South Australia. PLoS ONE, 2019; 14(3): e0208434. https://doi.org/10.1371/journal.pone.0208434.

Statement of Authorship:

Title of Paper:	Biomedical health profiles of unpaid family carers in an urban population in South Australia.
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	PLoS ONE, 2019; 14(3): e0208434. https://doi.org/10.1371/journal.pone.0208434. Received: May 1, 2018; Accepted: March 14, 2019; Published: March 28, 2019

Principal Author

Name of Principal Author (Candidate)	Anne F Stacey [AFS]		
Contribution to the Paper	My contribution to this paper was in the conceptualization of researching the biomedical [clinical and blood-based data] of informal caregivers in South Australia. I contributed to the drafting of the manuscript, was part of discussions on use of the survey methodology, wrote the literature review and discussion, interpreted the data after analysis, re-drafted manuscripts and statistical tables.		
Overall percentage (%)	60%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	30 October 2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Anne W Taylor [AWT]		
Contribution to the Paper	Participation as coordinator of all aspects of this large study, contributed to overall design, drafting and methodology of the research project. Critically reviewed & edited the manuscripts. Contributors AFS and AWT conceptualised the study. AWT and TKG supervised the study, and AFS drafted the manuscript. TKG conducted the statistical analyses, AFS interpreted the analyses. AWT, TKG and KP contributed to writing and critical review of the manuscript. All authors read and approved the final manuscript.		
Signature		Date	30 October 2019

Name of Co-Author	Tiffany K Gill [TKG]		
Contribution to the Paper	Contributed to conceptualisation of this study, provided advice on methods and analyses. Provided statistical tables for publication. Critically reviewed and edited the manuscript. Contributors AFS and AWT conceptualised the study. AWT supervised the study, and AFS drafted the manuscript. TKG and AFS conducted the statistical analyses. AWT, TKG and KP contributed to writing and critical review of the manuscript. All authors read and approved the final manuscript.		
Signature		Date	30 October 2019

Name of Co-Author	Kay Price		
Contribution to the Paper	Part of critical review and editing process of the manuscript. Read and approved the final manuscript.		
Signature		Date	30 October 2019

Contextual Statement

The aim of this part of the project was to answer the third research question *“Do family informal caregivers show differences in their biomedical profiles compared to non-carers?* It is the first study to examine biomedical profiles of carers in South Australia, and to our knowledge, the most comprehensive clinical review of carers in Australia.

The previous investigations provided findings on state-wide carer health, based only on self-report data. This next and final stage of the research project also collected self-report health data (using questionnaires from carers), but in addition, for the first time, empirical data was available about carer risk factors and chronic health conditions. This was using the NWAHS, a cohort of carers from an urban population in Adelaide.

The focus of this study was to include health-related variables that were in line with variables examined in previous studies. Inflammatory marker information was only available from participants aged 40 years and over and thus this age group only was included in the analysis. The literature review had revealed interesting but mixed relationships between with CRP, TNFα and IL-6 and informal caregivers, which could be contrasted with our South Australian carer cohort. The following chapter presents the results of analysis of the health profiles of carers aged 40 years and over.

The manuscript was published by PLoS One on 14 March 2019 and has been re-formatted for inclusion in this thesis which follows as Chapter 6. A reprint of the original publication is included in Appendix D.

Biomedical health profiles of unpaid family carers in an urban population in South Australia.

Anne F. Stacey[1], Tiffany K. Gill[2], Kay Price[3], Anne W. Taylor[1]

1 Population Research and Outcome Studies, Discipline of Medicine,

The University of Adelaide, South Australia, Australia

2 Adelaide Medical School, The University of Adelaide

3 School of Nursing and Midwifery, University of South Australia, South Australia, Australia.

Author Emails:

Corresponding Author: anne.stacey@adelaide.edu.au

tiffany.gill@adelaide.edu.au

Kay.Price@unisa.edu.au

anne.taylor@adelaide.edu.au

Short Title; Biomedical health profile of South Australian urban informal caregivers

6.1 Abstract

Objectives

To compare the biomedical health profile and morbidity of adult carers with non-carers.

Methods

The North West Adelaide Health Study (NWAHS) is a representative population-based longitudinal biomedical cohort study of 4056 participants aged 18 years and over at Stage One. Informal (unpaid) carers were identified in Stage 3 of the project (2008-2010). Risk factors, chronic medical conditions and biomedical, health and demographic characteristics using self-report and blood measured variables were assessed. Data were collected through clinic visits, telephone interviews and self-completed questionnaires. Risk factors included blood pressure, cholesterol/lipids, body mass index (BMI), smoking and alcohol intake. Chronic medical conditions included cardiovascular and respiratory diseases, diabetes, and musculoskeletal conditions. Blood measured variables were routine haematology, biochemistry, Vitamin D, and the inflammatory biomarkers high sensitivity C-Reactive Protein (hs-CRP), Tumor Necrosis Factor alpha (TNFα) and Interleukin-6 (Il-6).

Results

The prevalence of carers aged 40 years and over was 10.7%, n=191. Carers aged 40 years and over were more likely to assess their health status as fair/poor and report having diabetes, arthritis, anxiety and depression. They also reported insufficient exercise and were found to

have higher BMI compared with non-carers. Significant findings from blood measured variables were lower serum Vitamin D and haemoglobin. Male carers had raised diastolic blood pressure, higher blood glucose, lower haemoglobin and albumin levels and slightly elevated levels of the inflammatory biomarkers TNFα and hs-CRP.

Discussion and Conclusions

This study confirms informal carers had different biomedical profiles to non-carers that included some chronic physical illnesses. It identifies that both female and male carers showed a number of risk factors which need to be considered in future caregiver research, clinical guidelines and policy development regarding carer morbidity.

6.2 Introduction

Although research findings in the caregiving literature have been mixed and at times contradictory, providing long-term care of persons with disability, physical, mental health illnesses and frailty, has been associated with higher rates of hypertension, heart disease, arthritis and other chronic conditions in informal family carers [1-7]. The psychological impact of informal caregiving on carer health, which has received greater emphasis than chronic conditions in the caregiving literature, has indicated that carers frequently experience stress, distress, anxiety and depression, particularly female carers who usually represent the majority of carers [2,8-13]. Published research has mostly been based on self-reported data, while biomedical profiles of carer health that include clinic measured physical and physiological data have been slower to emerge, especially those using well-designed population studies.

Population studies based on self-report data

National surveys of family carers from the United Kingdom, Europe, Canada, Australia and other countries have described some international trends of carer morbidity at the population level[14-19]. They have found independent associations of chronic exposure to informal caregiving and self-reported poor health even at the extremes of the age range, in both younger and older carers[20]. In recent years surveys of the public health impacts of caregiving in the United States of America (USA) indicate family carers have had a slight to modest decline in their health [21,22]. Carers also reported chronic medical conditions such as diabetes, and joint pain was identified as a recurrent health problem. Assessing risk factors among carers revealed responsible health behaviours in relation to taking exercise and checking cholesterol levels, and those carers surveyed were less likely to be current smokers [23].

Biomedical measures of carer health: Inflammatory biomarkers

Biomedical studies in the caregiver literature examining inflammatory, immunological and metabolic profiles of carers include mainly small clinical studies. Some of these demonstrated associations between informal caregiving and altered biomarkers in carers of persons with stroke, cancer or the frail aged [4,24]. More detailed physiological assessments of carers' health have revealed elevated levels of pro-inflammatory biomarkers, in particular plasma cytokines such as Interleukin (IL-6), high sensitivity C-Reactive Protein (hs-CRP) and Tumor Necrosis Factor alpha (TNFα) [25-27].

There have been mixed results from other studies of biomarkers among carer participants. For example, a recent review of the literature (2017) found only weak associations between caregiving, stress and increased pro-inflammatory biomarkers, such as IL-6 and CRP among spousal and female home based relatives caring for older persons. The carers themselves were often aged sixty years and over [28]. Another systematic review that was specific to the psychobiological impact of dementia caregiving had a focus on chronic stress and incorporated a broad range of biological markers [29]. An overview of risk factors in carers confirmed differences in blood pressure and heart rate between carers and non-carers, also Body Mass Index (BMI) and weight gain were reported to be different between male and female carers [30]. Caregiving stress was found to be moderated by gender [30] while an earlier study had reported that the negative impact of caregiving on health was not observed in individuals who did not find caregiving to be stressful [7]. As much past research has been based on dementia caregiving and stress in carers, there is a lack of population research which can provide a broader profile of carer health characteristics and offer a different perspective of the distribution of chronic disease among informal carers.

This study therefore aimed to compare general and biomedical health status of informal carers with non-carers from the same population. Access to comprehensive self-reported and biomedical data from the North West Adelaide Health Study (NWAHS) made our investigation possible and provided a wider selection of haematological and biochemical blood variables rarely featured in carer projects. Research objectives were to analyse a range of risk factors and selected chronic medical conditions, using both self-report and clinically measured blood and other biomedical variables, including a selection of inflammatory biomarkers.

The research questions were: Do informal family carers show different biomedical profiles in terms of blood and other measured variables than non-carers? and secondly; Is there an association between the caregiving role, risk factors and chronic conditions amongst South Australian informal carers?

6.3 Methods

Study Design and Setting

The NWAHS is a representative population based longitudinal cohort study set in the north and western suburbs of Adelaide, which is the capital of South Australia. The northern and western regions of Adelaide number approximately half of the city's population and one quarter of South Australia's population. These regions reflected the demographic profile of the state's population at the time of the initial data collection. The study was designed to investigate the prevalence of a number of chronic conditions and health-related risk factors along a continuum. Stage 1 occurred between 1999 and 2003, Stage 2: 2004-6 and Stage 3: 2008-10. Details of all methods used in the NWAHS, including original sample selection procedure, entry and exclusion criteria, original interview schedules and biomedical measurements have been comprehensively described and published elsewhere [31,32].

Study population and participants

Initially 4,056 participants aged 18 years were randomly selected and recruited by telephone interview in Stage 1. The analysis for this paper focuses on data collected from Stage 3 (2008-2010). Data collection at Stage 3 included (1) a Computer Assisted Telephone Interview (CATI); (2) a self-completed questionnaire; (3) a biomedical examination at a clinic. Overall 2,487 (67%) of the eligible sample completed all of these assessments. The main focus of our study compared health risk factors, chronic medical conditions and biomedical health characteristics with non-carers, using self-report, clinic and blood measured variables. Only those aged over 40 years were included in this study as testing for all of the inflammatory biomarkers was only conducted on this group.

Self-reported variables

In order to determine the prevalence of carers within the cohort, participants were asked as part of the self-complete questionnaire:

> *Do you provide long-term care at home for a parent, partner, child, other relative or friend, who has a disability, is frail, aged or who has a chronic mental or physical illness?*

Demographic characteristics selected for this study included age, sex, marital status, work status, educational status, annual household income, and employment status (including whether participants received government support from age, carer or disability pensions). Participants self-reported if they had ever been diagnosed by a doctor for arthritis, cardiovascular (CVD) (i.e. heart attack, stroke, angina, transient ischaemic attack), or a mental health condition (i.e. anxiety, depression, stress related problems).

Smoking was assessed using standard questions which related to current smoking and the frequency of smoking and alcohol consumption was determined from questions based on the National Heart Foundation Risk Factor Prevalence Study undertaken in 1989 [33]. Physical activity was determined from the amount of walking, moderate and/or vigorous activity undertaken over a one week period, which was then categorized into “No activity”, “Insufficient activity” (less than 150 minutes of walking, moderate and/or vigorous activity) and “Sufficient” (150 minutes or more per week) [34]. General health was assessed using the SF-1, which is the first question of the Short Form 36 81(SF-36) [35].

Clinic measured variables

The presence of diabetes was derived from a self-reported doctor diagnosis of diabetes and/or a fasting plasma glucose level of greater than or equal to 7.0 mmol/L. The presence of asthma was determined using self-reported, doctor diagnosed asthma and spirometry measures following administration of salbutamol. For example, a change in Forced Expiratory Volume in one second, (FEV1) >=12% and >200ml, or absolute change greater or equal to 400ml from baseline measurements [36,37].

Other clinically measured risk factors included blood pressure readings, height and weight for calculation of BMI, and waist and hip circumference measurements to determine waist/hip ratio (WHR) using standardized measurement techniques. Details of procedures for measuring and techniques have been described and published elsewhere [38-40]. BMI was categorized according to the World Health Organization (WHO) criteria and a high WHR was defined as > 1.0 for males and >0.85 for females [41,42].

A fasting blood sample was collected by venipuncture from all participants who were able to provide an adequate amount of blood sample at the clinic visit. Samples were transported to an accredited National Association of Testing Associations (NATA) laboratory for analysis. Biochemical measurements of hs-CRP, glucose and albumin levels were determined using an Olympus AU5400 (Beckman Coulter, USA) and glycosylated haemoglobin (HbA1c) using a Bio-Rad Variant II (HPLC) (Bio-Rad, USA).

High density lipoprotein (HDL) and total cholesterol were analysed using an Olympus AU5402. Both low density lipoprotein (LDL) and the total cholesterol/HDL ratio were calculated from these results. Haemoglobin (Hb) levels were determined using a Sysmex XE (Japan). Vitamin D levels to April 2010 were determined using and enzyme Immunoassay method from Immunodiagnostic Systems (IDS, UK) and performed on a BEST 2000 automated enzyme-linked immunosorbent assay (ELISA) system from Biokit. From April 2010, Vitamin D was measured using and automated Chemiluminescent assay from IDS and performed on an iSYS Automated Immunoassay system from IDS. The patient comparison during the change-over gave a Passing-bablock regression equation of $y = -1.61 + 1.07x$ with a bias of -1.9nmol/L indicating good agreement.

The fasting blood sample measured a series of inflammatory biomarkers in study participants aged 40 years and over. IL-6, TNFα, e-Selectin (e-Sel) and Myeloperoxidase (MPO) levels were measured with an ELISA and Cobas autoanalyzer (Roche Diagnostics US).

Data weighting

In Stage 1, data were weighted by region (western and northern health regions), age group, sex and probability of selection in the household to the Australian Bureau of Statistics 1999 Estimated Resident Population and the 2001 Census data [43,44]. Weighting was undertaken to reflect the population of interest and to correct for potential non-response bias in which some groups of respondents may be over- or under-represented. Stage 3 was reweighted using the 2009 Estimated Resident Population for South Australia and incorporated participation in the three components (CATI), self-complete questionnaire, clinic), whilst retaining the original weight from Stage 1 in the calculation. All analyses in this paper, where applicable, are weighted to the population of the northern and western suburbs of Adelaide.

Data Analysis

Statistical analysis was conducted using SPSS version 24 (IBM, Armonk, NY, USA) and STATA version 14 (StataCorp, College Station, TX, USA)[166]. Descriptive analysis (proportions, means, medians where applicable) were determined for all of the predictor variables (demographic characteristics, chronic conditions and health risk factors). Bivariable analysis using chi-square tests and including post hoc tests using the adjusted residuals, were used to determine which categories were significantly different from the other categories, combined for both carers and non-carers. All continuous data were tested for normality using Kolmogorov-Smirnov and Shapiro-Wilk tests, and data that were not normally distributed were analysed using non-parametric tests (Mann-Whitney U). Generalised linear models using the binary outcome variable of presence carer or not a carer were used with the “svy” estimators in STATA and weighted data to determine the relative risks (RR) of each of the predictors, in association with the outcome variable. Separate multivariable models were created for males and females which included all possible predictors.

Ethical approval

All protocols and procedures were approved by the Human Research Ethics Committee of The Queen Elizabeth Hospital, in Adelaide, South Australia, and all participants provided written informed consent.

6.4 Results

The prevalence of carers aged 40 and over was 10.7% (95% CI 9.3-12.3), n=191. Table 1 presents the demographic characteristics for carers aged 40 years and over compared to non-carers. Carers were more likely to be female, married and have a lower education level. They were also more likely to be retired, undertake home duties or were unable to work. Carers had higher levels of uptake of carer pensions, age pension and disability pension. Carers were also more likely to be over 60 years of age and have an annual income of between $20,000 and $40,000 per year.

Table 2 presents bivariable analysis of general health, risk factor and chronic conditions of carers aged 40 years and over, compared to non-carers. Carers were more likely to have higher BMI and WHR than non-carers but were less likely to undertake a sufficient level of physical activity or have a high alcohol risk. Carers were also more likely to have diabetes, arthritis, anxiety, depression and fair/poor health status compared to non-carers.

Table 3 presents a comparison between carers and non-carers for clinic measured variables (blood pressure and blood measured tests). Significant differences were evident between carers and non-carers for the blood measured variables hs-CRP, HbA1c, Hb, and Vitamin D (Table 3). There were no significant differences with regard to the other inflammatory biomarkers IL-6, MPO, TNFα, and e-Sel.

Table 4 presents the results of the multivariable models for males and females. Pension type (carer, aged, disability) was excluded from the analysis, as were total cholesterol and total cholesterol/HDL ratio due to collinearity. Male carers compared with non-carer males were more likely not to be employed (RR 2.52, 95% CI 1.19-5.31; p=0.015); undertake some activity (RR 2.21, 95% CI 1.22-4.00; p=0.009); have lower systolic (RR 0.96, 95% CI 0.94-0.99; p=0.011) but higher diastolic blood pressure (RR 1.13, 95% CI 1.07-1.20; p=<0.001). Male carers were also more likely to have higher levels of blood glucose (RR 1.40, 95% CI 1.03-1.89; p=0.03), raised hs-CRP (RR 1.03, 95% CI 1.00-1.06; p=0.023) and TNFα (RR 1.12, 95% CI 1.06-1.20; p=<0.001) but lower levels of HbA1c (RR 0.54, 95% CI 0.33-0.89; p=0.016) and albumin (RR 0.90, 95% CI 0.82-1.00; p=0.040). Female carers were less likely to be widowed, separated or divorced and to have lower levels of income below $40,000 when compared with non-carer females.

6.5 Discussion

Reviewing our research questions, we examined whether informal family carers showed different biomedical profiles in terms of blood and other measured variables than non-carers. Overall our carers aged 40 years and over had only slightly elevated levels of the inflammatory biomarkers TNFα, hs-CRP, and HbA1c but they showed lower Vitamin D and Hb levels. The second research question investigated if there was an association between the caregiving role, risk factors and chronic conditions amongst informal carers.

Our findings indicate that when carers were compared with non-carers, they were more likely to have higher BMI and WHRs, report less than optimal physical activity and describe their health status as fair/ poor. In terms of chronic conditions carers were more likely to report diabetes, arthritis, anxiety and depression than non-carers. However, stress-related conditions were not evident amongst carers in our study and they reported significantly lower or no alcohol consumption risk (p=0.041). They were also less likely to be current smokers.

Vitamin D and other blood measured variables

Comparing the large number of haematological and biochemical variables of carers with non-carers in the NWAHS, yielded a few differences in blood pictures, for instance, levels of Vitamin D, Hb, HbA1c, TNFα and hs-CRP. Most of these results were within acceptable ranges, but of the five blood measured variables of interest, 25 (OH)D (Vitamin D) was the most notable result showing that carers had lower median levels when compared with non-carers. Despite a large body of research on Vitamin D in the biomedical literature, of the studies collated, no comparable clinical research and population surveys could be identified reporting any association of Vitamin D with carer health outcomes in the context of informal caregiving. One previous project involving Stage 3 participants of the NWAHS, although not specific to carers, does provide an insight into Vitamin D and associated characteristics of that population[45].

Obesity (indicating higher BMI), physical activity, gender and seasonality all appeared to have a strong association with Vitamin D levels. For instance, participants had lower Vitamin D levels even with seasonal variations during summer / spring months [45]. In our study based on participants from the same NWAHS population, carers had lower levels of Vitamin D in comparison to non-carers. This finding is important as Vitamin D can prevent conditions such as osteoporosis, particularly in post-menopausal women who represent up to half of all the female carers. Although osteoporosis was not significant amongst carers in our study, if carers were to develop osteoporosis related to low Vitamin D and nutritional deficiencies, they could be more at risk of injuries from frequently moving and lifting the persons being cared for [3].

Haemoglobin was found to be statistically different between the NWAHS carers and non-carers. Albumin, another blood measured variable, was lower amongst male carers who were more at risk of lower levels than non-carers (RR=0.90, CI 95% 0.82-1.00; p=0.040) however these levels were not of clinical significance. Again, of the studies reviewed in the literature, none specifically highlighted haemoglobin or albumin in carer populations. Several studies reported measuring haematological and serum chemistry in carers as part of larger projects but, found few notable differences between the full blood counts with non-carers, other than variables specific to their own studies [46,47].

Inflammatory biomarkers: TNFα and hs-CRP

In our study there were only slight statistically significant differences in blood measured inflammatory biomarkers amongst NWAHS carers aged 40 years and over. namely, the immune regulatory cytokines hs-CRP and TNFα. These are acute phase markers of inflammation, especially hs-CRP which is used as a non-specific but very sensitive biomarker for detecting systemic inflammatory conditions, tissue damage and infection, as well as early onset cardiovascular disease [48].

Although inflammatory biomarkers are not as frequently assessed in biomedical studies of caregivers, previous studies have identified male carers as more vulnerable to physiological and pathological changes as predicted by the presence of hs-CRP [25,49,50]. Our NWAHS male carers had minimally raised plasma levels of inflammatory biomarkers TNFα and to a lesser extent, hs-CRP when compared to non-carer male but the cytokine IL-6 levels were much lower in male carers when compared with male non-carers (RR 0.75, 95% CI 0.75-1.00; p=0.051) (See Table 4). Von Kanel et al. (2012) [30] had observed that being a carer did not necessarily show increased hs-CRP levels, but rather hs-CRP increased over time as the caregiving burden continued. The longer duration of caregiving with elevated biomarkers (TNFα and hs-CRP) suggested a pro-inflammatory state [25]. As we did not have equivalent carer details in our own study, we were unable to examine biomarkers in terms of the duration of caring to make a comparison.

HbA1c, Type II Diabetes and related chronic conditions

Blood measured HbA1c levels were inconsistent in our study. Glycated Haemoglobin (HbA1c) is a measure that provides information on long-term glucose control and is a recognised biomarker used to establish the prevalence or presence of Type 2 diabetes. Our findings showed significant but minimal differences in HbA1c blood levels in our sample of carers, however self-report data suggested carers were at greater risk of Type 2 diabetes than non-carers. This was a similar finding to a previous state-wide population survey also using self-report data from South Australian carers which we conducted between 2010-2015 [51].

Few published Australian population surveys that included carers have featured specific chronic conditions such as diabetes [20], while self-report health surveys conducted in Brazil, the USA and other countries have reported Type 2 diabetes in informal carers. In the biomedical literature there has been limited attention given to investigating diabetes-related characteristics in carers, and with the exception of one study [52], the emphasis has usually been on Type 2 diabetes in the person being cared for, rather than the carer.

Risk factors: physical activity and BMI

Carers in our study were more likely to report insufficient activity or “no activity” than non-carers, but how participants interpreted the questions about their own physical activity may have been a factor in their responses. For example, carers might be physically active but have a different type and level of activity associated with demanding caregiving duties. Older carers in particular and those with their own disabilities may not be able to participate in recreational exercise or sport. This was partly investigated in a population-based study which included community dwelling informal carers aged 40 years and over (n=1380) from the German Ageing Survey [53]. They found decreased sporting activities and higher BMI amongst carers could lead to adverse health outcomes for carers. It was also concluded that time spent caregiving performing regular personal care activities and nursing care services for persons in a poor state of health could be associated with stress and depression, which can in turn be linked with higher BMI [53]. These results are in keeping with trends from our own research confirming higher BMI in carers [54].

Stress and anxiety

In the caregiving literature, parent carers, dementia and mental health carers have reported lower perceived health status [55,56]. NWAHS carers were also more likely to state their health was fair/poor. From a large British study of over 8000 middle aged men and women, carers rated their physical or mental health as fair/poor however it was further suggested that the rating of *poor* health could be “proxy markers of perceived stress”[57]. Our findings from NWAHS carers overall did not specifically indicate carer-related stress which was unexpected, but anxiety and depression were two other aspects of psychological morbidity identified amongst our carers. Sherwood et al. had found a significant association between anxiety in male carers of spouses with cancer and anxiety was seen as a risk factor for higher levels of inflammation in male carers [58].

Female carers when compared with female non-carers in our study had fewer significant risk factors or chronic conditions, but male carers presented quite a mixed biomedical profile when compared with non-carer males. The female carers in our study tended towards more metabolic and anthropometric manifestations that suggested a stronger association with BMI and adiposity. Kang et al. however had found that while there was an association of metabolic dysfunction with family caregiving, no gender differences emerged from their large national study [59].

Strengths and limitations

The main strengths of this study are that both biomedical and self-report data were obtained from a large sample of metropolitan residents. It included a substantial number of blood tests and measured variables which were collected at clinics and during interviews. Clinically accessed information was a central part of this study which included a wide range of observed and measured variables for major risk factors, seven chronic conditions, inflammatory and other biomarkers. Carers in this study were more heterogeneous than recruited participants as they did not represent any one particular group of people living with specific disabilities or medical conditions. This type of large population study is usually cost prohibitive and requires the collaboration of a consortium of academic and government groups. It therefore offers a more comprehensive review of carer health characteristics than is usually possible.

There were limitations however in relation to the assessment of carer participants identified and grouped as a subset of this cohort study so they could be compared with the non-carers within the same population. The definition of *informal carer* chosen to identify carers was the standard used within Australia, however other carer specific questions were not included to further classify the type of caregiving. Within this study therefore we do not have details of the cared for person's age, diagnosis, health, disability or disease status, and their level of dependency, all of which have been reported as impacting on the role as informal carer. Nor was information collected on duration of caring - for example how long spent caring; how many hours per day or per week they were providing care and the level of intensity of their caring role. Further we do not have information on whether the participant was the main carer; if they were co-resident with the person being cared for; what other caregiving demands were put on the carers and which carers were combining personal caregiving with paid employment. Another weakness of this study is that we do not know which conditions reported by the carers, were pre-existing and therefore whether the risk factors and chronic conditions could be actual health outcomes of the caregiving experience. Also, we do not know the severity of carers' illnesses and if they had multiple health problems as not all potential chronic conditions were included in this research.

Conclusions and recommendations

Our study has demonstrated that in terms of blood and other clinic measured variables the NWAHS carers did show some differences in their biomedical health profiles when compared with non-carers. In contrast to other published studies our findings suggest carers may be at risk of lower Vitamin D and Hb levels thus revealing a possible gap in current knowledge of carer morbidity. It is acknowledged that the differences in other blood measured variables were minimal when compared with non-carers, but the significance of lower Hb, raised TNFα as well as hs-CRP in male carers highlights the need for ongoing assessments of their biomedical health status [60].

From a population perspective, urban carer participants' results indicated that there are carers providing care in less than optimum health, reporting chronic conditions of diabetes, arthritis, anxiety and to a lesser extent, depression. These cross-sectional analysis results provide only weak associations between the caregiving role, risk factors and chronic conditions. In contrast to previous studies, stress was not a significant finding. Higher BMI amongst carers generally, and particularly in female carers, combined with other risk factors such as insufficient physical activity, warrants closer scrutiny.

Our research therefore recommends closer monitoring of carer health and morbidity trends across populations over time with special attention to the choice of health variables requiring ongoing measurement and assessment. This would contribute to the development of more balanced health policies and clinical guidelines for chronic diseases that are carer specific and age sensitive. Policymakers and health professionals therefore need to take into account the differences in carer health status, risk factors and morbidities for male and female carers.

Acknowledgments and Declaration

We wish to acknowledge all participants of the North West Adelaide Health Study.

The NWAHS

Data from this study formed part of the NWAHS. As this has been an ongoing cohort study, these data are available on application to the chief investigators. Details are available at http://health.adelaide.edu.au/pros/data/nwahs/.

Authors' contributions

AT and AS conceptualised the study. AT, TG and KP supervised the study. AS drafted the manuscript. TG conducted the statistical analyses. All authors contributed to the planning, writing and critical review of the manuscript. All authors read and approved the final manuscript.

Competing Interests

The authors declare that they have no competing interests.

Table 6-1 Demographic characteristics of carers compared to non-carers, aged 40 years and over

Variable	**Carers**			**Non-carers**			**p value**
	n	%	95% CI	n	%	95% CI	X^2
GENDER							
Male	78	9.1 ↓	7.3-11.3	779	90.9 ↑	88.7-92.7	
Female	113	12.1 ↑	10.1-14.5	818	87.9 ↓	85.5-89.9	0.038
AGE GROUP (YEARS)							
40-59	92	9.1 ↓	7.3-11.3	921	90.9 ↑	88.7-92.7	
60 years and over	99	12.8 ↑	10.7-15.2	676	87.2 ↓	84.8-89.3	0.011
MARITAL STATUS							
Married/de facto	150	11.8 ↑	10.1-13.8	1122	88.2 ↓	86.2-89.9	
Divorced/Separated	9	5.3 ↓	3.2-8.7	160	94.7 ↑	91.3-96.8	
Widowed	10	6.1	2.7-13.2	146	93.9	86.8-97.3	
Never Married	11	12.6	6.8-22.2	73	87.4	77.8-93.2	0.015
EMPLOYMENT STATUS							
Self/ Full / Part time	63	6.6 ↓	5.1-8.6	883	93.4 ↑	91.4-94.9	
Unemployed	5	19.4	7.9-40.2	21	80.6	59.8-92.1	
Home duties	13	19.3 ↑	11.3-31.0	53	80.7 ↓	69.0-88.7	
Retired	74	13.3 ↑	10.8-16.3	482	86.7 ↓	83.7-89.2	
Student/Volunteer	2	13.0	3.4-38.9	12	87.0	61.2-96.6	
Unable to work	14	21.6 ↑	12.6-34.5	52	78.4 ↓	65.5-87.4	
Carer	8	100.0 ↑	-	-	-	-	<0.001
EDUCATIONAL STATUS							
High school	122	13.3 ↑	11.2-15.8	795	86.7 ↓	84.2-88.8	
Trade/ Cert./ Dip.	42	8.0 ↓	5.9-10.7	482	92.0 ↑	89.3-94.1	
Bachelor degree or higher	15	6.3 ↓	3.7-10.4	226	93.7 ↑	89.6-96.3	<0.001
ANNUAL HOUSEHOLD INCOME ($Aus)							
Up to $20,000	22	10.8	7.2-15.8	180	89.2	84.2-92.8	
$20,000-$40,000	75	18.3 ↑	14.9-22.3	332	81.7 ↓	77.7-85.1	
$40,000-$60,000	16	5.9 ↓	3.8-9.1	259	94.1 ↑	90.9-96.2	
$60,000-$80,000	20	9.4	5.8-14.8	193	90.6	85.2-94.2	
$80,000-$100,000	15	8.5	4.7-15.0	157	91.5	85.0-95.3	
More than $100,000	12	4.2 ↓	2.3-7.6	272	95.8 ↑	92.4-97.7	
Not stated	20	15.3	9.7-23.3	112	84.7	76.8-90.3	<0.001
PENSIONS							
Carer Payment							
No	63	6.2 ↓	4.7-8.0	959	93.8 ↑	92.0-95.3	
Yes	26	86.7 ↑	64.7-95.9	4	13.3 ↓	4.1-35.3	<0.001
Age Pension							
No	63	6.2 ↓	4.7-8.0	959	93.8 ↑	92.0-95.3	
Yes	64	15.1 ↑	12.1-18.8	357	84.9 ↓	81.2-87.9	<0.001
Disability Pension							
No	63	6.2 ↓	4.7-8.0	959	93.8 ↑	92.0-95.3	
Yes	14	16.8 ↑	10.1-26.5	69	83.2 ↓	73.5-89.9	<0.001

Chi square post hoc tests ↑↓ indicates statistically significantly difference in categories using adjusted standardised residual

Table 6-2 Risk factor and chronic conditions profile of carers compared with non-carers, aged 40 years and over

Variable	Carers			Non-carers			
	n	%	95% CI	n	%	95% CI	X^2
Body Mass Index							
Underweight/ normal	29	7.1 ↓	5.0-10.0	381	92.9 ↑	90.0-95.0	
Overweight	76	11.1	8.9-13.9	602	88.9	86.1-91.1	
Obese	72	12.2	9.8-15.2	515	87.8	84.8-90.2	0.027
Waist-to-hip ratio							
Normal	102	9.1 ↓	7.5-11.0	1025	90.9 ↑	89.0-92.5	
High	76	13.6 ↑	11.0-16.8	481	86.4 ↓	83.2-89.0	0.004
Smoking status							
Non smoker	91	11.7	9.0-13.6	733	88.9	86.4-91.0	
Ex-smoker	73	10.4	8.4-12.8	625	89.6	87.2-91.6	
Current smoker	27	10.7	7.3-15.5	224	89.3	84.5-92.7	0.919
Alcohol Risk							
Non-drinker, no risk	112	12.2	10.2-14.6	807	87.8	85.4-89.9	
Low risk	60	9.9	7.7-12.6	551	90.1	87.4-92.3	
Intermediate to very high	3	3.6 ↓	1.2-9.8	72	96.4 ↑	90.2-98.8	0.041
Physical Activity							
No activity	49	14.1 ↑	10.5-18.7	295	85.9 ↓	81.3-89.5	
Activity but not sufficient	71	12.5	10.0-15.6	498	87.5	84.4-90.0	
Sufficient activity	58	7.6 ↓	5.9-9.7	704	92.4 ↑	90.3-94.1	0.001
Asthma							
No	134	9.9	88.3-91.6	1218	90.1	88.3-91.6	
Yes	44	13.2	82.5-90.1	288	86.8	82.5-90.1	0.079
Cardiovascular disease							
No	158	10.3	8.9-12.0	1370	89.7	88.0-91.1	
Yes	22	13.8	8.7-21.1	135	86.2	79.0-91.3	0.185
Diabetes							
No	149	10.0 ↓	8.5-11.6	1344	90.0 ↑	88.4-81.5	
Yes	29	15.3 ↑	10.8-21.3	162	84.7 ↓	78.7-89.2	0.022
Arthritis							
No	95	9.1 ↓	7.4-11.2	945	90.9 ↑	88.8-92.6	
Yes	75	13.7 ↑	11.1-16.8	471	86.3 ↓	83.2-88.9	0.005
Anxiety							
No	140	9.9 ↓	8.4-11.7	1271	90.1 ↑	88.3-91.6	
Yes	18	19.2 ↑	12.0-29.2	76	80.8 ↓	70.8-88.0	0.005
Depression							
No	133	9.8 ↓	8.3-11.6	1222	90.2 ↑	88.4-91.7	
Yes	25	16.5 ↑	10.8-24.5	125	83.5 ↓	75.5-89.2	0.011
Stress							
No	145	10.2	8.6-11.9	1288	89.8	88.1-91.4	
Yes	12	17.1	10.3-27.1	58	82.9	72.9-89.7	0.062
SF-1							
Ex/very good/good	133	9.3 ↓	7.9-11.0	1287	90.7 ↑	89.0-92.1	
Fair/poor	57	16.2 ↑	12.5-20.7	293	83.8 ↓	79.3-87.5	<0.001

Chi square post hoc tests ↑↓ indicates statistically significantly difference in categories using adjusted standardised residual.

Table 6-3 Clinic measured variables, carers compared with non-carers, aged 40 years and over

Variable	**Carer**				**Non-carers**				
	n	Mean	SD	Median	n	Mean	SD	Median	p-value
Systolic BP	178	129.5	16.8	128.0	1505	129.4	19.2	127.0	0.568
Diastolic BP	178	78.0	8.6	78.0	1505	77.7	8.7	77.5	0.594
CRP	173	4.6	7.8	2.3	1490	3.4	4.7	2.0	0.015
HbA1c	176	6.0	0.8	5.8	1490	5.8	0.8	5.7	0.007
LDL	176	3.1	1.0	3.1	1473	3.1	1.0	3.0	0.405
HDL	176	1.5	0.4	1.4	1492	1.5	0.4	1.4	0.191
Total cholesterol	176	5.2	1.1	5.2	1492	5.3	1.1	5.2	0.755
Total cholesterol/ HDL ratio	176	3.7	0.9	3.6	1492	3.7	1.1	3.6	0.076
Glucose	176	5.4	1.2	5.1	1490	5.3	1.2	5.1	0.125
Hb	175	139.4	14.3	139.9	1489	142.8	13.3	143.0	0.014
Vitamin D	176	64.7	25.5	62.0	1466	70.1	27.9	66.0	0.009
Albumin	175	39.4	3.2	39.5	1491	39.8	3.2	40.0	0.111
Il-6	152	1.9	1.8	1.4	1220	1.7	1.6	1.2	0.352
MPO	152	218.6	229.4	143.4	1219	202.4	237.2	118.8	0.172
TNFα	152	2.2	3.8	1.6	1220	1.8	2.6	1.4	0.106
E-selectin	152	32.8	11.8	31.9	1219	32.9	16.7	30.2	0.796

Non-parametric tests undertaken for non-normally distributed data

Table 6-4 Relative risk of predictor variables associated with being a carer compared to non-carers, male and female, aged 40 years and over

	Male		Female	
	RR (95% CI)	*p*-value	RR (95% CI)	*p*-value
Marital status				
Never married	1.00		1.00	
Widowed	1.10 (0.08-15.39)	0.941	0.23 (0.07-0.77)	0.017
Separated/divorced	1.62 (0.16-16.27)	0.684	0.19 (0.06-0.64)	0.007
Married/ de facto	2.88 (0.32-26.13)	0.347	0.85 (0.36-2.01)	0.714
Annual household income				
More than $100,000	1.00		1.00	
$80,000-$100,000	1.16 (0.27-4.92)	0.842	3.09 (0.52-18.51)	0.217
$60,000-$80,000	1.05 (0.28-3.93)	0.938	3.80 (0.66-21.77)	0.134
$40,000-$60,000	0.59 (0.17-2.08)	0.411	1.56 (0.25-9.88)	0.638
$20,000-$40,000	1.49 (0.49-4.53)	0.478	6.64 (1.29-33.18)	0.024
Up to $20,000	3.24 (0.74-14.25)	0.119	7.59 (1.29-44.76)	0.025
Not stated	0.96 (0.16-5.65)	0.966	5.65 (1.07-29.78)	0.041
Employment status				
Self/ Full time employed/ Part time employed	1.00		1.00	
Not employed	2.52 (1.19-5.31)	0.015	1.55 (0.84-2.86)	0.159
Educational status				
Bachelor degree or Higher	1.00		1.00	
Trade/ Certificate/ Diploma	0.92 (0.37-2.33)	0.862	1.18 (0.36-3.90)	0.780
High school	1.17 (0.42-3.23)	0.763	1.58 (0.52-4.85)	0.420
Body Mass Index				
Underweight/normal	1.00		1.00	
Overweight	1.20 (0.41-3.53)	0.734	1.51 (0.74-3.05)	0.780
Obese	1.54 (0.53-4.48)	0.427	1.18 (0.54-2.60)	0.420
Waist: Hip ratio				
Normal	1.00		1.00	
High	0.65 (0.29-1.47)	0.304	1.23 (0.77-1.97)	0.379
Smoking status				
Non smoker	1.00		1.00	
Ex-smoker	0.90 (0.47-1.72)	0.747	1.11 (0.71-1.74)	0.650
Current smoker	1.46 (0.46-4.69)	0.522	1.14 (0.51-2.56)	0.746
Alcohol Consumption Risk				
High risk	1.00		1.00	
Low risk	7.01 (0.85-57.47)	0.070	2.17 (0.57-8.17)	0.254
Non-drinkers / no risk	6.06 (0.75-48.62)	0.090	3.29 (0.86-12.59)	0.082
Recreational physical activity				
Sufficient	1.00		1.00	
Activity but not sufficient	2.21 (1.22-4.00)	0.009	1.04 (0.6-1.78)	0.875
No activity	1.75 (0.73-4.16)	0.206	1.36 (0.78-2.38)	0.273
Diabetes				
No	1.00		1.00	
Yes	1.47 (0.63-3.39)	0.371	0.70 (0.22-2.21)	0.537
Asthma				
No	1.00		1.00	
Yes	0.84 (0.40-1.78)	0.653	1.12 (0.63-1.98)	0.701
Arthritis				
No	1.00		1.00	
Yes	1.80 (0.81-3.99)	0.146	1.03 (0.64-1.63)	0.915
Cardiovascular disease				
No	1.00		1.00	
Yes	1.61 (0.76-3.41)	0.218	1.23 (0.57-2.65)	0.604

Table 6-4 Continued

	Male RR (95% CI)	*p*-value	**Female** RR (95% CI)	*p*-value
Anxiety				
No	1.00		1.00	
Yes	0.35 (0.05-3.41)	0.307	1.67 (0.69-4.06)	0.255
Depression				
No	1.00		1.00	
Yes	0.79 (0.29-2.10)	0.630	0.98 (0.43-2.27)	0.970
Stress				
No	1.00		1.00	
Yes	2.19 (0.94-5.72)	0.109	1.24 (0.42-3.67)	0.702
General health				
Excellent/very good/good	1.00		1.00	
Fair/poor	0.82 (0.34-1.94)	0.645	1.24 (0.73-2.11)	0.418
Clinic Measured Variables				
Systolic blood pressure	0.96 (0.94-0.99)	0.011	0.99 (0.97-1.00)	0.133
Diastolic blood pressure	1.13 (1.07-1.20)	<0.001	1.02 (0.98-1.05)	0.357
Blood Measured Variables				
CRP	1.03 (1.00-1.06)	0.023	1.00 (0.94-1.06)	0.971
HbA1c	0.54 (0.33-0.89)	0.016	1.11 (0.67-1.84)	0.681
HDL	1.03 (0.36-2.92)	0.963	1.40 (0.81-2.40)	0.226
LDL	1.09 (0.81-1.46)	0.576	1.15 (0.90-1.47)	0.257
Glucose	1.40 (1.03-1.89)	0.031	0.90 (0.64-1.27)	0.551
Hb	0.98 (0.95-1.00)	0.087	1.00 (0.97-1.02)	0.715
Vitamin D	1.00 (0.99-1.01)	0.516	0.99 (0.99-1.00)	0.138
Albumin	0.90 (0.82-1.00)	0.040	0.97 (0.89-1.05)	0.419
IL-6	0.75 (0.57-1.00)	0.051	0.97 (0.83-1.14)	0.707
TNFα	1.12 (1.06-1.20)	<0.001	1.03 (0.98-1.07)	0.242
MPO	1.00 (1.00-1.00)	0.895	1.00 (1.00-1.00)	0.657
eSel	0.99 (0.97-1.00)	0.140	1.02 (1.00-1.03)	0.115

References

1. Vitaliano PP, Schulz R, Kiecolt-Glaser J, Grant I. Research on physiological and physical concomitants of caregiving: Where do we go from here? Annals of Behavioural Medicine. 1997; 19(2):117-123.
2. Pinquart M, Sorensen S. Differences between caregivers and non-caregivers in psychological health and physical health: A meta-analysis. Psychology and Aging. 2003; 18(2):250-267. Accessed 30.08.2015 http://www.researchgate.net/publication/10691251.
3. Australian Institute of Health and Welfare 2010. Primary carers of people with arthritis and osteoporosis. Arthritis series no. 12. Cat. no. PHE 124. Canberra: AIHW.
4. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. Journal of the American Medical Association. 2012; 307(4):398–403. doi:10.1001/jama.2012.29.
5. van Ryn M, Sanders S, Kahn K, van Houtven C, Griffin JM, Martin M, Atienza AA, Phelan S, Finstad D, Rowland J. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? Psycho-Oncology. 2011; 20:44–52. doi: 10.1002/pon.1703.
6. Hori Y, Hoshino J, Suzuki K. Physical and Psychological Health Problems Among Japanese Family Caregivers. Nagoya Journal of Medical Science. 2011; 73:107-115. PMCID: PMC4831219. PMID:21928692.
7. Schulz R, Beach SR. Caregiving as a risk factor for mortality. The caregiver health effects study. Journal of the American Medical Association. 1999; 282(23):2215-2219.
8. Vitaliano PP, Young HM, Zhang J. Is Caregiving a risk factor for illness? Current Directions in Psychological Science. 2004; 13(1):13-16.

9. Hirst M, Carer distress: A prospective, population-based study. Social Science and Medicine. 2005; 61:697-708. doi:10.1016/j.socscimed.2005.01.001.
10. Smith L, Onwumere J, Craig T, McManus S, Bebbington P, Kuipers E. Mental and physical illness in caregivers: results from an English national survey sample. British Journal of Psychiatry. 2014; 205:197-203. doi:10.1192/bjp.bp.112.125369.
11. Cooper C, Balamurali TBS, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. International Psychogeriatrics. 2007; 19(2):175–195. doi:10.1017/S1041610206004297.
12. Torres Á, Blanco V, Vázquez FL, Díaz O, Otero P, Hermida E. Prevalence of major depressive episodes in non-professional caregivers. Psychiatry Research. 2015; 226(1):333-9. doi:10.1016/j.psychres.2014.12.066.
13. Pinquart M, Sorensen S. Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. Journals of Gerontology, Series B, Psychological Sciences and Social Sciences. 2006; 61(1), P33–P45.
14. Legg L, Weir CJ, Langhorne P, Smith LN, Stott DJ. Is informal caregiving independently associated with poor health? A population-based study. Journal of Epidemiology and Community Health. 2013; 67:95–97. doi:10.1136/jech-2012-201652.
15. Verbakel E, Tamlagsrønning S, Winstone L, Fjær EL, Eikemo TA. Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. European Journal of Public Health. 2017; 27(suppl.1):90-95. doi:10.1093/eurpub/ckw229.
16. Sinha M. Portrait of Caregivers, 2012: Spotlight on Canadians: Results from the General Social Survey. 2012; Statistics Canada Catalogue no. 89-652-No. 001.
17. Health Quality Ontario. The Reality of Caring: Distress among the caregivers of home care patients. Toronto: Queen’s Printer for Ontario; 2016. ISBN 978-1-4606-7761-2.

18. Australian Bureau of Statistics (ABS). Disability, Ageing and Carers, Australia. Summary of Findings, 2012. Australian Bureau of Statistics. Cat. no. 4430.0. Canberra.

19. Laks J, Goren A, Duenas H, Novick D, Kahle-Wrobleski K. Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. International Journal of Geriatric Psychiatry. 2016, 31:176-185. doi:10.1002/gps.4309.

20. Doran T, Drever F, Whitehead M. Health of young and elderly informal carers: analysis of UK census data. British Medical Journal. 2003; 327:1388. doi.org/10.1136/bmj.327.7428.1388.

21. Trivedi R, Beaver K, Bouldin ED, Eugenio E, Zeliadt SB, Nelson K, A M, Szarka JG, JD. Characteristics and well-being of informal caregivers: Results from a nationally representative US survey. Chronic Illness. 2014; 10(3):167-179. doi.org/10.1177/1742395313506947.

22. Neugaard B, Andresen E, McKune SL, Jamoom EW. Health-Related Quality of Life in a national sample of caregivers: Findings from the Behavioral Risk Factor Surveillance System. Journal of Happiness Studies. 2008; 9(4):559-575. doi:10.1007/s10902-008-90892.

23. DeFries E, Bouldin ED, Andresen E. Caregiving across the United Sates. Caregivers of persons with Alzheimer’s disease or dementia in Illinois, Louisiana, Ohio, and the District of Columbia. Data from the 2009 Behavioral Risk factor Surveillance System. Report 2009; Florida Office on Disability and Health, Department of Epidemiology and Biostatistics, College of Public Health and Health Professions, University of Florida. http://fodh.phhp.ufl.edu.

24. Lovell B, Wetherell MA. The cost of caregiving: endocrine and immune implications in elderly and non-elderly caregivers. Neuroscience and Biobehavioral Reviews. 2011; 35;1342–1352.
25. von Kanel R, Mills PJ, Mausbach BT, Dimsdale JE, Patterson TL, Ziegler MG, Ziegler MG, Ancoli-Israel S, Allison M, Chattillion EA, Grant I. Effect of Alzheimer caregiving on circulating levels of C-Reactive Protein and other biomarkers relevant to Cardiovascular Disease risk: A longitudinal study. Gerontology. 2012; 58:354-356.
26. Kiecolt-Glaser JK, Preacher K J, MacCallum RC, Atkinson C, Malarkey WB, Glaser R. Chronic Stress and age-related increases in the proinflammatory cytokine IL-6. Proceedings of the National Academy of Sciences of the United States of America. 2003; 100(15):9090-9095. doi/10.1073/pnas.1531903100.
27. Johnson TV, Ammara Abbasi A, Master VA. Systematic review of the evidence of a relationship between chronic psychosocial stress and C-Reactive Protein. Molecular Diagnosis and Therapy. 2013; 17:147–164. doi 10.1007/s40291-013-0026-7.
28. Potier F, Degryse J-M, de Saint-Hubert M. Impact of caregiving for older people and pro-inflammatory biomarkers among caregivers: a systematic review. Aging Clinical and Experimental Research. 2017; doi:10.1007/s40520-017-0765-0. (Published online: 04 May 2017).
29. Allen AP, Curran EA, Duggan A, Cryan JF, Chorcoráin AN, Dinan TG, Molloy DW, Kearney P, Clarke G. Biological markers of chronic stress in informal caregivers for patients with dementia: a systematic review. PROSPERO, 2015. doi 10.15124/CRD42015020828. University of York. Centre for Review and Dissemination. National Institute for Health Research, http://www.crd.york.ac.uk/PROSPERO 015020828.

30. Allen AP, Curran EA, Duggan A, Cryan JF, Chorcoráin AN, Dinan TG, Molloy DW, Kearney M, Clarke G. A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience and Biobehavioral Reviews. 2017; 73:123-164. http://dx.doi.org/10.1016/j.neubiorev.2016.12.006.
31. Grant JF, Chittleborough CR, Taylor AW, Dal Grande E, Wilson DH, Phillips PJ, Adams RJ, Cheek J, Price K, Gill T, Ruffin RE. North West Adelaide Health Study Team: The North West Adelaide Health Study: methodology and baseline segmentation of a cohort along a chronic disease continuum. Epidemiologic Perspectives and Innovations. 2006; 3:4. doi:10.1186/1742-5573-3-4.
32. Grant JF, Taylor AW, Ruffin RE, Wilson DH, Phillips PJ, Adams RJT, Price K, North West Adelaide Health Study Team: Cohort profile: The North West Adelaide Health Study. International Journal of Epidemiology. 2008; 1-8.
33. Australian Institute of Health and Welfare and National Heart Foundation. Risk factor prevalence study: Survey no 3. 1989. Canberra: AIHW.
34. Armstrong T, Bauman A, Davies J. Physical activity patterns of Australian adults. 2000. Australian Institute of Health and Welfare, Canberra.
35. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). Medical Care. 1992; 30(6):473–483. doi:1097/00005650-199206000-00002.
36. National Heart Lung and Blood Institute Global Initiative for Asthma. National Institutes of Health, Bethesda (MD). 2003. Publication no. 02-3659.
37. Chronic Obstructive Pulmonary Disease. National clinical guideline on management of chronic obstructive pulmonary disease in adults in primary and secondary care. Thorax. 2004; 59(suppl 1):1-232.

38. Taylor AW, Dal Grande E, Gill TK, Chittleborough CR, Wilson DH, Adams RA, Grant JF, Phillips P, Appleton S, Ruffin RE. How valid are self-reported height and weight? A comparison between CATI self-report and clinic measurements using a large representative cohort study. Australian and New Zealand Journal of Public Health. 2006; 30(3):238-46.
39. Taylor A, Dal Grande E, Gill T, Pickering S, Grant J, Adams R, Phillips P. Comparing self-reported and measured high blood pressure and high cholesterol status using data from a large representative cohort study. Australian and New Zealand Journal of Public Health. 2010; 34:394-400. doi: 10.1111/j.1753-6405.2010.00572.x
40. Gill T, Chittleborough C, Taylor A, Ruffin R, Wilson D, Phillips P. Body mass index, waist hip ratio, and waist circumference: which measure to classify obesity? Sozial-und Praventivmedizin. 2003; 48(3):191-200.
41. WHO. Obesity: preventing and managing the global epidemic 2000 WHO Geneva Switzerland. http://www.who.int/nutrition/publications/obesity/WHO_TRS_894/en/
42. Australasian Society for the Study of Obesity. Healthy Weight Australia: A National Obesity Strategy. Australasian Society for the Study of Obesity. 1995.
43. Australian Bureau of Statistics: Population by age and sex. South Australia Canberra: Australian Bureau of Statistics. 2000; 30 June 1999.
44. Australian Bureau of Statistics: Census of Population and Housing Selected Social and Housing Characteristics for Statistical Local Areas South Australia, 2001. Australian Bureau of Statistics, Cat No. 2015.4 Canberra: Australian Bureau of Statistics; 2002.
45. Gill TK, Hill CL, Shanahan EM, Taylor AW, Appleton SL, Grant JF, Shi Z, Dal Grande E, Price K, Adams RJ. Vitamin D levels in an Australian population. BMC Public Health, 2014;14:1001. http://www.biomedcentral.com/1471-2458/14/1001.

46. Bauer ME, Vedhara K, Perks P, Wilcock GK, Lightman SL, Shanks N. Chronic stress in caregivers of dementia patients is associated with reduced lymphocyte sensitivity to glucocorticoids. Journal of Neuroimmunology. 2000; 103(1):84–92. https://doiorg/10.1016/SO165-5728(99)00228-3.

47. Torimoto-Sasai Y, Igarashi A, Wada T, Ogata Y, Yamamoto-Mitani N. Female family caregivers face a higher risk of hypertension and lowered estimated glomerular filtration rates: a cross sectional, comparative study. BMC Public Health. 2015; 15:177. doi:10,1186/s12889-015-519-6.

48. Koenig W, Sund M, Frohlich M, Fischer H-G, Lowel H, Doring A, Hutchinson WL, Pepys MB.. C-reactive protein, a sensitive marker of systemic inflammation, predicts future risk of coronary heart disease in initially healthy middle-aged men. Results from the MONICA-Augsburg cohort study 1984–92. Circulation. 1999; 99(2):237–242. PMID: 9892589.

49. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler IC. A path model of chronic stress, the Metabolic Syndrome, and coronary heart disease. Psychosomatic Medicine. 2002;64:418–435.PMID: 12021416.

50. Mills PJ, Ancoli-Israel S, von Kanel R, Mausbach BT, Aschbacher K, Patterson TL, Ziegler MG, Dimsdale JE, Grant I. Effects of gender and dementia severity on Alzheimers disease caregivers’ sleep and biomarkers of coagulation and inflammation. Brain, Behaviour and Immunity. 2009; 23(5):605–610. doi:10.1016/j.bbi.2008.09.014 PMID: 18930805.

51. Stacey AF, Gill TK, Price K, Taylor AW. Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia. BMJ Open 2018; 8:e020173. https://doi.org/10.1136/bmjopen-2017-020173 PMID: 30037861.

52. Lebrec J, Ascher-Svanum H, Chen YF, Reed C, Kahle-Wrobleski K, Hake AM, Raskin J, Naderali E, Schuster D, Heine RJ, Kendall DM. Effect of diabetes on caregiver burden in an observational study of individuals with Alzheimer's disease. BMC Geriatrics. 2016; 16:93. doi 10.1186/s1 2877-016-0264-8.
53. Hajek A, Bock J-O, Konig H-H. Association of informal caregiving with body mass index and frequency of sporting activities: evidence of a population-based study in Germany. BMC Public Health. 2017;17:755. https://doi.org/10.1186/s12889-017-4786-6 PMID: 28962607.
54. Finucane MM, Stevens GA, Cowan MJ, Danaei G, Lin JK, Paciorek CJ, et al. (2011). National, regional, and global trends in body-mass index since 1980: Systematic analysis of health examination surveys and epidemiological studies with 960 country-years and 9.1 million participants. Lancet; 377;557–567.https://doi.org/10.1016/S0140-6736(10)62037-5 PMID: 21295846.
55. Gupta S, Isherwood G, Jones K, Van Impre K. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. BMC Psychiatry. 2015; 27(3):292–297. https://doi.org/10.1186/s12888-015-0547-1 PMID: 26194890
56. Ho SC, Chan A, Woo J, Chong P, Sham A. Impact of Caregiving on Health and Quality of Life: A Comparative Population-Based Study of Caregivers for Elderly Persons and Noncaregivers. Journal of Gerontology: Medical Sciences. 2009; 64A(8): 873–879. https://doi.org/10.1093/gerona/glp034 PMID:19351695.
57. Buyck JF, Ankri J, Dugravot A, Bonnaud S, Nabi H, Kivimaki M, Singh-Manoux A. Informal Caregiving and the risk for Coronary Heart Disease: The Whitehall II Study. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences. 2013; 68(10):1316–1323. https://doi.org/10.1093/gerona/glt025PMID: 23525476.

58. Sherwood PR, Price TJ, Weimer J, Ren D, Donovan HS, Given CW, et al. Neuro-oncology family caregivers are at risk for systemic inflammation. Journal of Neuro-Oncology. 2016; 128:109–118. https://doi.org/10.1007/s11060-016-2083-3 PMID: 26907491.
59. Kang SW, Marks NF. Filial caregiving is associated with greater neuroendocrine dysfunction: Evidence from the 2005 National Survey of Midlife in the United States. SAGE Open Medicine. 2014;2:2050312113520152. https://doi.org/10.1177/2050312113520152 PMID: 25309742
60. Baker KL, Robertson N. Coping with caring for someone with dementia: Reviewing the literature about men. Aging and Mental Health. 2008; 12(4): 413-422. https://doi.org/10.1080/13607860802224250PMID: 18791888.

Chapter 7. Discussion and Conclusions

7.1 In Summary

This thesis investigates the health status of adult informal carers in South Australia and is based on the findings, and the strengths and limitations of three internationally published peer reviewed articles. Different age groups of adult informal carers were included to address the following H_o hypotheses:

1. There is no increase in the prevalence of carers in South Australia over the 20 year period from 1994-2014.
2. There is no association between the caregiving role as a risk factor for chronic disease in carers.
3. There is no difference between biomedical profiles of carers and non-carers.

Central to how this thesis was constructed are the recognised strengths that underpinned the three separate manuscript analyses (Chapters 4, 5 and 6). An extensive review of the related caregiving literature highlighted a gap in knowledge of specific chronic health conditions across informal carer groups, including biomedical health profiles. In particular there was a lack of studies using consistent robust methodologies investigating informal carer physical health and risk factors. The current published analyses were based on biomedical and self-report data obtained from large representative population-based samples using standardized validated instruments, including the use of a well-established definition of informal carers.

Based on epidemiologically-sound population data collected in South Australia, it is acknowledged that while the prevalence of informal carers increased during the two decades under investigation, the findings in subsequent Papers 2 and 3 (Chapters 5 and 6) demonstrate informal caregiving was firstly, not found to be a significant risk factor associated with most of the selected chronic diseases and secondly that while carers may be at risk of lower Vitamin D and Hb levels, there were minimal differences in other blood measured variables when compared with non-carers from the same population. Yet what is also recognised is that the analytical approach and population sample represents only a small cross section of the diseases, disabilities and risk factors found within modern day populations as described in burden of disease studies[14-16.]

More significantly, while a well-established definition of informal carers was used, it was the informal carer who was the sole focus of attention with no links of their health to their role as an informal carer and/or the health status of the cared-for person. Also, no specific questions were asked of diagnosed pre-existing or potential chronic health problems in carers and no measures were used to ascertain the complex structure and functioning of a caregiving dyad on an informal carer's health status.

The discussion that follows draws on the implications of findings of the three internationally peer reviewed publications in the context of related literature to explore potential measures needed to ensure the appropriate identification in research of an informal carer and their specific demographics and to extract an understanding of how their caregiving dyad impacts their health status. Recommendations for future work in the fields of population research, clinical practice and policy development will then be proposed.

7.2 Exploring the caregiving dyad

In Chapter 2 it is made clear how, worldwide, there is a real challenge to meet the care and support needs of an ageing population both now and in the future. Caregiving by family and informal carers has become a necessity as more persons undertake this role. Informal caregiving varies across populations, communities and within family units due to differing cultural, psychosocial situations and medical conditions of cared-for people. How to effectively assess, measure, manage and support informal carers' own health in the context of their challenging and ongoing caregiving role, the caregiving dyad, has emerged as an important research focus.

The caregiving dyad has been referred to as a unit of attention, which is a useful description as it highlights and prioritises the dyad as a separate entity that can be identified and assessed[192]. Based on understandings gained from this thesis, it is the dynamic nature of the ongoing and changing caring role and its impact on the health status of both the informal carer and of the cared-for person that continues to remain poorly investigated. As Tommis et al.[193] found in Wales, informal carers living with their own chronic conditions showed a decline in their physical health over a relatively short period of eighteen months, whereas non carers with chronic conditions remained stable. Buyck et al.[74] suggested that although prevalent disease could worsen caregivers' burden, there was a possibility that increased burden itself could lead to a decline in health status**.** How to measure if the caregiving role increases burden over time, with a subsequent decline in the health status of an informal carer and/or the cared-for person, is important work to be undertaken.

Therefore, the monitoring of informal carer health and morbidity trends across populations over time requires not only (a) inclusion of informal carers within representative population-based surveys, but more importantly, (b) attention to the definition of the informal carer; (c) the choice of health, physiological, psychological and socio-demographic variables requiring ongoing measurement and assessment; and (d) details collected about the cared for person and informal carer, especially changes that occur within the informal caregiving context. This includes the capacity to undertake care-related tasks, interactions and time to complete them as well as their impact on the carer.

7.3 Profiling informal carers

A clear definition of an informal carer is not always provided in the caregiving literature[193]; however it is essential. This definition needs to include whether the informal carer is the main or primary informal carer. In addition, establishing the relationship to the cared-for person (partner, spouse, sibling, adult child, other relative or closer friend), if they reside with the cared-for person, reasons for caregiving and knowing if the person had any diagnosed pre-existing or potential chronic health (physical and psychological) problems before undertaking a caregiving role is important data to collect.

Most importantly, to understand if increasing burden is of concern, ongoing assessment of the health of informal carers requires attention to their clinical health status, and biomedical profiles that combine physiological in addition to psychological approaches to health. To achieve a balanced and representative view of the extent of informal care and its effects, population-based studies can provide a guide to major trends in risk factors and chronic disease prevalence. Monitoring biomedical variables and physiological markers has highlighted some important trends and offers a useful baseline for predicting health changes and outcomes in future populations of carers.

As was also discussed in the published papers (Chapters 5 and 6), identifying anxiety and depression as well as psychological distress and perceived health status is important. This is important given Ratcliffe et al.[79], in another South Australia survey of carers, highlighted younger informal carers being more at risk from the emotional impact of their caregiving roles. Emotional impact can be both positive and negative. How mental health and psychological issues are considered and balanced against informal carer physical health brings attention to what Roth et al. [69] referred to as reporting bias. Roth et al.[69], as well as Brown and Brown[70], were critical of the dominance of stress-related studies throughout the caregiving research, which yielded mostly negative assessments of carer health.

As mentioned earlier in Chapter 2, Brown and Brown[70] highlighted the methodological limitations of research based on stress theories. They challenged the chronic stress model of informal caregiving, which has been popular over the past three decades, concluding that it was in need of revision[70]. This does not detract from the notion that caregiving can be interpreted as a stressor, but, as authors have emphasised, caregiving is complex[63,84] and may be associated with a range of lifestyle domains and social determinants of health. In other words, different types of stress may be influenced by social and cultural contexts other than caregiving[195].

The debate about stress theories has led to different approaches in developing theoretical frameworks of caregiving, most based on models, processes and pathways ranging from carers with mild stress through to acute, cumulative, excessive, and to high chronic stress[127, 130 196,197]. Results from stress-related research of informal carers have therefore been mixed, while authors such as Schulz and Beach[61] initially suggested the stress of caregiving was an independent risk factor. In contrast, Dich et al.[71] raised the question of whether caregiving had adverse health effects when not associated with stress. Measuring psychological and physical health of informal carers is therefore critical to their own care. Where and when it is possible, psychological assessment needs to be combined with assessment of their physical health and physiological measurements over time.

7.3.1 Measurement of chronic diseases in carers

From the self-report findings of our study, the presence of chronic physical conditions of diabetes, asthma and arthritis were evident among South Australian carers when compared with non-carers. The finding of arthritis in the urban carers surveyed was not unexpected due to the high prevalence of osteoarthritis in older age groups of the general population[198]**.** To further clarify the validity of the findings from our state-wide surveys, differences in the level of risk that caring might have on major chronic conditions were further analysed using population PAR. All associations with chronic conditions disappeared and, on further analysis, any high prevalence for the selected chronic conditions disappeared for male carers. Only diabetes and asthma among female carers remained after statistical adjustments.

The presence of diabetes (Type II) in carers was consistent with a limited number of studies across the caregiving literature [58,60,72,122,199]. Lovell and Wetherall[72] had reported that diabetes was sensitive to chronic low-grade inflammation along with CVD and MSK disorders; Capistrant et al.[60] referred to diabetes as a caregiver health risk factor, a covariate and a confounder based on other research. Buyck[200] found diabetes in their sample of informal carers, but with a similar prevalence to that of non-carers. Some clinical studies have occasionally identified carers with diabetes, but a wider range of physical health problems are not always included in the research design, particularly if laboratory measurement is required. This means carers may be incompletely assessed and opportunities to check their physical health are missed. Surveys in Australia[22,40] and the USA[111] in recent years have identified carers with diabetes and other chronic health conditions from national surveillance initiatives using self-report methods to collect carer data[22,40].

Considering chronic diseases in informal carers more broadly, Tommis et al.[193] in 2009 found those carers with chronic conditions showed a decline in their physical health over time, whereas non-carers with chronic conditions remained stable, suggesting that could be partly due to informal carers neglecting their own health[193]. Buyck et al.[74] suggested that although prevalent disease could worsen the caregivers' burden, there was a possibility that increased burden itself could lead to a decline in health status[74].

7.4 The biomedical profile of carers: measuring physiological parameters

Most importantly for assessing the health of informal carers is attention to their clinical health status and biomedical profiles that combine physiological in addition to psychological approaches to health. To achieve a balanced and representative view of the extent of informal care and its effects, population-based studies can provide a guide to major trends in risk factors and chronic disease prevalence. In reporting this particular research, featuring South Australian informal carers, it became clear that while there were significant associations, a lot of comparisons were made and it is likely that associations did occur by chance. Thus, these findings need to be taken in context.

7.4.1 Vitamin D

Results from the studies of the physiological health of NWAHS carers revealed some previously unreported findings of lower serum Vitamin D and haemoglobin levels. Vitamin D has important benefits in reducing the risk of many conditions such as CVD[201], diabetes mellitus[202], several bacterial and viral infections, and autoimmune diseases[203]. As a nutritional marker, serum 25-hydroxy vitamin D (25 (OH)D) can indicate underlying or developing Vitamin D deficiencies associated with the development of osteoporosis[204].

The implications of these findings were discussed in the published paper (Chapter 6), concluding that ongoing measurement and monitoring of carer serum Vitamin D levels in vulnerable older South Australian informal carers would enable preventive or treatment initiatives to be considered. However, there is an important caveat to consider in terms of the wider issues associated with the finding of lower levels of Vitamin D in informal carers; that of informal carers being assessed in the context of their geographical location. In this instance, it was already known that Vitamin D deficiency was prevalent in South Australia, affecting almost one quarter of the population[204] but it was subsequently found that informal carers not only shared that tendency, but were measured to have lower levels than non-carers from the same population. Therefore, discussing carer health risks more broadly, they may have similar characteristics to the general population profile, specific to their geographical location, and represent a sub-group of that population, who may be at greater risk of certain conditions. These profiles could provide useful indicators to measure in informal carers, particularly where population-based surveillance and cohort studies are already carried out or planned.

7.4.2 Haemoglobin

The finding of differences between haemoglobin levels of informal carers when compared with non-carers in our study was unusual and, to our knowledge, not evident in recent published studies. Another unexpected finding was the lower Hb levels in male informal carers when compared with non-carer males; a difference that was not evident when female informal carers were compared with female non-carers. From very early research using self-report data, Pruchno et al.[205] had found that spouse carers of persons with Alzheimer's disease reported higher rates of anaemia, but it was not confirmed by laboratory measured Haemoglobin, nor were there clear differences between male and female informal carers.

7.4.3 Inflammatory Biomarkers

The remainder of the laboratory-measured variables showed informal carers and non-carers aged 40 years and over to be very similar. Although differences were minimal and not clinically significant, the slightly elevated serum inflammatory biomarkers of TNFα and hs-CRP found in male informal carers (Chapter 6) merit further investigation among men who are carers, particularly as there were no such differences when female carers were compared with non-carer females. Measuring hs-CRP might be useful as an indicator of low-grade inflammation among long term vulnerable informal carers, again with particular reference to male informal carers[26,135]. The presence of raised TNFα is noteworthy as TNFα is recognised not only in terms of its role in immunity as the master cytokine that can initiate inflammatory cascades, but TNFα also has a metabolic role as a pro-inflammatory cytokine in inducing insulin resistance[206]. It warrants attention as raised CRP may also be a risk factor for diabetes, cardiovascular events such as coronary heart disease, increased risk of incident stroke, and some cancers[146, 207].

Monitoring biomedical variables and physiological markers has highlighted some important trends and offers a useful baseline for predicting health changes and outcomes in future populations of carers. However, measuring inflammatory biomarkers in informal carers raises important methodological issues, as highlighted by Vitaliano et al.[54], who stated that monitoring immunological changes in informal carers requires longer time periods. This is because physiological responses in informal carers can take several years to manifest, as observed by von Kanel et al.[125], who, in their 2006 study, found no significant differences in plasma levels of CRP between informal carers and matched controls[125]. The fact that the published findings for our research challenged those cited in the literature review of the thesis, suggests a need for more data to be collected for future research. Thus, rigorous monitoring of informal carers would involve repeated measuring of immunological markers, which in turn means using longitudinal or prospective research designs and methods to follow-up informal carers during and beyond the period of caring.

Secondly, as many of the immunological studies of CRP have been limited to recruiting participants caring for people with Alzheimer’s disease or frail older people, a more heterogeneous and representative sample of carers would be required. Vitaliano et al.[54] acknowledged that, although ideal, these methods would create problems of time constraints and funding for researchers.

7.5 Information technology challenges with carer general assessment instruments

With the rapid introduction of the digital age over the past decade, additional challenges for researchers are already starting to affect methodological aspects of modern research, such as sample selection and data collection. As more households and members of the public exclusively use mobile phones[171], landline telephones and accompanying local telephone directories are disappearing, which would otherwise have been used for random selection of the population (sampling). This represents a major technological transition that not only has the potential to alter established survey methods and surveillance systems but is a barrier to obtaining and contacting representative samples of participants from the community for research purposes.

An additional technological challenge is the use of the internet for survey research. Traditional, face-to-face interviewing, (used for the first project, HOS), has gradually been replaced by telephone interviewing techniques, (e.g. CATI, which was integral to the second SAMSS project) reported in this thesis. Ensuring a balanced selection of respondents is becoming more difficult. The next step where more, if not the majority, of respondents are being surveyed via the internet, may result in a greater likelihood of sample errors and bias in results. Gupta et al.[87] suggested in a recent study that internet-based surveys are more likely to have a sample of younger caregivers, as they are the age group who are better educated on how to use the internet. Gupta et al. further surmised that the older carers who do respond to internet surveys may be both better educated and healthier than the general caregiver population, leading to bias due to oversampling of healthier carers[87]. However, Gupta et al were unsure about self-reported responses because of the potential for recall bias and measurement error[87]. These examples thus highlight a transition stage as the digital age imposes new methodologies on research and, as explained above, are likely to influence who participates in research, as well as how carers are sampled, analysed and assessed.

The demographic profiles of carers presented below, however, represent population research based on rigorous data collection techniques, which will provide a useful baseline for future studies.

7.6 Sociodemographic and economic data

To understand the influence of cultural differences, patterns of education, employment and income, household circumstances and access to services on carers, socio-demographic and economic data is needed. Significant socio-demographic and economic factors known to impact carer lifestyle and wellbeing were identified and reported in the first and third published papers (Chapters 4 and 6). These factors included informal carers from the low/lowest annual household incomes, unemployed, carers in older age groups and informal carers in paid employment. In addition, there were increased proportions of carers from different cultures whose country of birth was from outside Australia or the UK. Also of significance is the gender of the informal carer. Although female and married or partnered (spouse) informal carers were providing the greater amount of care, the proportions of male carers are increasing, particularly older male carers. Gender roles are changing in modern communities, but this is not always recognised in health policy or within clinical research[84].

The finding of increased proportions of informal carers in both full time and part time occupations was consistent with international evidence, where increasing numbers of working age informal carers are combining careers with their informal caring roles[208]. Such is the extent of changes to family life in the new Millennium, policies to protect the health and rights of this group of informal carers are being debated and developed across international borders. Part of that process involves the continued identification and collection of socio-demographic and economic data of working informal carers and carers who want to work. Carer-specific data is already collected as part of the ABS Disability Ageing and Carer surveys conducted every five years or so and described in the AIHW biennial publications, Australia's Welfare reports. An additional source of sociodemographic and economic information on carers is available through HILDA, as described in Chapter 2.

The trend of informal carers working in paid roles is expected to increase in the future, as is the likelihood of informal carers facing more out of pocket costs for household expenses to purchase care products and in-home services[209]. From the informal carer perspective, carrying out the equivalent of two work roles over extended periods of time can have implications for their health[57, 136]. Parents of autistic or disabled children who are their carers are one such group who have been identified in the literature as occupying this dual role[46]. Informal carers are increasingly providing intergenerational care, looking after, for example, spouses who are chronically ill and disabled, older frail parents and other family members. That in turn has been recognised as putting the health and wellbeing of vulnerable informal carers at risk of decline[104,210]. Therefore, in Australia and a number of other developed countries, financial assistance, specific to informal carers, through government pensions and allowances for informal carers have been made available[209]. This has been an important source of income for unemployed and retired informal carers, especially those who had given up paid work to take on a long-term caring role. Findings from our South Australian surveys revealed a high percentage of informal carers (86.7%) in metropolitan Adelaide were receiving this carer pension (payment), and some were also eligible for other government assistance in the form of aged and disability pensions. Even with this support, it was shown that many informal carers remained in the low and lowest household income quintiles of below $20,000 or up to $40,000 per annum, when compared with the general population between 2008 and 2010.

While research linking informal caregiving with low income to poorer health outcomes among informal carers has revealed mixed findings[211], there was no overall evidence of higher morbidity present in South Australian carers. Whether access to government subsidies might have had a moderating effect on carer health status and wellbeing by providing regular income to offset some caregiving costs, is unknown. British and other international research suggests financial support is an important adjunct to other forms of carer respite and practical support[211,212]. From published findings, improved education among carers and the increased number of informal carers in paid employment may have also contributed to some household incomes. Measuring and monitoring carer financial and economic variables may contribute to a better understanding of relationships between carer income and health status.

Published findings have also highlighted an additional trend of informal carers being from more culturally diverse backgrounds, which is expected to continue over the coming decades[213]. Despite that, there remains a lack of detailed health information collected about these informal carers, especially people from the growing number of non-English speaking backgrounds who have, and are, settling in Australia. Identifying informal carers from the wide range of different cultures, including Indigenous groups across Australia, provides improved ways of monitoring and measuring their own health risks, vulnerabilities and chronic medical conditions. This is especially relevant to older informal carers and women caring for ageing relatives from migrant backgrounds who may present with different health and psychosocial profiles[210,213,214].

A culturally appropriate, informal carer-sensitive approach to research design and informal carer support has important implications for assessing potential socioeconomic inequalities and barriers when informal carers use the health care system. How to measure this sociodemographic may require quantitative and qualitative data collection methods which are inclusive of a wider choice of health indicators that are culturally discerning.

In general population surveys or census, ‘informal carer’ needs to be added to the list of demographic variables under the category of work or employment status. This would enable data on carer-related prevalence, morbidity and determinants of health and disease to be obtained more widely, to “piggy-back” on other research. Also, data on the country of origin of informal carers and informal carers in paid employment needs to be collected, as well as extending demographic age groups to include persons over 90 years old who are carers. Although this thesis is focused on adult carers, it is acknowledged that children and young teens are also providing vital informal caregiving support to family members. These young informal carers need to be identified and included in demographic profiles of population surveys and other research. Additionally, understanding the health status of an informal carer requires data on the frequency, intensity, duration of care required, skill and capacity to perform the required care and the environment in which caregiving is provided by the informal carer.

To assist researchers and practitioners when assessing informal carer characteristics and caregiving consequences, the National Consensus Development Conference, convened by the Family Caregiver Alliance in the USA in 2005, has produced two editions of a resource inventory of caregiver assessment measures[215]. The latest Inventory (2012) lists several hundred measures, combining a comprehensive range of specific scales and subscales across seven different conceptual domains associated with caregiving, in particular socio-demographic, and wellbeing related variables that can impact carers. Most scales are part of carer specific measures and represent potential areas of interest to researchers, policy makers and clinicians, but the document lacks measures for assessing the physical health of informal carers. By contrast, psychometric measures are numerous in the Inventory[215]. For example, out of the total 230 instruments, there were multiple scales and subscales specific for depression (17 measures), emotional assessment (35 measures) and seven quality of life measures, but only three included assessment of the carer's physical health, which were based on wellbeing, burden, and strain measures[215]. There was no clear reference to biomedical measures, therefore the inventory does not facilitate a comprehensive profile of carer health characteristics.

Most of the above 'tools' originate from published instruments that measure different constructs of caregiving, but therein lies the quandary, as many of the measures are copyrighted and require permission to use them and, in some instances, payment to access instructions and scoring information. This already occurs with the popular quality of life instrument of Ware et al.[94] and other health and wellbeing instruments, which can be very costly if researchers have research designs that require a large sample size. Considering these constraints may provide an insight into firstly, why the caregiving literature lacks balance between psychological, mental and physical health research and secondly, why there are fewer large population-based research projects published.

7.7 Measuring the caregiving dyad

Very few quantitative measures specific to the caregiving dyad are found in the caregiving literature and often focus on psycho-social parameters of reciprocity, adjustment and relationship strain[215] between the informal carer and the person being cared for. While a psycho-social focus is important, the imbalance negates the ongoing and continuing workload of providing physical care and the consequences of this on the health of the cared for person. Managing the physical health of carers in the context of a heavy caring workload involved with assisting the sick or disabled person within the caregiving dyad, is not often addressed in research. The emphasis is usually on managing the condition of the cared for person. Monitoring the health status of both persons along a shared pathway over time, particularly if the informal carer has existing health conditions or develops health issues and needs medical treatment of their own, lacks attention and clinical guidelines.

An earlier initiative from the Netherlands by van Heugten et al.[216] was the development of evidence-based clinical practice guidelines to provide better recognition and support for family members caring for persons with a stroke. It was acknowledged that in addition to informal caregivers sharing the care, carers also needed to be seen as people with their own special needs and health problems. In these guidelines, the recommended screening instrument to assess carer burden was the Caregiver Strain Index (CSI), which was developed in the early 1980s by Robinson[217] specifically for informal caregivers and chosen to measure high levels of burden in the informal carers. Although the van Heugten et al.[216] study highlighted the importance of identifying carers who might be at risk of burn-out or physical problems, there were no clear references to obtaining detailed physical health assessments of carers using the Caregiver Strain Index or any other instruments. The focus was on psychosocial problems, particularly carers at risk of depression. The concept of clinical guidelines for informal carers thus provided a structure within clinical practice to extend the attention of health professionals beyond that of the patient, but attention to informal carers' physical and other functional health problems remained vague.

Interpreting findings collated in the context of the wider literature, what is often missing from data collected are details that include both members of the caregiving dyad as part of the informal caring situation. For example, data is needed on the length of time spent caring; how many hours of care per day or week are provided and the type and level of intensity of the caring role. Details of the cared for person’s changing health status need to be better understood in terms of how changes to their level of dependency, disability or disease status can impact on the informal carer over time. In addition, the impact of the environment in which care is provided needs to be explored. Different domestic housing situations and equipment and services available to the informal carer in the home setting are inevitable and need to be considered so as to measure what impact these differences may have on the health status of both the informal carer and the cared for person.

To sum up, informal carers enter the caregiving relationship with their own individual vulnerabilities and genetic pre-dispositions to health problems. In contrast with non-carers, each person who is an informal carer is part of a unique and dynamic relationship: the person as the informal carer and the person they are looking after in the home environment. Focusing on the caregiving dyad shifts attention to ensuring that, over the time of the relationship, the health and wellbeing status of both persons does not decline as a consequence of being in this relationship. Different informal carers carry different burdens, which can change on a daily basis according to the health status and level of disability of the persons they are caring for, as well as their own. Recognising this dynamic in policy is the first step to identifying appropriate measures of the caregiver dyad.

7.8 Future directions in policy development

Recognising the caregiving dyad in culturally sensitive policies across government and industry is needed, as demand for informal carers will be ongoing and increase. It will also need to accommodate the differing cultures of long-term migrants, (e.g. European and South East Asian) now ageing and new migrants who are currently settling in Australia from a range of different countries (India, Middle East, Africa). Development of appropriate carer policies depends on the most comprehensive current information that can predict the future needs of both informal carers and the cared-for across the population. Economic analyses comparing the costs of supporting informal carers versus the need for government funded care packages to attend to the needs of the cared for person are warranted. Initial and follow-up assessments of the health and well-being of these informal carers and the person they care for requires recognition in health and social care policies, as well as in education policy.

Maintaining carer physical and functional health and emotional wellbeing is influenced by a combination of social, psychological and other determinants of health, as well as timely financial support. Maintaining informal carer physical health involves early recognition of the caring role(s), measurement and monitoring of any prior medical disorders, risk factors and assessment of existing or diagnosis of new chronic conditions. This requires policy to ensure informal carers are tracked at the population level to provide the larger picture of epidemiological trends across specific geographical regions, such as urban, rural or remote areas. Such information enables ongoing mapping of informal carer characteristics and needs.

In Australia, what is still lacking is in-depth biomedical details and prevalence of informal carer morbidity in comparison with what is known about the general population. The Australian

National Health Surveys[218] include laboratory-based (biomedical and blood measured) data, but do not identify informal carers as a separate group within demographic categories. In the future, informal carers could easily be included. Certainly, it will be necessary as changing trends in caring for people with a disability and caring for an aging population in the domestic home and community will have significant implications, as demand for service requirements increases.

Policy to ensure informal carer education for self-care is needed, specifically if carers have chronic conditions of their own, such as diabetes, asthma, arthritis, disability, heart and lung conditions, emotional problems or psychological distress, resulting in anxiety, depression or stress. Training to provide the personal health care to meet the needs of the cared for person and education to monitor their own health risks and that of the cared for person will have the potential to mitigate risks of injuries or declining health from carer burden as a consequence of their caring role.

A review of how multi-disciplinary health professionals are educated about the caregiving dyad, specifically those working in hospitals, general practice and palliative care, is needed to ensure informal carers of all ages are clearly identified so they can be assessed and assisted along their caregiving journey. As more cared for people express a preference to die in their own homes, liaison with professionals from palliative care services will be essential to monitor informal carer health and support informal carers during and after care of relatives who are dying and die at home.

7.9 Clinical recommendations

The translation of findings from this research therefore has particular relevance within the field of medicine. For example, developing informal carer-specific clinical guidelines and protocols within General Practice, hospitals and across other sectors of the health care system would enable (1) the identification of informal carers from all age groups (2) assessment of their health status and diagnosis of health problems and (3) management of their long-term chronic disease in the context of their caring activities. Having informal carers recognised within care plans and/or discharge plans is an important first step. These include cared for individuals of all ages living with chronic diseases or for persons who have had a stroke, have Alzheimer's disease and other dementias, disabilities, neurological conditions (in particular brain injury, Parkinson's disease, Multiple sclerosis etc). Also, children with developmental difficulties and severe health problems, the frail aged with multi-morbidity, and care of family members with cancer represent the widening spectrum of medical conditions requiring long term care.

7.9.1 Informal carers are sometimes likely to be 'patients' themselves

Full health assessments prior to, during and after caregiving, either before taking on the caring role or soon after it starts (similar to a person taking on a new position for paid employment) need to be undertaken. During any health consultation with informal carers, health practitioners need to check for the presence of diabetes, arthritis, osteoporosis, asthma and other lung conditions, metabolic profiles, immune function where appropriate, cardiovascular conditions, emotional and mental health related conditions. The statistically significant diabetes / asthma findings from this study warrant further attention particularly information on the influence of asthma among informal carers on their caring burden or quality of life is sparse.

Assessing clinic and blood measured risk factors including blood pressure, elevated BMI: overweight / obese ranges (adiposity), smoking, lipoproteins, and blood glucose, reduced or insufficient physical activity is needed and should be reviewed within the context of the caring role.

7.9.2. Making visible the caregiving dyad

It will be important for health and social care practitioners to recognise the caregiving dyad when they have initial and ongoing conversations with the informal carer and the cared for person, so as to identify mutually agreed expectations and what risks to monitor in both individuals in the short and longer term. Tracking specific and mutually agreed upon features of the cared for person's progress and an informal carer's health concurrently is advantageous to identify risk factors.

7.10 Strengths and limitations

This research used rigorous methods to randomly select and access large numbers of participants, from three different representative populations, two of which were state-wide surveys and the third, part of a cohort study. Due to the large sample sizes, the findings could be generalised to wider populations. The surveys used a nationally accepted and well-established Australian definitions of informal carers when identifying the carer participants from each of the three surveys. The project is novel in that observed clinic and blood measured empirical data were obtained from participants of the cohort study. In addition, the number of biomedical, behavioural and socio-demographic variables available was extensive, particularly as information and questions were based on well-validated instruments, representing a valuable cross section of health conditions and risk factors.

Logistic regression analysis, multivariable analysis and descriptive analyses were applied to compare differences between informal carers and non-carers. Additional analysis of primary data included the application of Age-Period-Cohort (APC) and Population Attributable Risk (PAR) using a number of different models to control for confounding. Age and sex were the only variables controlled for in these models and therefore it is possible some of the differences in health outcomes may be due to unmeasured confounding and represent a possible weakness of the study. Also in relation to the PAR analysis, while the sample size for the saturated models may be small once multivariable models are estimated, thus creating issues of power and degrees of freedom, which may be possible limitations, the multivariable models are robust and the confidence intervals not extremely large. Predictor variables were used to further differentiate between carer populations, as well as male and female carers.

Most research limitations have been addressed and reported at the end of each publication, in Chapters 4, 5 and 6, however it is acknowledged there has been limited reflection in relation to the strengths and weaknesses of previous methodological designs beyond what was included in this thesis. Although a large study, this research was limited to investigating a selected range of common major health conditions, risk factors and demographic variables of carers to use for analysis. As data were cross-sectional in design, the results do not provide evidence of cause and effect, and only associations between carers and chronic illnesses and risk factors could be reported.

Due to slight variations in the terms used for identifying carers in the early questionnaires, and because individuals may not have seen themselves as ‘carers’ per se, the difference in proportion of carers across time may be a limitation of the study. It is acknowledged that the inclusion of the term ‘carer’ in the early studies may possibly have identified slightly fewer participants.

The following details were not available about the carers: duration and severity of carers’ illnesses, if they were pre-existing health conditions and co-morbidity. Additional information was not collected on the duration of the caring role; for example, how long had been spent caring; how many hours / day or / week they were providing care or the type and level of intensity of their caring role. Details of the cared for person’s health and demographic characteristics were not available such as age, relationship to the carer (partner, spouse, sibling, adult child, other relative or close friend), disability or disease status, and their level of disability and dependency, all of which have been reported as impacting on the role of an informal carer. It is acknowledged that pairing of survey results with qualitative research is important and would have provided a greater understanding of the nuances between the carer, any pre-existing illness and the structure and functioning of caregiving relationships, however this was not possible, and is recognized as a weakness of the study design.

Additionally, the study did not have details about the cared for person’s diagnosis, co-morbidity, and their level of disability. It would also have been valuable to have data on the frequency, intensity and duration of the caregiving provided by the informal carer to ascertain the carers’ exposure to different types of caring. The review of the literature could have expanded on carer heterogeneity reported in previous studies of informal caregiving but the literature base was extensive and therefore for this thesis, focused on heterogeneity related to carer health outcomes. Lastly there were smaller numbers of younger carers, especially in those studies which included clinical and blood measured data, where the focus was on adult carers aged 40 and over.

7.11 In conclusion

7.11.1 Were South Australian carers healthy or unhealthy?

The fundamental questions which prompted this study asked if the health of carers was different to people who were not in a caring role. From the caregiving literature, a prevailing argument emerged that carers were at greater risk of poorer health and were likely to be carrying their own burden of disease or disability. Findings from international research published over the past two to three decades on carer health were mixed and frequently inconsistent, and so were the methodologies used to collect that data from carers. The preference was for smaller studies, with an emphasis on the psychological and social impacts of caregiving, as well as an interest in biological consequences. Data were mostly self-reported and by comparison there were fewer clinic and laboratory based biomedical studies other than immunological changes in informal carers.

Drawing data from three large representative surveys, findings presented from this large study showed that South Australian informal carers overall were healthier than expected, with evidence of fewer risk factors and chronic conditions than reported in other research. Both state-wide and urban informal carers shared some similar chronic physical and psychological health problems with the general population. There was evidence of a small to moderate association between the caregiving role as a risk factor for having a chronic physical condition such as diabetes and asthma, which was more evident in female informal carers from the state-wide (SAMSS) surveys (Chapter 5), while arthritis and diabetes were more significant among the metropolitan cohort (NWAHS) of carers (Chapter 6). Additional analysis indicated there were some differences between the physical health of informal carers and non-carers, for example diabetes, arthritis, respiratory conditions, as well as anxiety and depression. However, there were few differences between informal carers and non-carers in terms of self-reported stress.

Results presented revealed unexpected gender differences, with males found to be more at risk of physiological changes; however there were stronger trends of adiposity with female informal carers and there was evidence of a lack of physical activity among both male and female informal carers (Chapters 5 and 6). Gender differences also suggested the health of male carers could be more physiologically at risk than females, however the risks were not clinically significant.

New evidence of differences between carers and non-carers, showing lower Vitamin D and haemoglobin levels is presented. Immunological assessments of South Australian carers revealed the presence of only slightly raised inflammatory biomarkers (hs-CRP and TNFα) and, based on the current literature, this could indicate chronic low-grade inflammation in some informal carers, especially males. This study therefore demonstrates the advantages of measuring biomedical parameters, such as metabolic, endocrine and nutritional markers, in the assessment of informal carer health, in contrast to other carer research, which has frequently relied on self-report data rather than observed in the clinic setting or blood-measured laboratory data to assess informal carer physical health. Having reported these comparisons, it is likely that some associations occurred by chance and therefore the biomedical findings need to be kept in context.

7.11.2 Tracking trends of the health of future informal carers

During the coming decades, people in the wider community are likely to experience life-changing transitions in health. From the sociodemographic evidence, it is clear that transitional changes have occurred as men and women live longer, but still with some risk of disability, dementia and a range of medical disorders requiring long term home care. There will be implications for older informal carers, as increasing numbers are expected to care for spouses in their later years, especially males.

A cultural transformation is also occurring in Australia as increasing numbers of carers represent those born in countries other than Australia and the UK. This greater diversity of both carers and those they look after will involve more emphasis on providing culturally sensitive services and protecting the health of those carers. This is pertinent in view of policy changes recently introduced across Australia over the past three or four years, which are bringing major structural changes to the provision of aged and disability care. They will include cash for care, along with rationed subsidised government packages to support people in their homes. From a technological view, entry into the digital age is ushering in not only new opportunities but also new challenges for researchers, as old methods are changing or disappearing.

Carers are an increasingly heterogeneous group, entering the caregiving relationship with their own individual vulnerabilities and health problems. Their responses to the burdens of caregiving vary according to the type of family members (or friends) they care for, their home situation and their relationship with that person. In contrast to non-carers, each person who is a carer is part of a unique and dynamic caregiving dyad: the family (or other informal) carer and the person they are looking after, in the home environment. Different informal carers carry different burdens which can change on a daily basis according to the health status and level of disability of the persons they are caring for, as well as their own. The impact of caregiving on their health, and the health of the cared for person, is unknown.

This thesis highlights the need for a carer-centred, and caregiving dyad approach, not only to address gaps in the measurement of informal carer physical health, but also gaps in the approach to the management of the health of informal carers**.** Therefore, informal carer health should not be seen in isolation from their caring role. This thesis adds to the knowledge base about measuring the health status of informal carers, including what to measure and why it is important.

References

1. Travis RC, Talley SS. The Status of Professional Caregiving in America. Introduction; P. 3, in Talley RC, Travis SS (eds.), Multidisciplinary Coordinated Caregiving, 2014; Caregiving: Research • Practice • Policy, DOI 10.1007/978-1-4614-8973-3_1, ISSN 2192-3418 (electronic), Springer NewYork.
2. Bruhn JG, Rebach HM. The Sociology of Caregiving. Clinical Sociology and Practice. 2014. Springer; Dordrecht Heidelberg New York London. ISBN 1566-7847. DOI 10.1007/978-94-017-8857-1.
3. Bauer JM, Sousa-Poza A. Impacts of Informal Caregiving on Caregiver Employment, Health and Family. Population Ageing, 2015; 8:13-145. doi 10.1007/s12062-015-9116-0.
4. Stajduhar KI, Funk L, Toye C, Grande GE, Aoun S, Todd CJ. Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008): Part 1. Palliative Medicine, 2010; 24(6):573-593. doi:10.1177/0269216310371412.
5. McDonald J, McKinlay E, Keeling, Levack W. How family carers engage with technical health procedures in the home: a grounded theory study. BMJ Open 2015;5:e007761 doi:10.1136/bmjopen-2015-007761.
6. Levine C, Reinhard SC, Feinberg LF, Albert S, Hart. Family caregivers on the job: moving beyond ADLs and IADLs. Generations: Journal of the American Society on Aging, 2003; 27:17-23.
7. Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Chronic Care, 2012. AARP Public Policy Institute and the United Hospital Fund: October 2012: Washington DC, USA.

8. Twigg J, Atkin K, Perring C. Carers and Services: A Review of Research. 1990 SPRU (Social Policy Research Unit, University of York), HMSO, UK.
9. Schofield H, Bloch S, Herrman H, Murphy B, Nankervis J, Singh B. (Eds). Family caregivers: Disability, illness and ageing. 1998. Melbourne: Allen and Unwin in association with the Victorian Health Promotion Foundation.
10. McKeown RE. The Epidemiologic Transition: Changing Patterns of Mortality and Population Dynamics. American Journal of Lifestyle Medicine, 2009; 3(Suppl.1):19S-26S. doi:1177/1559827609335350.
11. Omran AR. The epidemiologic transition: A theory of the epidemiology of population change. The Milbank Quarterly, 83 (4):731-57, doi:101111/j.1468-0009.2005.00398.x Reprinted from the Milbank Memorial Fund Quarterly, 1971; 49 (4,Pt.1):509-538.
12. Lee R. The Demographic Transition: Three Centuries of Fundamental Change. Journal of Economic Perspectives, 2003*;* 17 (4):167-190. doi: 10.1257/089533003772034943.
13. Kuate Defo B. Beyond the ‘transition’ frameworks: the cross-continuum of health, disease and mortality framework. Global Health Action, 2014; 7:1, 24804.
14. GBD 2015 Neurological Disorders Collaborator Group. Global, regional, and national burden of neurological disorders during 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. The Lancet Neurology, 2017; 16:877-896. doi: http://dx.doi.org/10.1016/S1474-4422(17)30299-5.
15. GBD 2015 DALYs and HALE Collaborators. Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. The Lancet, 2016; 388:1603–1658.
16. Australian Institute of Health and Welfare (AIHW) 2016. Australia’s health 2016. Australia’s health series no. 15. Cat. no. AUS 199. Canberra: AIHW.

17. Australian Institute of Health and Welfare (AIHW) 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.
18. Australian Institute of Health and Welfare (AIHW) 2019. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2015. Australian Burden of Disease series no. 19. Cat. no. BOD 22. Canberra: AIHW.
19. Australian Burden of Disease Database and Australian Burden of Disease Study 2015: Interactive data on disease burden. Available at https://www.aihw.gov.au/reports/burden-of-disease/abds-2015-interactive-data-disease-burden/contents/comparisons-over-time.
20. World Health Organisation and The World Bank. World Report on Disability. World Health Organisation 2011. ISBN 978 92 4 068521 5 (PDF).
21. Australian Bureau of Statistics (ABS). 2015 Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2015. ABS cat. no. 4430.0. Canberra: ABS.
22. Australian Institute of Health and Welfare (AIHW) 2017 Australia’s welfare 2017. Australia’s welfare series no. 13. AUS 214. Canberra: AIHW.
23. Australian Institute of Health and Welfare (AIHW) 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW
24. The National Centre for Social and Economic Modelling **(**NATSEM**),** Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, 2018, University of Canberra.
25. Australian Institute of Health and Welfare (AIHW) 2018. Australia’s health 2018. Australia’s health series no. 16. AUS 221. Canberra: AIHW.
26. Von Kanel R, Mills PJ, Mausbach BT, Dimsdale JE, Patterson TL, Ziegler MG, Ziegler MG, Ancoli-Israel S, Allison M, Chattillion EA, Grant I. Effect of Alzheimer

Caregiving on Circulating Levels of C-Reactive Protein and other biomarkers relevant to Cardiovascular Disease risk: A longitudinal Study. Gerontology. 2012; 58:354-356.

27. Brown L, Hansnata E, Anh La H. NATSEM. The Economic Cost of Dementia in Australia 2016-2056. Report Prepared for Alzheimer's Australia 2017.

28. Jenkins A, Rowland F, Angus P & Hales C. The future supply of informal care, 2003 to 2013: alternative scenarios. AIHW cat. no. AGE 32. Canberra: AIHW.

29. Fine MD. Employment and informal care: Sustaining paid work and caregiving in community and home-based care. Ageing International, 2012; 37(1):57-68. doi:http://dx.doi.org.proxy.library.adelaide.edu.au/10.1007/s12126-011-9137-9.

30. Alpass F, Szabo A, Allen J, Stephens C. Health effects of informal caring in New Zealand: longitudinal findings from the Health, Work and Retirement study. International Journal of Care and Caring, 2017; 1(3):309-329(21). https://doi.org/10.1332/239788217X15040798472015.

31. Lilly MB, Robinson CA, Holtzman S, Bottorff JL. Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. Health and Social Care in the Community, 2012; 20(1):103–112 doi: 10.1111/j.1365-2524.2011.01025.x.

32. Sinha M. Portrait of Caregivers, 2012: Spotlight on Canadians: Results from the General Social Survey. 2012; Statistics Canada Catalogue no. 89-652-No. 001.

33. Talley RC, Crews JE. Framing the public health of caregiving. American Journal of Public Health, 2007; 97(2):224–228. doi:10.2105/AJPH.2004.059337.

34. Australian Institute of Health and Welfare (AIHW). Australia's welfare 2013. Australia's welfare series no.11. Cat. no. AUS 174. Canberra: AIHW.

35. Australian Bureau of Statistics (ABS). The Survey of Handicapped Persons, 1981, Canberra: ABS.

36. Australian Bureau of Statistics (ABS). The Survey of Disabled and Aged Persons 1988, Canberra: ABS.
37. Australian Bureau of Statistics (ABS). 1993 Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 1993 ABS cat. no. 4430.0. Canberra: ABS.
38. Australian Bureau of Statistics (ABS). 1998 Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 1998 ABS cat. no. 4430.0. Canberra: ABS.
39. Wilkins R. (Ed.) Families, Incomes and Jobs, A statistical Report on Waves 1 to 11 of the Household, Income and Labour Dynamics in Australia (HILDA) Survey. 2016. Volume 9. Part 12. The characteristics and wellbeing of carers. Melbourne Institute of Applied Economic and Social Research. The University of Melbourne. https://www.melbourneinstitute.com/hilda/Reports/statreport.html.
40. Australian Bureau of Statistics (ABS). 2012 Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2012 ABS cat. no. 4430.0. Canberra: ABS.
41. Australian Institute of Health and Welfare (AIHW) 2011. Australia’s welfare 2011. Australia’s welfare series no. 13. AUS 214. Canberra: AIHW.
42. Gill T, Jury H, Warmington R, Stacey A, Taylor A. The Health and wellbeing of adult family carers in SA. An Epidemiological Analysis 1994-2004. 2008. Department of Health, Government of South Australia, Adelaide.
43. Hugo G, Luszcz M, Carson E, Hinsliff J, Edwards P, Barton C, King P. State of ageing in South Australia. A report to the South Australian Office for the Ageing. Section 8: Older Carers. Carers in South Australia. 2009:233, Department for Families and communities, Government of South Australia. Adelaide. ISBN: 9781920983819.
44. Qu L, Edwards B, Gray M. Ageing parent carers of people with a disability. Commonwealth of Australia 2012, ISBN 978-1-921414-92-3 Commissioned by Carers Victoria.

45. Brehaut JC, Kohen DE, Garner RE. Health among caregivers of children with health problems: findings from a Canadian population-based study. American Journal of Public Health, 2009; 99:1254-1262 doi:10.2105/AJPH.2007,129817.

46. Brehaut JC, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL, Kohen DE. Changes over time in the health of caregivers of children with health problems: Growth-curve findings from a 10-year Canadian population-based study. American Journal of Public Health, 2011; 101:2308-2316. doi:10.2105/AJPH.2011.300298.

47. van Excel NJA, Koopmanschap MA, van den Berg B, Brouwer WBF, van den Boss GAM. Burden of informal caregiving for stroke patients. Identification of caregivers at risk of adverse health effects. In Cerebrovascular Diseases, 2005; 19(1):11-17.

48. Van Den Wijngaart MAG, Vernooij-Dassen MJFJ, Felling AJA. The Influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. Aging and Mental Health, 2007;11(6):626-636.

49. van Ryn M, Sanders S, Kahn K, van Houtven C, Griffin JM, Martin M, Atienza AA, Phelan S, Finstad D, Rowland J. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? Psycho-Oncology, 2011; 20:44–52. doi: 10.1002/pon.1703.

50. Bevans M, Sternberg EM. Caregiving burden, stress and health effects among family caregivers of adult cancer patients. Journal of the American Medical Association, 2012; 307(4):398–403. doi:10.1001/jama.2012.29.

51. Viana MC, Gruber MJ, Shahly V, Alhamzawi A, Alonso J. Family Burden related to mental and physical disorders in the world; results from the WHO World Mental Health (WMH) surveys. Revista Brasileira de Psiquiatria. 2013; 35:115-125. doi:10.1590/1516-4446-2012-0919.

52. Saria MG, Nyamathi A, Phillips LR, Stanton AL, Evangelista L, Kesari S, Maliski S. The hidden morbidity of cancer. Burden in caregivers of patients with brain metastases. Nursing Clinics of North America Journal, 2017, 52:159-178. http://dx. doi.org/10.1016/j.cnur.2016.10.002.

53. Schulz, R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S. Health effects of caregiving: The Caregiver Health Effects Study: An ancillary study of the Cardiovascular Health Study. Annals of Behavioral Medicine, 1997; 19(2):110–116.

54. Vitaliano PP, Schulz R, Kiecolt-Glaser J, Grant I. Research on physiological and physical concomitants of caregiving: Where do we go from here? Annals of Behavioural Medicine, 1997; 19(2):117-123.

55. Navaie-Waliser M, Spriggs A, Feldman PH. Informal caregiving: differential experiences by gender. Medical Care, 2002; 40:1249–1259.

56. Carers Association of Australia. Results of the 1999 National Survey of Carer Health and Wellbeing warning – caring is a health hazard. 2000, Carers Association of Australia, Canberra.

57. Kenny PK, King MT, Hall J. The physical functioning and mental health of informal carers: evidence of care-giving impacts from an Australian population-based cohort. Health and Social Care in the Community, 2014; 22(6):646-659.

58. von Kanel R, Mausbach BT, Patterson TL, Dimsdale JE, Aschbacher K, Mills PJ, Ziegler MG, Ancoli-Israel S, Grant I. Increased Framingham Coronary Heart Disease Risk Score in dementia caregivers relative to non-caregiving controls. Gerontology 2008; 54:131–137.

59. King AC, Oka RK, Young DR. Ambulatory blood pressure and heart rate responses to the stress of work and caregiving in older women. Journal of Gerontology, 1994; 49: M239–M245.

60. Capistrant BD, Moon JR, Glymour MM. Spousal Caregiving and Incident Hypertension. American Journal of Hypertension, 2012; 25(4):437-443. doi:10.1038/ajh.2011.232.

61. Schulz R, Beach SR. Caregiving as a risk factor for mortality. The caregiver health effects study. Journal of the American Medical Association, 1999; 282(23):2215-2219.

62. Schulz R, Sherwood PR. Physical and Mental Health Effects of Family Caregiving. American Journal of Nursing, 2008; 108 (9 Supplement): 23-27. doi:10.1097/01.NAJ.0000336406.45248.4c.

63. Legg L, Weir CJ, Langhorne P, Smith LN, Stott DJ. Is informal caregiving independently associated with poor health? A population-based study. Journal of Epidemiology and Community Health. 2013; 67:95–97. doi:10.1136/jech-2012-201652.

64. Lee C. Health, stress and coping among women caregivers. A Review. Journal of Health Psychology, 1999; 4(1):27-40.

65. Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: A Meta-Analysis. Journals of Gerontology, Series B, Psychological Sciences and Social Sciences, 2007;62B(2):P126-P137.

66. Fredman, L, Cauley JA, Satterfield S, Simonsick E, Spencer M, Ayonayon HN, Harris TB. Caregiving, mortality, and mobility decline: The health, aging, and body composition (Health ABC) study. 2008. Archives of Internal Medicine, 168; (19):2154–2162.

67. Vlachantoni A, Evandrou M, Falkingham J, Robards J. Health and mortality. Maturitas, 2013; 74(2):114-118.

68. O'Reilly DO, Rosato M, Maguire A, Wright D. Caregiving reduces mortality risk for most caregivers: a census-based record linkage study. International Journal of

Epidemiology, 2015; 44(6):1959–1969. doi: 10.1093/ije/dyv172. Accessed November 1, 2016.

69. Roth DL, Fredman L, Haley WE. Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies. Gerontologist, 2015; 55(2):309–319. doi:10.1093/geront/gnu177.

70. Brown RM, Brown SL. Informal Caregiving: A reappraisal of effects on caregivers. Social Issues and Policy Review, 2014; 8(1):74-102.

71. Dich N, Head J, Hulvej Rod N. Role of psychosocial work factors in the relation between becoming a caregiver and changes in health behaviour: results from the Whitehall II cohort study. Journal of Epidemiology and Community Health, 2016; 70:1200-1206. 2016,pii:jech-2015-206463. doi.10.1136/jech-2015-206463.

72. Lovell B, Wetherell MA. The cost of caregiving: endocrine and immune implications in elderly and non-elderly caregivers. Neuroscience and Biobehavioral Reviews, 2011; 35:1342–1352.

73. von Kanel R, Mausbach BT, Mills PJ Dimsdale JE, Patterson TL, Ancoli-Israel S, Ziegler M, Allison M, Chattillion EA, Grant I. Longitudinal relationship of low leisure satisfaction but not depressive symptoms with systemic low-grade inflammation in dementia caregivers. Journals of Gerontology, Series B, Psychological Sciences and Social Sciences, 2014; 69:397–407. doi:10.1093/geronb/gbt020.

74. Buyck JF, Bonnaud S, Bourmendi A, Andrieu S, Bonenfant S, Goldberg M, Zins M, Ankri J. Informal caregiving and self-reported mental and physical health: results from the Gazel Cohort Study. American Journal of Public Health, 2011; 101(10):1971-9. doi: 10.2105/AJPH.2010.300044.

75. Bertrand RM, Saczynski, JS, Mezzacappa C, Hulse, M, Ensrud K, Fredman L. Caregiving and cognitive function in older women: Evidence for the Healthy Caregiver

Hypothesis. Journal of Aging and Health, 2012; 24(1):48–66. doi: 10.1177/0898264311421367.

76. Roth DL, Haley WE, Hovater M, Perkins M, Wadley VG, Judd S. Family caregiving and all-cause mortality: Findings from a population-based propensity-matched analysis. American Journal of Epidemiology, 2013; 178:1571-1578. doi:10.1093/aje/kwt225.

77. Aneshensel CS, (Ed), Pearlin LI, Mullan JT, Zarit SH, Whitlatch CS. In: Profiles in caregiving, the unexpected career. 1995 San Diego, CA: Academic.

78. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. International Journal of Geriatric Psychiatry, 2002; 17:184-188. doi:10.1002/gps.561.

79. Ratcliffe J, Lester LH, Couzner L, Crotty M. An assessment of the relationship between informal caring and quality of life in older community-dwelling adults – more positives than negatives? Health and Social Care in the Community, 2013; 21(1):35–46. doi:10.1111/j.1365-2524.2012.01085x

80. Lovell B, Moss M, Wetherell M. The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD. Psychoneuroendocrinology, 2012; 37:534-542. doi:10.1016/j.psyneuen.2011.08.003.

81. Luecken LJ, Lemery KS. Early caregiving and physiological stress responses. Clinical Psychology Review, 2004; 24:171–191. doi:10.1016/j.cpr.2004.01.003.

82. Hirst M. Carer distress: A prospective, population-based study. Social Science and Medicine, 2005; 6:697–708.

83. Cooper C, Balamurali TBS, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. International Psychogeriatrics, 2007; 19(2):175–195. doi:10.1017/S1041610206004297.

84. Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A Meta-Analysis. Journal of Gerontology: Psychological Sciences, 2003; 58B(2):P112-128.

85. Whitlatch CJ, Feinberg LF, Sebasta DS. Depression and health in family caregivers. Journal of Aging and Health, 1997; 9(2), 222–243.

86. Phillips AC, Gallagher S, Hunt K, Der G, Carrol D. Symptoms of depression in non-routine caregivers: The role of caregiver strain and burden. British Journal of Clinical Psychology, 2009; 48:335–346 doi:10.1348/014466508X397142.

87. Gupta S, Isherwood G, Jones K, Van Impre K. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. BMC Psychiatry, 2015; 27(3):292–297.

88. Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM. Care for the Caregivers: A review of self-report instruments developed to measure the burden, needs, and Quality of Life of informal caregivers. Journal of Pain and Symptom Management, 2003; 26(4): 922-953. doi:10.1016/S0885-3924(03)00327-0.

89. Mosquera I, Vergara I, Larranaga I, Machon M, del Rio M, Calderon C. Measuring the impact of informal elderly caregiving: a systematic review of tools. Quality of Life Research, 2016; 25:1059-1092. doi:10.1007/s11136-015-1159-4.

90. Bastawrous M. Caregiver burden – A critical discussion. International Journal of Nursing Studies, 2013; 50:431-441. http://dx.doi.org/10.1016/j.ijnurstu.2012.10.005.

91. Adelman, RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden. A clinical review. Care of the aging patient: From Evidence to Action, Clinical Review and Education. Journal of the American Medical Association, 2014; 311(10):1052-1059. doi:10.1001/jama.2014.304.

92. Doran T, Drever F, Whitehead M. Health of young and elderly informal carers: analysis of UK census data. British Medical Journal, 2003; 327:1388.

93. Smith L, Onwumere J, Craig T, McManus S, Bebbington P, Kuipers E. Mental and physical illness in caregivers: results from an English national survey sample. British Journal of Psychiatry, 2014; 205:197-203. doi:10.1192/bjp.bp.112.125369.

94. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). 1. Conceptual Framework and Item Selection. Medical Care, 1992; 30(6):473–483. doi:1097/00005650-199206000-00002.

95. Page TE, Farina N, Brown A, Daley S, Bowling A, Basset T, Livingston G, Knapp M, Joanna Murray J, Banerjee S. Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: a systematic review. BMJ Open, 2017; 7(3);e013611. doi:10.1136/bmjopen-2016-013611. PMID:28360239.

96. Alshubaili AF, Ohaeri JU, Awadalla AW, Mabrouk AA. Family caregiver quality of life in multiple sclerosis among Kuwaitis: a controlled study. BMC Health Services Research, 2008; 8:206. doi:10.1186/1472-6963-8-206.

97. Thomas GPA, Saunders CL, Roland MO, Paddison CAM. Informal carers' health-related quality of life and patient experience in primary care: evidence from 195,364 carers in England responding to a national survey. BMC Family Practice, 2015; 16:62. doi 10.1186/s12875-015-0277-y.

98. Persson J, Holmegaard L, Karlberg I, Redfors P, Jood K, Jern C, Blomstrand C. Spouses of stroke survivors report reduced Health-Related Quality of Life even in long-term follow-up results from Sahlgrenska Academy Study on Ischemic Stroke. Stroke, 2015; 46:00-00. doi: 10.1161/STROKEAHA.115.009791.

99. Peters M, Jenkinson C, Doll H, Playford D, Fitzpatrick R. Carer quality of life and experiences of health services: a cross-sectional survey across three neurological

conditions. Health and Quality of Life Outcomes, 2013; 11:103. doi:10.1186/1477-7525-11-103.

100. Lim J-w, Zebrack B. Caring for family members with chronic physical illness: A critical review of the caregiver literature. Health and Quality of Life Outcomes, 2004; 2:50. doi: 10.1186/1477-7525-2-50.LIM

101. Vogler J, Klein A-M, Bender A. Long-term health-related quality-of-life in patients with acquired brain injury and their caregivers. Brain Injury, 2014; 28(11): 1381–1388. doi: 10.3109/02699052.2014.919536.

102. Cummins RA, Hughes J, Tomyn A, Gibson A, Woerner J, Lai L. Australian Unity Wellbeing Survey:17.1. The wellbeing of Australians: Carer health and wellbeing. (Special Report). 2007. Melbourne: Deakin University. Carers Australia and Australian Unity. Available at: http://www.acqol.com.au/reports/auwbi.php.

103. Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish a general population. Health and Quality of Life Outcomes, 2015; 13(1):109. doi 10.1186/s12955-015-0309-2.

104. Verbakel E, Tamlagsrønning S, Winstone L, Fjær EL, Eikemo TA. Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. European Journal of Public Health, 2017; 27(Suppl.1):90-95. doi:10.1093/eurpub/ckw229.

105. Hiel L, Beenackersa MA, Renders CM, Robroek SJW, Burdorf A, Croezena S. Providing personal informal care to older European adults: Should we care about the caregivers' health? Preventive Medicine, 2015; 70:64–68. http://dx.doi.org/10.1016/j.ypmed.2014.10.028.

106. Lüdecke D, Bien B, McKee K, Krevers B, Mestheneos E, Di Rosa M, von dem Knesebeck O, Kofahl C. For better or worse: Factors predicting outcomes of family care of older people over a one-year period. A six-country European study. PLOS ONE, 2018; 13(4): e0195294. https://doi.org/10.1371/journal.pone.0195294.

107. Kim Y, Carver CS, Cannady RS, Shaffer KM. Self-reported medical morbidity among informal caregivers of chronic illness: the case of cancer. Quality of Life Research, 2013; 22:1265-1272. doi 10.1007/s11136-012-0255-y.

108. Kim Y, Spillers RL. Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. Psycho-Oncology, 2010; 19(4): 431-440.

109. DeFries E, Bouldin ED, Andresen E. Caregiving Across the United States. Caregivers of persons with Alzheimer's disease or dementia in Illinois, Louisiana, Ohio, and the District of Columbia. Data from the 2009 Behavioral Risk factor Surveillance System. Report 2009; Florida Office on Disability and Health, Department of Epidemiology and Biostatistics, College of Public Health and Health Professions, University of Florida. http://fodh.phhp.ufl.edu.

110. Bouldin ED, Andresen E. Caregiving Across the United States: BRFSS data reveal the impact of Alzheimer's disease and dementia (Connecticut, New Hampshire, New Jersey, New York, Tennessee and Virginia), 2010. Alzheimer's and Dementia: The Journal of the Alzheimer's Association, 2010; 8(4):599. Available at: http://doi.org/10.1016/j.jalz2012.05.2082

111. Crawford A, DeFries E, Brumback B, Andresen E. Characteristics of caregivers and care recipients: Results from 2007 Kansas Behavioral Risk Factor Surveillance System. Kansas BRFSS. Office of Health Promotion. Kansas Department of Health and Environment, 2009. Access www.kdheks.gov/brfss/index.html.

112. Anderson LA. Edwards VJ, Pearson WS, Talley RC, McGuire LC, Anderson EM. Adult Caregivers in the United States: Characteristics and differences in well-being, by caregiver age and caregiving status. Preventing Chronic Disease. 2013; 10:E135. doi:10.5888/pcd10.130090. Accessed 17.09.2015.137.

113. Giovannetti ER and Wolff JL. Cross-survey differences in national estimates of numbers of caregivers of disabled older adults. Milbank Quarterly 2010; 88:310–349.

114. Neugaard B, Andresen E, McKune SL, Jamoom EW. Health-related quality of life in a national sample of caregivers: Findings from the Behavioral Risk Factor Surveillance System. Journal of Happiness Studies, 2008; 9(4):559-575. doi:10.1007/s10902-008-90892.

115. Trivedi R, Beaver K, Bouldin ED, Eugenio E, Zeliadt SB, Nelson K, Rosland A-M, Szarja JG, Piette JD. Characteristics and well-being of informal caregivers: Results from a nationally-representative US survey. Chronic Illness, 2014; 10(3)167-179. doi.org/10.1177/1742395313506947.

116. Ji J, Zöller B, Sundquist K, Sundquist J. Increased risks of coronary heart disease and stroke among spousal caregivers of cancer patients. Circulation, 2012; 125:1742-1747. https://doi.org/10.1161/CIRCULATIONAHA.111.057018.

117. Schneiderman N, Kim Y, Shaffer KM. Spouses of patients with cancer have an increased risk of cardiovascular disease. What do we know about this link. Circulation, 2012; 125:1721-1722. https://doi.org/10.1161/CIRCULATIONAHA.112.099226.

118. Laks J, Goren A, Duenas H, Novick D, Kahle-Wrobleski K. Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. International Journal of Geriatric Psychiatry, 2016; 31:176-185 doi:10.1002/gps.4309.

119. Lacey RE, McMunn A, Webb E. Informal caregiving and markers of adiposity in the UK Household Longitudinal Study. Plos One, 2018; 13(7):e0200777. doi:10.1371/journal.pone.0200777.

120. Lacey RE, McMunn A, Webb E. Informal caregiving and metabolic markers in the UK Household Longitudinal Study. Maturitas, 2018; 109:97-103. Accessed 1 June 2018/ https:// doi.org/10.1016/j.maturitas.2018.01.002.

121. Sherwood PR, Price TJ, Weimer J, Ren D, Donovan HS, Given CW, Given BA, Schulz R, Jennifer Prince J, Bender C, Boele FW, Marsland AL. Neuro-oncology family caregivers are at risk for systemic inflammation. Journal of Neuro-Oncology, 2016; 128:109–118. doi 10.1007/s11060-016-2083-3.

122. Kiecolt-Glaser JK, Preacher K J, MacCallum RC, Atkinson C, Malarkey WB, Glaser R. Chronic stress and age-related increases in the proinflammatory cytokine IL-6. Proceedings of the National Academy of Sciences of the United States of America. 2003; 100(15):9090-9095. doi/10.1073/pnas.1531903100.

123. Kuo HK, Yen C-J, Chang C-H, Kuo C-K, Chen J-H, Sorond F. Relation of C-reactive protein to stroke, cognitive disorders, and depression in the general population: systematic review and meta-analysis. Lancet Neurology 2005, 4(6):371-380. doi: 10.1016/S1474-4422(05)70099-5.

124. Damjanovic AK, Yang Y, Glaser R, Kiecolt-Glaser JK, Nguyen H, Laskowski B, Zou Y, Beversdorf DQ, Weng NP. Accelerated telomere erosion is associated with a declining immune function of caregivers of Alzheimer’s disease patients. Journal of Immunology, 2007; 179:4249–4254.

125. von Kanel R, Dimsdale JE, Mills PJ, Ancoli-Israel S, Patterson TL, Mausbach BT, Grant I. Effect of Alzheimer caregiving stress and age on frailty markers Interleukin-6,

C-Reactive Protein, and D-Dimer. Journal of Gerontology: The Gerontological Society of America, 2006; 61A, (9):963–969.

126. Roepke SK, Mausbach BT, Patterson TL, von Kanel R, Ancoli-Israel S, Harmell AR, Dimsdale JE, Aschbacher K, Mills PJ, Ziegler MG, Allison M, Grant I. Effects of Alzheimer caregiving on allostatic load. Journal of Health Psychology, 2011; 16(1):58-69. doi:10.1177/1359105310369188.

127. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler IC. A path model of chronic stress, the Metabolic Syndrome, and coronary heart disease. Psychosomatic Medicine, 2002; 64:418-435.

128. Kang SW, Marks NF. Filial caregiving is associated with greater neuroendocrine dysfunction: Evidence from the 2005 National Survey of Midlife in the United States. SAGE Open Medicine, 2, 2050312113520152, 2014. https://doi.org/10.11772050312113520152.

129. McEwen BS, Stellar E. Stress and the individual: Mechanisms leading to disease. Archives of Internal Medicine. 1993; 153:2093–2101. [PubMed: 8379800].

130. Allen AP, Curran EA, Duggan A, Cryan JF, Chorcoráin AN, Dinan TG, Molloy DW, Kearney M, Clarke G. A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience and Biobehavioral Reviews, 2017; 73:123-164. http://dx.doi.org/10.16/j.neubiorev.2016.12.006.

131. Oken BS, Fonareva I, Wahbeh H. Stress-related cognitive dysfunction in dementia caregivers. Journal of Geriatric Psychiatry Neurology, 2011; 24(4): 191-198. doi:10.1177/0891988711422524.

132. Gouin JP, Hantsoo L, Kiecolt-Glaser JK. Immune dysregulation and chronic stress among older adults: a review. Neuroimmunomodulation, 2008; 15:251–259. doi:10.1159/000156468.

133. Vitaliano PP, Young HM, Zhang J. Is caregiving a risk factor for illness? Current directions in psychological science, 2004; 13(1): 13-16.

134. Zhang J, Vitaliano PP, Lin HH. Relations of caregiving stress and health depend on the health indicators used and gender. International Journal of Behavioral Medicine, 2006; 13(2):173–181.

135. Mills PJ, Ancoli-Israel S, vonKanel R, Mausbach BT, Aschbacher K, Patterson TL, Ziegler MG, Dimsdale JE, Grant I. Effects of gender and dementia severity on Alzheimer's disease caregivers' sleep and biomarkers of coagulation and inflammation. Brain, Behaviour and Immunity, 2009; 23(5):605-610. doi:10.1016/j.bbi.2008.09.014.

136. Faran-Portet M-I, Popham F, Mitchell R, Swine C, Lorant V. Caring, employment and health among adults of working age: evidence from Britain and Belgium. European Journal of Public Health, 2009; 20:(1)52–57. doi:10.1093/eurpub/ckp045.

137. Prince M, Brodaty H, Uwakwe R, Acosta D, Ferri CP, Guerra M, Huang Y, Jacob KS, Llibre Rodriguez JJ, Salas A, Sosa AL, Williams JD, Jotheeswaran AT, Liu Z. Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. International Journal of Geriatric Psychiatry, 2012; 27:670–682. doi: 10.1002/gps.2727.

138. Edwards AB, Zarit S, Stephens MAP, Townsend A. Employed family caregivers of cognitively impaired elderly: An examination of role strain and depressive symptoms. Aging and Mental Health, 2002; 6(1):55-61. doi: 10.1080/13607860120101149.

139. Adair T, Williams R, Taylor P. A juggling act: Older carers and paid work in Australia. Melbourne; National Seniors Productive Ageing Centre (NSPAC): 2013. ISBN 978-0-9923781-2-7.

140. Stoltz P, Uden G, Willman A. Support for family carers who care for an elderly person at home – a systematic literature review. Scandinavian Journal of Caring Sciences, 2004; 18:111–119.

141. Rostgaard T, Timonen V, Glendinning C. Guest editorial: Reforming Home Care in Ageing Societies, Health and Social Care in the Community, 2012; 20(3): 225–227 doi: 10.1111/j.1365-2524.2012.01071.x.

142. Kroger T, Leinonen A. Special Issue. Transformation by stealth: the retargeting of home care services in Finland. Health and Social Care in the Community, 2012; 20(3):319–327. doi: 10.1111/j.1365-2524.2011.01047.x.

143. Da Roit B. Special Issue. The Netherlands: the struggle between universalism and cost containment. Health and Social Care in the Community, 2012; 20(3):228–237 doi: 10.1111/j.1365-2524.2011.01050.

144. Le Bihan B. Special Issue. The redefinition of the familialist home care model in France: the complex formalization of care through cash payment. Health and Social Care in the Community, 2012; 20(3):238–246 doi: 10.1111/j.1365-2524.2011.01051.x

145. Duxbury L, Higgins C, Smart R. Eldercare and the health of employed caregivers. Work, 2011; 40:29–40. doi: 10.3233/WOR-2011-1204.

146. Glendinning C. Home care in England: markets in the context of under-funding. Health and Social Care in the Community, 2012; 20(3): 292-299. doi: 10.1111/j.1365-2524.2012.01059.x.

147. Osterle A, Gudrun Bauer G. Home care in Austria: the interplay of family orientation, cash-for-care and migrant care. Health and Social Care in the Community, 2012; 20(3):265–273. doi: 10.1111/j.1365-2524.2011.01049.x.

148. Gori C. Special Issue Home care in Italy: a system on the move, in the opposite direction to what we expect. Health and Social Care in the Community, 2012; 20(3):255–264. doi: 10.1111/j.1365-2524.2011.01052.x

149. Kemp B, King S, Paleologos Z, Bellamy J, Mollenhauer J. Carers: Doing it tough, doing it well. Anglicare Diocese of Sydney, 2016. Social Policy and Research Unit. ISBN 978-0-9875870-4-6.

150. Hill T, Thomson C, Cass B, Raven M, Wong M, Yeandle S Buckner L. Carers and Social Inclusion. Social Policy Research Centre, 2016; UNSW Australia ISBN: 978-1-925218-64-0.

151. Cass B, Yeandle S. ‘Policies for carers in Australia and the UK. Social policy ideas, practices and their cross-national transmissions: Social movements, parliamentary inquiries and local innovations’ paper for RC19 Conference Montreal August 2009.

152. Schene AH, Tessler RC, Gamache GM. Instruments measuring family or caregiver burden in severe mental illness. Social Psychiatry and Psychiatric Epidemiology, 29(5):228-240.

153. Freeman HE, Simmons OG. Mental patients in the community. Family settings and performance level. American Sociological Review, 1958, 22:147–154.

154. Grad J, Sainsbury P. The effects that patients have on their families in a community care and a control psychiatric service. British Journal of Psychiatry, 1968, 114: 265–278.

155. Gilleard CJ, Belford H, Gilleard E, Whittick JE, Gledhill K. Emotional distress amongst the supporters of the elderly mentally infirm. British Journal of Psychiatry, 1984; 145:172-7.

156. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. The Gerontologist, 1986, 26,260–266.

157. Boyer L, Caqueo-Urízar A, Richieri R, Lancon C, Gutiérrez-Maldonado J, Auquier P. Quality of life among caregivers of patients with schizophrenia: a cross-cultural comparison of Chilean and French families. BMC Family Practice, 2012; 13:42. http://www.biomedcentral.com/1471-2296/13/42.

158. Hastrup LH, Van Den Berg B, Gyrd-Hansen D. Do informal caregivers in mental illness feel more burdened? A comparative study of mental versus somatic illnesses. Scandinavian Journal of Public Health, 2011; 39:598-607. doi: 10.1177/143494811414247.

159. Department of Health, Population Research & Outcome Studies. The Health Omnibus Survey. http://www.dh.sa.gov.au/pehs/HOS.html.

160. Wilson DH, Wakefield M, Taylor AW. The South Australian Omnibus Survey. Health Promotion Journal of Australia, 1992; 2(3):47-9.

161. The HOS methods 2002-04. The Health Omnibus Survey (HOS) Methodology Health Omnibus Survey (HOS) Evaluation Report. December 2005.

162. Taylor AW, Dal Grande E, Wilson D. The South Australian Health Omnibus Survey 15 years on: has public health benefited ? Public Health Bulletin 2006;3.

163. PROS. Carers in South Australia. February 2014. Health Omnibus Survey (HOS). Autumn 2013. Prepared by Population Research and Outcomes Studies, Discipline of Medicine, Division of Health Sciences, University of Adelaide.

164. Australian Bureau of Statistics (ABS). Statistical Geography Volume 1- Australian Standard Geographical Classification (ASGC), Jul 2006. 1216.0.

165. Australian Bureau of Statistics (ABS). Census of Population and Housing. Socio-economic Indexes for Areas (SEIFA). Australia, 2011 (cat. no. 2033.0.55.001).

166. Rutherford MJ, Lambert PC, Thompson JR. Age-period-cohort modelling. Stata Journal, 2010; 606-627.

167. SAMSS Brief Report. No. 2002-20. Adelaide: Department of Health; 2002. Available from: http://www.health.sa.gov.au/ pros.

168. SAMSS Technical Working Paper No1/04 August 2004. Available from: http://www.dh.sa.gov.au/pehs/PROS/samss.html.

169. Taylor A. Chronic disease surveillance in South Australia. Public Health Bulletin. 2006; 3:6-9.

170. Taylor A, Dal Grande E. Chronic disease and risk factor surveillance using the SA Monitoring and Surveillance System (SAMSS)-history, results and future challenges. Public Health Bulletin. 2008; 3(5); 17-21.

171. Dal Grande E, Fullerton S, Taylor AW. Reliability of self-reported health risk factors and chronic conditions questions collected using the telephone in South Australia, Australia. BMC Medical Research Methodology, 2012; 12(1):108. http://www.biomedcentral.com/1471-2288/12/108.

172. Dal Grande E, Chittleborough CR, Campostrini S, Tucker G, Taylor AW. Health estimates using survey raked-weighting techniques in an Australian population health surveillance system. American Journal of Epidemiology, 2015; 182(6):544-556. doi: 10.1093/aje/kwv080.

173. Armstrong T, Bauman A, Davies J. Physical Activity Patterns of Australian Adults. Results of the 1999 National Physical Activity Survey. Canberra: Australian Institute of Health and Welfare; 2000.

174. World Health Organization (WHO) (2010). BMI classification. Geneva, Switzerland: World Health Organization, (updated 30/04/2013 Accessed 29/04/2013); Available from: http://apps.who.int/bmi/index.jsp?introPage=intro_3.html.

175. National Health and Medical Research Council (NHMRC). Australian Guidelines to Reduce Health Risks from Drinking Alcohol, Canberra, Australia: National Health and Medical Research Council; 2009.

176. National Health and Medical Research Council) (NHMRC). Food for health, dietary guidelines for Australians: a guide to healthy eating. 2005; Australian Government, Canberra (2005) Available from: http://www.nhmrc.gov.au/publications/synopses/_files/n31.pdf [22.09.08]

177. SAMSS Technical Paper 1 – Method. Population Research and Outcomes Studies Unit. South Australian Monitoring and Surveillance System (SAMSS). Survey Methodology. SAMSS Technical Paper Series No.1/04, August 2004. Adelaide: Department of Health.

178. Kessler RC, Mroczek DK. Final versions of our non-specific psychological distress scale. University of Michigan, Ann Arbor: Survey Research Centre of the Institute for Social Research; 1994.

179. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. Psychological Medicine, 1979;9(1):139-45.

180. Goldney RD, Dal Grande E, Fisher LJ et al. Population attributable risk of major depression for suicidal ideation in a random and representative community sample. Journal of Affective Disorders 2003;74(3):267-272.

181. Rockhill B, Newman B, Weinberg C. Use and misuse of population attributable fractions. American Journal of Public Health 1998; 88:15-19.

182. Grant JF, Taylor AW, Ruffin RE, Wilson DH, Phillips PJ, Adams RJT, Price K, North West Adelaide Health Study Team: Cohort profile: The North West Adelaide Health Study (NWAHS). International Journal of Epidemiology, 2009; 38(6):1479-1486. doi: 101093/ije/dyn262.

183. Grant JF, Chittleborough CR, Taylor AW, Dal Grande E, Wilson DH, Phillips PJ, Adams RJ, Cheek J, Price K, Gill T, Ruffin RE, North West Adelaide Health Study Team: The North West Adelaide Health Study: methodology and baseline segmentation of a cohort along a chronic disease continuum. Epidemiologic Perspectives & Innovations. 2006; 3:4. doi:10.1186/1742-5573-3-4.

184. Grant JF, Chittleborough CR, Dal Grande E, Taylor AW. Baseline biomedical and self-report data. 2005. The North West Adelaide Health Study (NWAHS). South Australian Department of Health. Population Research and Outcome Studies Unit. ISBN 0 7308 9392 8. http://www.dh.sa.gov.au/pehs/PROS/NWhealth.html.

185. Australian Institute of Health and Welfare and National Heart Foundation. Risk factor prevalence study: Survey no 3. 1989. Canberra: AIHW.

186. National Heart Lung and Blood Institute Global Initiative for Asthma. National Institutes of Health, Bethesda (MD). 2003. Publication no. 02-3659.

187. Chronic Obstructive Pulmonary Disease. National clinical guideline on management of chronic obstructive pulmonary disease in adults in primary and secondary care. Thorax, 2004; 59(Suppl 1):1-232.

188. WHO. Obesity: preventing and managing the global epidemic. 2000 WHO Geneva, Switzerland. http://www.who.int/nutrition/publications/obesity/WHO_TRS_894/en/.

189. Australasian Society for the Study of Obesity. Healthy Weight Australia: A National Obesity Strategy. Australasian Society for the Study of Obesity, 1995.

190. Australian Bureau of Statistics: Population by age and sex. South Australia. Canberra: Australian Bureau of Statistics (ABS). 2000; 30 June 1999.

191. Australian Bureau of Statistics: Census of Population and Housing Selected Social and Housing Characteristics for Statistical Local Areas South Australia, 2001. In Australian Bureau of Statistics, Cat No.2015.4 Canberra: Australian Bureau of Statistics (ABS). 2002.

192. Moon H, Betts Adams K. The effectiveness of dyadic interventions for people with dementia and their caregivers. Dementia, 2012; 12(6):821–839. doi: 10.1177/1471301212447026.

193. Tommis Y, Robinson CA, Seddon D, Woods B, Perry J, Russell IT. Carers with chronic conditions: changes over time in their physical health. Chronic Illness, 2009; 5:155–164. doi: 10.1177/1742395309339251.

194. Van Durme T, Macq J, Jeanmart C, Gobert M. Tools for measuring the impact of informal caregiving of the elderly: A literature review. International Journal of Nursing Studies, 2012; 49:490–504. doi:10.1016/j.ijnurstu.2011.10.011.

195. Gallo LC, Jiménez JA, Shivpuri S, Espinosa de los Monteros K, Mills PJ. Domains of chronic stress, lifestyle factors, and allostatic load in middle-aged Mexican-American Women. Annals of Behavioural Medicine, 2011; 41:21-31. doi 10.1007/s12160-010-9233-1.

196. Cacioppo JT, Burleson MH, Poehlmann KM, Malarkey WB, Kiecolt-Glaser JK, Bernston GG, Uchino BN, Glaser R. Autonomic and neuroendocrine responses to mild psychological stressors: effects of chronic stress on older women. Annals of Behavoural Medicine, 2000; 22(2):140-148.

197. Carretero S, Garces J, Rodenas F, Sanjose V. The informal caregiver's burden of dependent people: Theory and empirical review. Archives of Gerontology and Geriatrics, 2009; 49:74-79. doi:10:1016/j.archger.2008.05.004

198. Australian Institute of Health and Welfare (AIHW) 2010. Primary carers of people with arthritis and osteoporosis. Arthritis series no. 12. Cat. no. PHE 124. Canberra: AIHW.

199. Mortensen J, Clark AJ, Lange T, Andersen GS, Goldberg M, Ramlau-Hansen CH, Head J, Kivimaki M, Madsen IEH, Leineweber C, Lund R, Rugulies R, Zins M, Westerlund H, Rod NH. Informal caregiving as a risk factor for type 2 diabetes in individuals with favourable and unfavourable psychosocial work environments: A longitudinal multi-cohort study. Diabetes and Metabolism, 2018; 44(1):38-44. doi: 10.1016/j.diabet.2017.04001.

200. Buyck JF, Ankri J, Dugravot A, Bonnaud S, Nabi H, Kivimaki M, Singh-Manoux A. Informal Caregiving and the risk for Coronary Heart Disease: The Whitehall II Study. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences. 2013; 68(10):1316–1323. https://doi.org/10.1093/gerona/glt025PMID: 23525476.

201. Guessous I, Bochud M, Bonny O, Burnier M: Calcium, vitamin D and cardiovascular disease. Kidney Blood Pressure Research, 2011, 34:404–417.

202. Gagnon C, Lu ZX, Magliano DJ, Dunstan DW, Shaw JE, Zimmet PZ, Sikaris K, Grantham N, Ebeling PR, Daly RM: Serum 25-hydroxyvitamin D, calcium intake, and risk of type 2 diabetes after 5 years. Diabetes Care 2011,34:1133–1138.

203. Cutolo M, Plebani M, Shoenfeld Y, Adorini L, Tincani A: Vitamin D, endocrine system and the immune response in rheumatic diseases. Vitamins and Hormones; 2011; 86:327–351. https:/doi.org/10.1016.B978-0-12386960-9.00014-9.

204. Gill TK, Hill CL, Shanahan EM, Taylor AW, Appleton SL, Grant JF, Shi Z, Dal Grande E, Price K, Adams RJ. Vitamin D levels in an Australian population. BMC Public Health; 2014; 14:1001. http://www.biomedcentral.com/1471-2458/14/1001.

205. Pruchno RA, Potashnik SL. Caregiving spouses: Physical and mental health in perspective. Journal of the American Geriatrics Society, 1989; 37(8):697-705.

206. Clark I, Atwood C, Bowen R, Paz-Filho G, Vissel B. Tumor Necrosis Factor-induced cerebral insulin resistance in Alzheimer’s disease links numerous treatment rationales. Pharmacological Reviews, 2012; 64(4):1004–1026.

207. Poole EM, Lee I-M, Ridker PM, Buring JE, Hankinson SE, Tworoger SS. A prospective study of circulating C-Reactive Protein, Interleukin-6, and Tumor Necrosis Factor α Receptor 2 levels and risk of ovarian cancer. American Journal of Epidemiology, 2013; 178(8):1256-1264. doi: 10.1093/aj2/kwt098.

208. Kroger T, Yeandle S (Eds). Combining paid work and family care: policies and experiences in international perspective. 2013. Bristol: The Policy Press. ISBN: 9781 447306818.

209. Morgan F. The treatment of informal care-related risks as social risks: An analysis of the English care policy system. Journal of Social Policy, 2018; 47(1):179-196. doi: 1017/8004727941000265.

210. Tooth L, Loxton D, Chan H, Coombe J, Dobson A, Hockey R, Townsend N, Byles J & Mishra G. From child care to elder care: Findings from the Australian Longitudinal Study on Women’s Health. Report prepared for the Australian Government Department of Health, May 2018.

211. van den Berg B, Fiebig DG, Hall J. Well-being losses due to care-giving. Journal of Health Economics, 2014; 35:123–131. doi: 10.1016/j.jhealeco.2014.01.008 PMID: 24662888.

212. Colombo F, Llenz-Noza A, Mercier J, Tjadens F. Help wanted? Providing and paying for long-term care, OECD Publishing, 2011. OECD Health Policy Studies, Organisation for Economic Cooperation and Development. http://dx.doi.org/10.1787/9789264097759-en

213. Olaussen SJ, Renzaho AMN. Establishing components of cultural competence healthcare models to better cater for the needs of migrants with disability: a systematic review. Australian Journal of Primary Health, 2016; 22:100-112. https://doi.org/10.1071/PY14114.

214. Trang T. Health issues for women of non-English speaking backgrounds. Australian Journal of Primary Health, 1998; 4(3) 93-96.

215. Family Caregiver Alliance. Selected caregiver assessment measures: A Resource Inventory for Practitioners (2nd Edition). Compiled by Schwartz S and Darlak L. December 2012. Family Caregiver Alliance. National Center on caregiving in collaboration with Benjamin Rose Institute on Aging. The Margaret Blenkner Research Institute of the Benjamin Rose Institute on Aging.

216. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: Evidence-based clinical practice guidelines. Rehabilitation Medicine, 2006; 38:153-158. doi: 10.1080/16501970500441898.

217. Robinson BG. Validation of a Caregiver Strain Index. Journal of Gerontology, 1983; 38(3):344-8.

218. Australian Bureau of Statistics (ABS). Australian Health Survey: 2011-13. Biomedical Measures Users' Guide, 2011-13. Australian Bureau of Statistics (ABS). 4363.0.55.001.

Appendices

Appendix A: Conference presentation

7th International Conference of Carers: 4-6 October 2017

Adelaide Convention Centre, North Terrace Adelaide, South Australia

Presentation at Concurrent Session, Wednesday 4 October, 4-5-30pm on Carer Health and Wellbeing

Title of Presentation: A Report Card on Carer Health in SA

Abstract: Title: A report card on carer health: Fostering partnerships between researchers, carers and clinicians to monitor the health of carers at both population and clinical levels].

Presenter: Anne F Stacey

Co-Authors: Professor Anne Taylor; BA, MPH, PhD. (Population Research & Outcome Studies, Discipline of Medicine, University of Adelaide, Australia)

Dr Tiffany K. Gill; BAppSc, MAppSc, CertHealthEc, PGradDip(HlthSc), MBA, PGradDip(Biostats), PhD. (Population Research & Outcome Studies, Discipline of Medicine, University of Adelaide, Australia)

Associate Professor Kay Price; RN, PhD (School of Nursing and Midwifery, University of South Australia)

Conference Abstract: A proportion of family (informal) carers report personal health problems, disabilities and chronic conditions themselves whilst providing long-term home-based support of family members with complex care needs. In South Australian surveys, carers' perceptions of their own health indicated that up to 34% felt their caregiving role affected their physical or emotional health. This is a growing global phenomenon. Therefore, monitoring carer health is important, but there are limited representative population-based survey data that give detailed information on the health status and biomedical profiles of carers. Establishing more formal links between mainstream research and health related researchers, clinicians, carer groups, governments and policy makers would help facilitate the ongoing collection of base-line data about carer morbidity amongst these unpaid informal carers.

This presentation features original research that provides a snapshot of general health characteristics and biomedical status of adult carers [aged 16 and over]. It combines selected results from two cross-sectional studies conducted between 2008 and 2016 in South Australia. Our study showed that more carers reported fair to poor health, disability and psychological distress than non-carers. Initial findings indicated there was a higher prevalence of key risk factors, such as smoking, raised cholesterol and blood pressure amongst carers. Although the overall risk of SA carers having major chronic conditions was low when compared with non-carers, carers had a greater likelihood self-reporting chronic conditions such as diabetes, asthma, arthritis and depression.

Currently this type of detailed health information on carers is lacking in the published literature. Fostering partnerships between researchers, carers and health professionals and including informal carers within mainstream research will enable the monitoring of carer health and morbidity in much greater detail. The challenge is to identify, improve and protect the health of vulnerable informal carers now and in the future.

*SA HEALTH, for access to SAMSS: South Australian Monitoring and Surveillance System

(* SA HEALTH refers to the South Australian Department of Health and Ageing, Government of South Australia)

Appendix B: Reprint of published paper- PLoS One

Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects 1994–2014

PLOS ONE

RESEARCH ARTICLE

Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects 1994–2014

Anne F. Stacey[1]*, **Tiffany K. Gill**[1], **Kay Price**[2], **Rosemary Warmington**[3], **Anne W. Taylor**[1]

1 Population Research & Outcome Studies, Discipline of Medicine, The University of Adelaide, Adelaide, South Australia, Australia, **2** School of Nursing and Midwifery, The University of South Australia, Adelaide, South Australia, Australia, **3** Carers SA, Adelaide, South Australia, Australia

* anne.stacey@adelaide.edu.au

Abstract

Background

The ongoing need for an availability of informal carers is taking on greater relevance as the global burden of disease transitions from acute fatal diseases to long term morbidity. Growing evidence suggests that extra burden on family carers may further impact on their health and ability to provide care. Important as it is to monitor the prevalence of those conditions which influence the burden of disease, it is also important to monitor the prevalence and health profiles of those who provide the informal care. The aim of this study was to demonstrate the prevalence and demographics of adult carers aged 15 and over in the state of South Australia over 20 years between 1994 and 2014.

Methods

Data from nine representative, cross-sectional population surveys, conducted in South Australia, Australia were used, (total N = 26,788 and n = 1,504 carers). The adjusted prevalence estimate of carers and their demographic characteristics were determined. So as to examine whether there were any generational effects on the prevalence of carers, an Age-Period Cohort (APC) analysis was undertaken.

Results

The prevalence estimates of carers increased during the two decades from 3.7% in 1994 to 6.7% by 2014. Large increases in the proportion of retired carers, those aged 70 years and over, those carers employed, and those with higher educational qualifications were observed. There were also larger proportions of respondents with a country of birth other than Australia, UK, Ireland and European counties. The APC analysis illustrated an increasing prevalence rate over each decade for carers aged 20–80 years, especially for those over the age of 60 years.

OPEN ACCESS

Citation: Stacey AF, Gill TK, Price K, Warmington R, Taylor AW (2016) Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects 1994–2014. PLoS ONE 11(9): e0161994. doi:10.1371/journal.pone.0161994

Editor: Francesco Pappalardo, Universita degli Studi di Catania, ITALY

Received: April 13, 2016

Accepted: August 16, 2016

Published: September 20, 2016

Data Availability Statement: Data are from the South Australia Health Omnibus Survey whose authors may be contacted at anne.stacey@adelaide.edu.au.

Funding: Funding was received from Carers SA. The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing Interests: The authors have declared that no competing interests exist.

Conclusions

The results illustrate changing carer characteristics and carer prevalence estimates in South Australia as new generations of carers take on the caring role. There is a need to include questions regarding informal carers within ongoing mainstream population surveys, particularly at state levels, so as to plan for their future health care and home support.

Background

Although the concept of kinship support and filial piety has existed throughout history across most cultures, the importance of family members caring for ill or aged relatives was not adequately recognised at the level of social policy of western countries until later in the twentieth century [1–2]. Traditional expectations of family meant that the caring efforts of informal carers (unpaid caregivers) were often taken for granted [3]. Today carers are more readily recognised as a separate group in their own right. Their pivotal role in health and social support systems are acknowledged for their significant economic contribution to containing health care costs [4–5]. Defining an informal carer or family caregiver is however problematic as carers can be any age, from children to the elderly, younger than nine years old to over 90 years of age. They may care for a child or adult age person with a disability, a chronic physical or mental illness, is recovering from illness or accident or who is a frail aged person. Carers are referred to as unpaid, informal or family caregivers who provide in-home support to a family member or friend who needs assistance in their daily living activities.

Globally the ongoing need for an availability of informal carers is taking on even greater critical relevance. Firstly as life expectancy increases and the population ages; secondly as studies of global burden of disease show a transitioning from early mortality associated with acute fatal diseases to long term morbidity dominated by chronic conditions [6–7]. Not only have these phenomena resulted in higher proportions of disability and impairment across populations, but are impacting at community and individual levels [8]. For example informal family carers of all ages provide multifaceted care for children and adults with a disability, persons who are frail and aged, chronically ill partners and friends with complex and demanding physical and mental health problems [9].

Growing evidence suggests that the extra burden on carers can put them at risk of physical health and emotional stress and strain [10–12]. Therefore important as it is to track the prevalence of those conditions which influence the burden of disease, (for example cancers, cardiovascular diseases, injury as well as dementias), it is also necessary to track the prevalence, demographic profiles and health status of those who provide the informal care.

Over the past thirty years, prevalence figures of informal caregiving at the population level have emerged haphazardly across industrialised nations and more recently from developing countries [13–14]. The methodology to identify informal caregivers still remains inconsistent, with international surveys providing estimates ranging from 15% to 39% [9,15]. It is acknowledged that prevalences are affected by different definitions of informal carers thus it is difficult to compare prevalences across countries and across studies or surveys. However some larger population studies do provide an overview. For example, in 2011, 12% of the British (adult) population were identified as caregivers [16]. Canadian surveys have estimated that overall 28% of adult Canadians aged 15 or over were caregivers although rates varied considerably across the provinces [17]. In the United States (US) it was estimated that up to 25–30% of the adult population were providing care and support to family and friends, but again rates varied by state [18–19]. In both the 2009 and 2012 Australian Bureau of Statistics (ABS) Disability Ageing and Carers surveys (SDAC), approximately 12% of the Australian population was identified as providing some care while approximately a third were primary carers [20–21]. ABS limit their definition to care provided to people with disability, long-term conditions, or care for persons who are aged 60 years and over [21].

At state levels in Australia, population-based details of carer prevalence have also mostly come from data collected by the national ABS surveys. These have been conducted approximately every five to six years since 1993. In the state of South Australia (SA), the prevalence of carers has been determined through additional separate state wide Health Omnibus Surveys (HOS) which have included carer status questions in nine of the annual surveys between 1994 and 2014.

The aim of this paper is to show changes over 20 years, between 1994 and 2014, in the prevalence and demographic characteristics of adult carers aged 15 and over in the state of SA. To achieve this, the trend over the past decades was analysed. Secondly, multivariable analyses were conducted to determine the demographic characteristics of those reporting that they were carers, from three time points. Thirdly, the percentage differences for demographic and socio-economic variables were analysed across the two decades from 1994 to 2014. Lastly the age-period-cohort (APC) effects were also examined. The benefits of APC analysis allow the effects of age, period and cohort to be interpreted independently whilst taking into account a plethora of individual, societal, historical and cultural aspects [22]. Age relates to the physiological processes associated with growing older, period effects relate to particular time points with the assumption that populations are all equally affected, and cohort effects relate to experiences during particular time frames.

Methods

The Health Omnibus Survey is a population-based cross-sectional, representative survey that has been undertaken annually or bi-annually in SA since 1990. It investigates a range of health and health service issues as requested by health related organisations and researchers in SA and beyond. The full HOS methodology has been previously described [23] but in brief, each survey is a clustered, multi-stage, systematic, self-weighting sample selected from the Adelaide metropolitan area with the remainder being drawn from those country areas with a population of 1000 or more, based on ABS Census information. Each survey is face-to-face and interviews are undertaken by trained interviewers.

Carer questions

Informal carers are those who provide the main care in the home setting, are aged 15 years or older, and are giving ongoing personal care and assistance to dependent relatives and individuals with a chronic mental or physical illness or who are frail and aged. Providing this care is beyond that which is expected in a normal relationship [24–25]. Data pertaining to informal carer status was from selected years between 1994 to 2014. In 1994 and 1998, the carer question used was, *"Are you a carer of a dependent person? (A dependent person is someone who has a chronic condition that is unlikely to improve, for example frail aged, disabled etc.)*. In the remaining surveys (2000–2002, 2004, 2008, 2013–2014) the carer question was, *"Do you provide long-term care at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness, where long-term care is a minimum of 6 months and may extend into years."* Refer to S1 File.

Demographic and socio-economic questions

Demographic variables included in the surveys are gender, age group, area of residence, country of birth and marital status. Socio-economic variables included educational attainment and work status. Details of the annual income for each household was obtained and the socio-economic disadvantage of neighbourhood at an environmental level (using postcode) was classified into the Socio Economic Index for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage from which quintiles were determined [26]. Refer to S2 File.

Data analysis

The survey data were weighted by age, gender and geographic locations so that the findings apply to the demographic profile of SA using either the ABS census data or the most recent estimated residential population for each year. Initially the trend in prevalence was determined using the nine years of data. Age and sex standardized prevalence estimates were also produced. For ease of interpretation data from three surveys collected ten years apart (1994, 2004 and 2014) were selected to highlight specific demographic changes. Analysis was undertaken using SPSS Statistics, Version 19 (IBM SPSS Statistics, New York, NY, USA).

For the APC analysis, the combined data from the nine years were used and an APC model was constructed using STATA Version 13 (StataCorp, College Station, TX, USA) with the 'apcfit' command [27]. APC analysis was chosen so as to interpret the effects of ageing, birth cohorts and time periods in relation to carer prevalence and odds ratios. In this analysis, 'AGE' was the self-reported age of the respondents at the time of the survey interview. 'COHORT' was the age subtracted from the survey year. This ranged from the oldest respondents (80 years and over) to the youngest respondents (aged 15 years). 'PERIOD' represents the years of data collection (1994 to 2014).

Ethical approval

This procedure was approved by both the Research Ethics Committee of The University of Adelaide (U of A H-097-2010), and previously with South Australia Health and the South Australian Department of Health, (310/07/2012).

Participants provided informed verbal consent for each of the surveys used between 1994 and 2014 for this study. In line with other epidemiologically-based surveillance systems, verbal consent was obtained from the participant before the interview commenced. Participation in each HOS study is voluntary. An approach letter introducing HOS was sent to selected households prior to all interviews, including a brochure outlining confidentiality and privacy assurance, how the information was to be used and which organisations were involved in each survey. If the selected respondents had any queries or did not wish to participate in the survey, they were able to call a 1800 free call telephone number listed in the introductory letter.

Verbal consent was obtained by the interviewers at the time of the face-to-face interview and upon initial contact, the interviewers repeat the purpose of the survey as well as the expected length of time to complete the interview. The respondent could choose to not answer any question or section throughout the interview or could terminate participation at any time. Continued participation was taken as evidence as continued willingness to participate (implied consent) however if the participant withdrew their consent to participate at any time, the interview was terminated and no information collected.

Results

Overall, the total sample for the nine surveys was N = 26,788 (n = 1,504 were carers). The survey response rates decreased over the 20 year period from 72.4% in 1994 to 54.4% in 2014. The prevalence trend using data from nine surveys which included carer status questions is presented in Table 1 and Fig 1. In SA over the two decades from 1994 to 2014, there was almost a

Table 1. Crude & Age / Sex Standardised Prevalence Estimates of Adult Carers, South Australia 1994–2014.

Year	HOS Total N	CarersTotal n	SA Estimate Prevalence % (95% CI)	Age and Sex Standardised Prevalence Estimate % (95% CI)
1994	3010	104	3.4% (2.9–4.2)	3.7% (2.9–4.4)
1998	3010	127	4.5% (3.6–5.0)	4.6% (3.5–5.6)
2000	3027	141	4.7% (4.0–5.5)	4.8% (4.0–5.6)
2001	3037	170	5.6% (4.8–6.5)	5.9% (4.9–5.6)
2002	3015	154	5.0% (4.3–5.9)	5.2% (4.2–6.2)
2004	3015	177	5.9% (5.1–6.8)	5.9% (5.1–6.8)
2008	3034	239	7.9% (6.8–8.9)	7.9% (6.8–8.9)
2013	2908	218	7.5% (6.6–8.5)	7.5% (6.2–8.8)
2014	2732	174	6.4% (5.5–8.3)	6.7% (5.4–7.7)

doi:10.1371/journal.pone.0161994.t001

doubling of the prevalence of carers increasing from 3.7% 1994 to a peak of 7.9% in 2008 then declining to 6.7% by 2014.

Table 2 highlights the unadjusted and adjusted odds ratios of carers over three specific years; 1994, 2004 and 2014 by a range of demographic variables. Multivariable analysis shows that in 2014 carers were more likely to be female (OR 1.43; 95% CI 1.00–2.05, $p = 0.050$), be aged 50–69 (OR 1.82; 95% CI 1.11–3.01 $p = 0.0.019$), be born in countries other than Australia, UK or Ireland, (OR 1.82; 95% CI 1.08–3.07, $p = 0.02$), be never married (OR 0.47; 95% CI 0.26–0.83, $p = 0.011$), declare their work status as 'home duties' (OR 1.88; 95% CI 1.02–3.48, $p = 0.043$) and have annual household incomes of $20,000–40,000 (OR 2.38; 95% CI 1.29–4.02, $p = 0.005$).

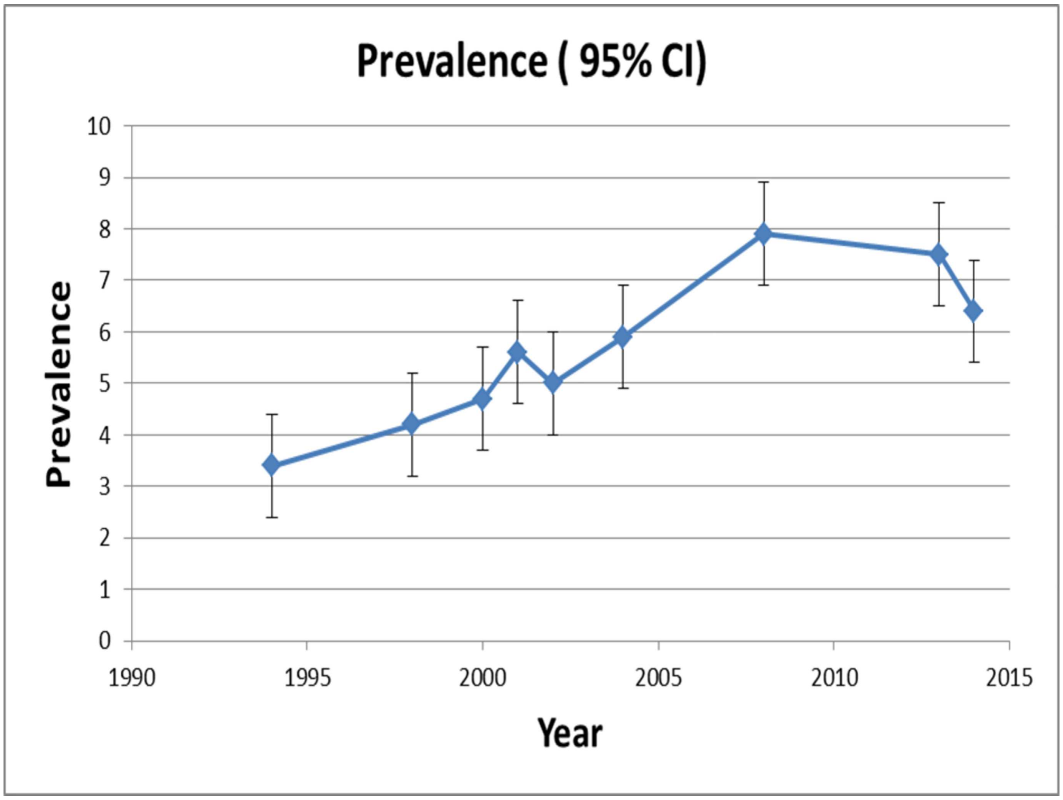


Fig 1. Prevalence Estimates of Adult Carers in South Australia: 1994 to 2014.

doi:10.1371/journal.pone.0161994.g001

Table 2. Unadjusted and adjusted odds ratios of carers over three time periods by demographic variables: Health Omnibus Survey: 1994, 2004, 2014.

		1994				2004				2014			
		unadjusted		adjusted		unadjusted		adjusted		unadjusted		adjusted	
		odds ratio	pval	odds ratio	pval	odds ratio	pval	odds ratio	pval	odds ratio	pval	odds ratio	pval
SEX	Male	1.00		1.00		1.00		1.00		1.00		1.00	
	Female	1.41 (0.90–2.20)	0.131	1.01 (0.56–1.81)	0.981	1.50 (1.04–2.17)	0.030	1.31 (0.87–1.98)	0.200	1.51 (1.06–2.15)	0.022	1.43 (1.00–2.05)	0.050
AGE GROUP	18 to 49	1.00		1.00		1.00		1.00		1.00		1.00	
	50 to 69	3.10 (1.97–4.88)	0.000	2.08 (1.22–3.54)	0.007	1.90 (1.30–2.77)	0.001	1.48 (0.95–2.29)	0.084	2.34 (1.60–3.44)	0.000	1.82 (1.11–3.01)	0.019
	70+	2.41 (1.18–4.91)	0.016	1.74 (0.69–4.35)	0.237	2.38 (1.52–3.71)	0.000	1.73 (0.93–3.20)	0.083	2.80 (1.73–4.55)	0.000	1.73 (0.79–3.77)	0.167
AREA	Metro. Adelaide	1.00		1.00		1.00		1.00		1.00		1.00	
	Country	1.19 (0.69–2.05)	0.521	1.07 (0.59–1.93)	0.829	1.24 (0.89–1.71)	0.197	1.13 (0.81–1.59)	0.471	1.19 (0.77–1.84)	0.427	1.14 (0.72–1.80)	0.580
COUNTRY OF BIRTH	Australia	1.00		1.00		1.00		1.00		1.00		1.00	
	UK/Ireland	2.26 (1.35–3.78)	0.002	1.89 (1.09–3.25)	0.022	1.30 (0.75–2.25)	0.350	1.04 (0.57–1.88)	0.901	1.66 (1.06–2.60)	0.027	1.25 (0.79–1.98)	0.343
	Other	1.09 (0.59–2.02)	0.793	0.90 (0.47–1.74)	0.750	0.73 (0.42–1.27)	0.263	0.66 (0.38–1.16)	0.149	1.54 (0.96–2.46)	0.073	1.82 (1.08–3.07)	0.026
MARITAL STATUS #													
	Married/defacto	1.00		1.00		1.00		1.00		1.00		1.00	
	Separated/Divorced	1.01 (0.53–1.92)	0.971	1.05 (0.53–2.05)	0.893	0.88 (0.53–1.48)	0.635	0.68 (0.39–1.19)	0.176	1.12 (0.73–1.73)	0.593	0.94 (0.56–1.58)	0.819
	Never married	0.33 (0.16–0.69)	0.003	0.62 (0.28–1.38)	0.239	0.47 (0.26–0.85)	0.012	0.59 (0.31–1.14)	0.117	0.35 (0.22–0.54)	0.000	0.47 (0.26–0.83)	0.011
EDUCATIONAL ATTAINMENT													
	Up to secondary	1.00		1.00		1.00		1.00		1.00		1.00	
	Trade qualifications, certificate, diploma	1.33 (0.57–3.09)	0.506	1.02 (0.61–1.69)	0.953	1.62 (0.87–3.00)	0.127	1.06 (0.71–1.60)	0.766	1.52 (0.91–2.56)	0.111	0.94 (0.67–1.32)	0.704
	Degree or higher	1.49 (0.66–3.35)	0.337	1.19 (0.48–3.00)	0.706	1.86 (1.03–3.37)	0.040	0.81 (0.43–1.53)	0.512	1.70 (1.10–2.65)	0.018	0.70 (0.42–1.17)	0.169
WORK STATUS													
	Employed full or part time	1.00		1.00		1.00		1.00		1.00		1.00	
	Home duties	3.37 (1.96–5.82)	0.000	2.19 (1.13–4.23)	0.020	3.32 (1.99–5.54)	0.000	2.34 (1.34–4.07)	0.003	2.80 (1.50–5.21)	0.002	1.88 (1.02–3.48)	0.043
	Retired	2.71 (1.47–4.99)	0.001	1.31 (0.58–2.96)	0.511	2.50 (1.66–3.78)	0.000	1.55 (0.92–2.61)	0.096	2.70 (1.80–4.07)	0.000	1.45 (0.84–2.50)	0.176
HOUSEHOLD ANNUAL INCOME													
	$40,000	1.00		1.00		1.00		1.00		1.00		1.00	
	$20-$40,000	1.72 (0.78–3.81)	0.181	1.39 (0.57–3.36)	0.465	1.82 (1.17–2.82)	0.008	1.36 (0.82–2.25)	0.234	3.44 (2.06–5.73)	0.000	2.28 (1.29–4.02)	0.005
	< $20,000	3.14 (1.59–6.17)	0.001	1.99 (0.83–4.80)	0.124	2.35 (1.59–3.46)	0.000	1.71 (0.98–2.98)	0.060	2.03 (1.13–3.64)	0.018	1.55 (0.82–2.94)	0.174
SOCIAL DISADVANTAGE (SEIFA)													
	Middle to highest	1.00		1.00		1.00		1.00		1.00		1.00	
	Lowest to low	1.27 (0.81–2.02)	0.299	1.06 (0.65–1.73)	0.804	1.01 (0.74–1.39)	0.928	0.88 (0.62–1.24)	0.455	1.28 (0.90–1.81)	0.161	1.20 (0.85–1.68)	0.297

Widowed excluded

doi:10.1371/journal.pone.0161994.t002

Table 3 details the percentage increase across the two decades from 1994 to 2014 by demographic characteristics. Moderate increases across the 20 years from 1994 to 2014 were seen for females (100% increase, from 4.0% (95% CI 3.0–5.4) to 8.0% (95% CI 6.6–9.5), with a 86.2% increase in males over the same time period from 2.9% (95% CI 2.1–4.0) to 5.4% (95% CI 4.0–7.4). There was a larger 120% increase for carers aged 70 years or more, from 5.0% (95% CI 3.0–8.4) to 11.0% (95% CI 8.0–14.8). It is also noted in carers aged 15–49 years, there was a 90.9% increase from 2.2% (95% CI 1.5–3.1) to 4.2% (95% CI 3.1–5.7).

Other socio-demographic increases over the 20 years included a 108.1% increase for carers with a secondary school level or less education, from 3.7% (95% CI 2.8–4.8) to 7.7% (CI 95% CI 6.2–9.6), however in terms of educational attainment, there was a 112.1% increase in carers with trade qualifications, certificates and diplomas, increasing from 3.3% (95% CI 2.2–4.9) to 7.0% (95% CI 5.3–9.0).

Again, large percentage increases were recorded for work status, with a 119.0% increase for employed carers (full or part time) from 2.1% (95% CI 1.4–3.3) to 4.6% (95% CI 3.5–6.2), and a 110.9% increase in those carers nominating they were retired, from 5.5% (95% CI 3.8–7.9) to 11.6% (95% CI 9.3–14.4). Annual household income of $40,000 or more showed a 172.2% increase from 1.8% (95% CI 1.0–3.3) to 4.9% (95% CI 3.5–6.8) and a 403.3% increase for annual household income of $20–40,000 was recorded, from 3.0% (95% CI 1.9–4.8) to 15.1% (95% CI 11.5–19.6).

Other demographic percentage increases included a 163.6% increase for other country of birth, increasing from 3.3% (95% CI 1.8–5.7) to 8.7% (95% CI 5.9–12.6). Carers born in Australia showed a 93.3% percentage increase from 3.0% (95% CI 2.3–3.9) to 5.8% (95% CI 4.6–7.3), however there was a smaller 43.1% increase in carers whose country of birth was UK/Ireland, from 6.5% (95% CI 4.3–9.8) to 9.3% (95% CI 6.4–13.4).

In terms of percentage differences over the most recent decade, from 2004 to 2014, highest percentage increases were seen for annual household income of $20,000–40,000 (104.1% increase) from 7.4% (95% CI 5.4–10.1) to 15.1% (95% CI 11.5–19.6). No change in the most recent decade to 2014 was found for carers in the 18–49 age group (4.2%). The only negative percentage differences occurred in the most recent decade to 2014 was for carers born in Australia (-1.7%) and carers who were never married (-14.3%).

Fig 2 provides the results of the APC analysis. On the left axis is shown the independent effects of age (prevalence) and on the right axis the birth cohort and period effects, both using rate ratios are shown. The peak age for carers was around 80 years and showed a steady increasing rate over each decade for those aged 20–80 years. The graph indicates that the prevalence of being a carer increases, especially after the age of 60. In the cohort analysis the Baby Boomers born around 1951–2 are the reference point [= 1] and also represent the point of acceleration of risk which for the purposes of this paper, can be interpreted as each cohort's exposure to informal caregiving. The graph also shows a higher ratio of caring in the later cohorts born mid1970s to 2000, suggesting that persons born around 1975 (Generation X) may be twice as likely to become carers, whereas persons born 1980s to 2000 (Generation Y) have a three-fold likelihood of becoming carers. The Estimated Period Effect represents the specific calendar period when the sample population were surveyed. The resulting period effects of the graph show increasing prevalence from 1994, peaking at 2008 then falling into negative effects by 2014.

Discussion

The results indicate an inital increase in the prevalence of carers from 1994, a doubling of the proportion of carers by 2008 (3.7% to 7.9%), then a slight decline to 6.7% by 2014. Increases in proportions of carers across all ages were found, especially the 50–69 year old group and the 70

Table 3. Prevalence of carer status by demographic variables, by three time periods: Health Omnibus Survey,- 1994, 2004, 2014.

			1994			2004			2014		% diff 1994 &2014	% diff 2004 &2014
		n	% (95% CI)	p value	n	% (95% CI)	p value	n	% (95% CI)	p value		
Sex	Male	43	2.9 (2.1–4.0)	0.13	70	4.8 (3.6–6.2)	0.029	73	5.4 (4.0–7.3)	0.021	86.2	12.5
	Female	61	4.0 (3.0–5.4)		107	7.0 (5.8–8.4)		110	8.0 (6.6–9.5)		100.0	14.3
Age groups	18 to 49	43	2.2 (1.5–3.1)	<0.001	77	4.2 (3.3–5.4)	<0.001	64	4.2 (3.1–5.7)	<0.001	90.9	0.0
	50 to 69	44	6.4 (4.8–8.5)		62	7.8 (6.1–9.8)		80	9.3 (7.3–11.8)		45.3	19.2
	70+	17	5.0 (3.0–8.4)		39	9.5 (7.0–12.9)		39	11.0 (8.0–14.8)		120.0	15.8
Area	Metropolitan	68	3.3 (2.6–4.1)	0.521	117	5.5 (4.6–6.6)	0.196	131	6.4 (5.2–7.9)	0.426	93.9	16.4
	Country	36	3.9 (2.4–6.1)		61	6.7 (5.3–8.6)		52	7.5 (5.3–10.6)		92.3	11.9
Country of birth	Australia	68	3.0 (2.3–3.9)	0.005	132	5.9 (4.9–7.1)	0.29	113	5.8 (4.6–7.3)	0.046	93.3	-1.7
	UK/Ireland	23	6.5 (4.3–9.8)		28	7.5 (4.8–11.6)		24	9.3 (6.4–13.4)		43.1	24.0
	Other	13	3.3 (1.8–5.7)		18	4.4 (2.7–7.0)		47	8.7 (5.9–12.6)		163.6	97.7
Marital status # Married/defacto	Married/defacto	79	4.3 (3.4–5.4)	0.003	133	7.1 (6.0–8.5)	0.003	137	8.0 (6.5–9.8)	<0.001	86.0	12.7
	Separated/Divorced	11	4.3 (2.3–7.9)		16	6.3 (4.0–9.9)		20	8.9 (6.2–12.7)		107.0	41.3
	Never married	10	1.4 (0.7–2.9)		25	3.5 (2.1–5.8)		19	3.0 (2.0–4.4)		114.3	-14.3
Educational Attainment	Secondary schooling	64	3.7 (2.8–4.8)	0.628	101	6.6 (5.4–8.0)	0.16	83	7.7 (6.2–9.6)	0.092	108.1	16.7
	Trade qualifications, Certificate, Diploma	33	3.3 (2.2–4.9)		61	5.8 (4.4–7.6)		68	7.0 (5.3–9.0)		112.1	20.7
	Bachelor Degree	7	2.5 (1.1–5.5)		15	3.6 (2.1–6.1)		32	4.7 (3.1–7.0)		88.0	30.6
Work status # Employed full or part time	Employed full or part time	33	2.1 (1.4–3.3)	<0.001	64	3.8 (2.9–5.1)	<0.001	71	4.6 (3.5–6.2)	<0.001	119.0	21.1
	Home duties	37	6.8 (4.8–9.4)		39	11.7 (8.2–16.4)		18	12.0 (6.8–20.1)		76.5	2.6
	Retired	27	5.5 (3.8–7.9)		51	9.1 (6.9–11.7)		65	11.6 (9.3–14.4)		110.9	27.5
Household annual income # $40,000 or more	$40,000 or more	16	1.8 (1.0–3.3)	0.004	63	4.2 (3.2–5.5)	<0.001	68	4.9 (3.5–6.8)	<0.001	172.2	16.7
	$20-$40,000	22	3.0 (1.9–4.8)		42	7.4 (5.4–10.1)		47	15.1 (11.5–19.6)		403.3	104.1
	Less than $20,000	47	5.4 (4.0–7.1)		58	9.4 (7.4–11.8)		15	9.5 (5.8–15.2)		75.9	1.1
Index Relative Socio-disadvantage (SEIFA)												
	Middle to highest	54	3.1 (2.3–4.1)	0.492	103	5.9 (4.8–7.1)	0.928	99	6.1 (4.9–7.5)	0.161	96.8	3.4
	Lowest low	49	3.9 (2.8–5.5)		75	5.9 (4.8–7.4)		84	7.6 (5.8–10.0)		94.9	28.8
	Total	**104**	**3.4 (2.8–4.3)**		**177**	**5.9 (5.1–6.8)**		**183**	**6.7 (5.6–8.0)**		**97.1**	**13.6**

Widowed (Marital Status: excluded

Not stated (Work Status): excluded

Not stated (Household annual income): excluded

doi:10.1371/journal.pone.0161994.t003

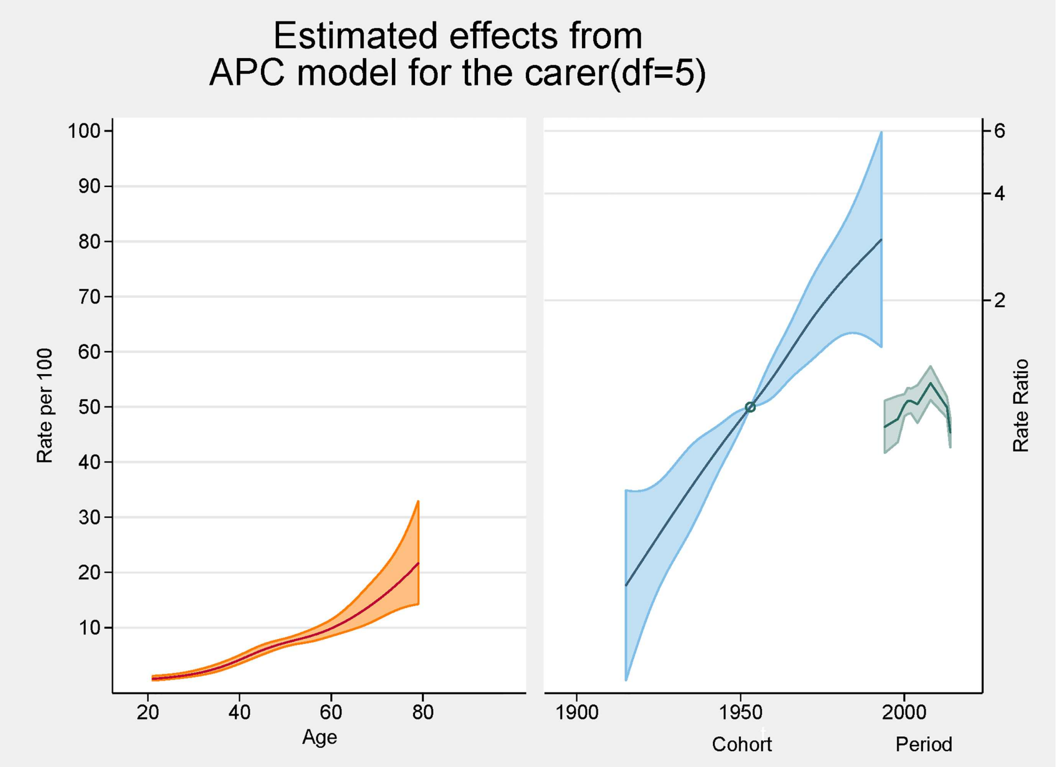


Fig 2. APC analysis of informal caregiving in South Australia shown as line graphs representing rates (%) and rate ratios, with 95% confidence intervals.

doi:10.1371/journal.pone.0161994.g002

years and over age groups, a finding consistent with SA having been the state with the highest proportion of older age population in Australia [28–30]. In our surveys there was still a considerable proportion of carers whose education was secondary school or less, but there were higher prevalences of carers who had high educational attainment and tertiary training. Carers were more likely to be employed either full time or part time, but as would be expected with an ageing population, there were also more carers who had left work and retired. In terms of annual household incomes of carers which have increased over the past 20 years, much of this would be the result of inflation and many carers still remain in the low/ lowest most disadvantaged quintiles compared with the wider community.

It is well documented that women have been the traditional and dominant family caregivers in societies of all cultures [2]. Although there was a slight increase in proportions of male carers in our earlier SA survey of 2004, overall male percentage increases (86%) remained below the 100% increase of females. ABS national surveys across Australia amongst 'all' carers in 1998 showed there was some narrowing of the gender gap with just over a half of all carers being female. In the over 75 age group there were slightly more male primary carers. Interestingly Australian disability surveys revealed that after the age of 85, carers were frequently males caring for a disabled wife [31] The implications of this changing demographic with an increasing number of male carers in this older age group raise questions about the mix and type of services needed for the future.

There is a paucity of published literature on informal caregiving in terms of surveys applying Age-Period-Cohort methods. Earlier studies include one that explored changes in attitudes towards caring for ageing parents [32]. More general research examined trends in disability in older adult cohorts using APC [33]. Other APC studies and those specific to carers using methodology comparable to this paper have not been sourced to date, except those applied to prevalence rates of chronic disease topics such as diabetes, and obesity [34].

Our APC analysis (Fig 2) illustrates the combined impact of caregiving and ageing on several birth cohorts, which range from the older carers of pre-war generations (born early 1900s to 1945), to the Baby Boomers (born 1946–1964) and Generation X, (born 1965–1980s). The prevalence of becoming a carer showed a steady increase over each decade, especially after the age of 60. Using the APC analysis, carers' peak age was around 80 years. Again our study indicates there has been a trend for older age carers to continue caregiving into their late 70s, 80s and beyond. Other authors have observed that the onset of caregiving peaked in late middle age and older, and that informal care could span three decades or more of adult life [35]. Of concern has been the lack of data on prevalence of those much older generations who might be providing care for a spouse, relative or an adult child with a disability. Literature is more readily available on social and health impacts on those cohorts [36–38].

Our study highlights changes in carers' country of birth, an aspect that reflects sixty years of increased immigration to South Australia. Although our results show that there has been a 93% percent increase in carers born in Australia, by 2014 there were large percentage increases (over 163%) in carers born in countries other than Australia, UK, Ireland or Europe. This change from earlier carer profiles of the 1990s reflects the wider cultural characteristics of people (families) who have migrated to SA since the 1950s and 1960s. Australia has a rich multicultural heritage of people from over 200 countries. Those overseas-born persons aged 65 or over, have expanded in recent decades, doubling since 1991 [39–40]. There is potential for this cultural influence to impact on carers' use of home based care if there are inadequate culturally appropriate respite services or facilities. Further, there could be a reluctance on the part of older persons from different cultures to accept support services creating additional difficulties for the spouse or other family carers [41].

The results of our surveys show that new generations of carers have emerged with different characteristics in areas of education and employment and this can be a challenge for many to combine with their informal caring. The higher proportion of working carers in our study, (both full time and part time), takes on greater importance because of the many Baby Boomers who are the current generation of informal carers. This transition occurred as older Pre-World War II carers, (for example, ageing parents of the early Baby Boomers), became the recipients of care over the past 20 years. This coincided with a greater emphasis on community care in Australia during the past decades, which is being further developed as new government reforms and initiatives for carers and consumers [42]. For example they focus on consumer directed care packages based on ageing in place (and in the home) and in disability 'consumer choice and control' through the NDIS. Both models emphasise that they are consumer directed for home based care. Current integrated support services for carers are undergoing further development.

Younger working carers, especially parent-carers, are another group that cannot be overlooked. Carers of younger children with chronic health conditions and disabilities are more likely to be subject to employment constraints. Employment for carers can be problematic and research is emerging of the negative effects on the parents who are the informal carers [43]. In general, of those carers who also work, many do manage well without adverse health changes, but Schofield concluded that 'working carers providing high levels of care represent a vulnerable subgroup where supportive and preventive services might be focused' [44]. In our study there was a higher proportion of working carers overall, but on a global scale, Australia has had a lower percentage of employed carers (38.4%), than other countries such as Canada, USA or the UK (55–60%) [45–48].

While the changing prevalence of carers in our study showed an increase over time, the later decline by 2014 could have been influenced by a number of factors. For example natural attrition (deaths) amongst carers from the oldest birth cohorts would have been occuring during that time. On a national scale reduced disability rates amongst both children and adults were observed which could have resulted in slightly less demand for informal carers [20]. Other factors impacting on carer numbers may be due to younger generations choosing careers over caring roles, especially with greater labour force participation of women [49]. Also it is not uncommon for people to choose to work beyond the ages of 65 and 70 years old which would lessen their availability for complex caregiving in the home. There have also been trends towards more active retirement, especially amongst baby boomers and later generations [40]. It is conjectured that some of these socio-economic factors surrounding caregiving may have been further influenced by the Global Financial Crisis (GFC) with a general reluctance to give up paid work and income during such uncertain times. Those directly affected by the GFC may have had to actively seek employment, as a priority over any caring role.

The strengths of this study are that the results provide an analysis of carer prevalence and demographics over a twenty year period. It has used population-based data using face-to-face interviews, the gold standard of surveys, and a significant number of interviews were conducted. It is therefore more generalizable to other ageing populations and includes a number of relevant demographic covariates.

Limitations of the study include definitional issues which continue to influence all caregiving research and make comparisons of carer / caregiver prevalence figures difficult across studies [18]. Although the data were age/sex standardized no adjustment for Consumer Price Index (CPI) was undertaken, so those household income results should be assessed with caution. There was a potential bias from survey non-response in the latter surveys in this study and this should be seen as a weakness of the project. There is a general trend towards lower response rates in all types of population surveys as people protect their privacy, or are overwhelmed by marketing telephone calls or mail outs.

Due to their small numbers, non-English speaking individuals, Indigenous and those from specific cultures are included in the data collection but not in the analysis. Also the small numbers of young carers meant that meaningful analysis could not be included in our study, however this is a limitation that does not detract from their vital roles and urgent need for further research [50–51].

In conclusion, this study demonstrates there has been an overall increase in informal caregiving in SA, a state which over the past two decades has shown higher proportions of people aged 65 years and over, than those in other mainland Eastern Australian states [29]. Our research has highlighted major demographic shifts between 1994 and 2014 and it is important that policy and planning keep pace with these changes and projections. As future prevalence rates are watched with interest in SA, these findings may also be relevant in other specific populations with similar demographic profiles. If we are to sustain the current model of care in the community and the informal carers in their caring role it is important to continue monitoring the prevalence, demographic and health profiles as emerging generations of informal carers with more diverse characteristics take on the caring roles. To achieve this there is an urgent need to include informal carers within ongoing mainstream population surveys, wherever appropriate, so as to provide statistics to plan for their future health care and home support. As the literature suggests, many carers themselves have health problems or suffer diminished quality of life [52–53]. Therefore carer well-being and particularly their health status needs to be considered in parallel with those persons they are caring for. Important as it is to track the prevalence of the wide range of conditions which influence the burden of disease, it is also important to track the prevalence, demographic profiles and health status of those who provide the informal care, as many are carrying a double burden of disease. That of the care recipient, and their own.

Supporting Information

S1 File. Carer Questions (Health Omnibus Surveys 1994–2014).
(PDF)

S2 File. Socio-demographic Questions (Health Omnibus Surveys 1994–2014).
(PDF)

Acknowledgments

Thanks to Zumin Shi, Eleonora Del Grande, Jodie Avery, for assistance with data manipulation and analysis.

Author Contributions

Conceptualization: AFS TKG KP RW AWT.

Methodology: AWT RW AFS.

Writing – original draft: AFS AWT.

Writing – review & editing: AFS TKG KP RW AWT

References

1. Park H-J. Legislating for Filial Piety: An Indirect Approach to Promoting Family Support and Responsibility for Older People in Korea. Journal of Ageing & Society. 2015; 27:280–293.
2. Bryant L, Lim S. Australian-Chinese families caring for elderly relatives. Ageing & Society. 2013; 33:1401–1420.
3. Hirst M. Transitions to informal care in Great Britain during the1990s. Journal of Epidemiological Community Health. 2002; 56:579–587
4. Australian Institute of Health and Welfare (AIHW). Australia's Welfare 2013. Australian Institute of Health and Welfare 2013. Australia's welfare series no.11. Cat. no. AUS 174. Canberra: AIHW.
5. Faran-Portet M-I, Popham F, Mitchell R, Swine C, Lorant V. Caring, employment and health among adults of working age: evidence from Britain and Belgium. European Journal of Public Health. 2009; 20:(1)52–57. doi: 10.1093/eurpub/ckp045 PMID: 19372192
6. Australian Institute of Health and Welfare (AIHW) AIHW 2015. Australian Burden of Disease Study: fatal burden of disease 2010. Australian Burden of Disease Study series no. 1. Cat. No. BOD 1. Canberra: AIHW.
7. Australian Institute of Health and Welfare (AIHW). Australia's Health 2014. Ch.4. Leading types of ill health. Australian Institute of Health and Welfare. Canberra.
8. Bruhn JG, Rebach HM. The Sociology of Caregiving. Clinical Sociology and Practice. 2014. Springer; Dordrecht Heidelberg New York London. ISBN 1566–7847. doi: 10.1007/978-94-017-8857-1
9. Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Chronic Care, 2012, AARP Public Policy Institute and the United Hospital Fund: October 2012: Washington DC, USA.
10. Hastrup LH, Van Den Berg B, Gyrd-Hansen D. Do informal caregivers in mental illness feel more burdened? A comparative study of mental versus somatic illnesses. Scandinavian Journal of Public Health. 2011; 39:598–607. doi: 10.1177/1403494811414247 PMID: 21752848
11. Prince M, Brodaty H, Uwakwe R, Acosta D, Ferri C, Guerra M et al. Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey the Public Health of Caregiving. American Journal of Public Health. 2007; 97(2):224–228.
12. Talley R, Crews JE. Framing the Public Health of Caregiving. American Journal of Public Health. 2007; 97(3):393.

13. Viana MC, Gruber MJ, Shahly V, Alhamzawi A, Alonso J. Family burden related to mental and physical disorders in the world; results from the WHO World Mental Health (WMH) surveys. Revista Brasileira de Psiquiatria. 2013; 35:115–125. doi: 10.1590/1516-4446-2012-0919 PMID: 23904015

14. Colombo F, Llena-Nozal A, Mercier J, Tjadens F. Help Wanted? Providing and Paying for Long-Term Care. 2011; OECD Health Policy Studies, OECD Publishing, doi: 10.1787/9789264097759-en+-

15. Grady P, Gullatte M. The 2014 National Nursing Research Roundtable: The science of caregiving. Nursing Outlook. 2014; 62(5):362–365. doi: 10.1016/j.outlook.2014.05.007 PMID: 25015405

16. Buckner L, Yeandle S. Valuing Carers 2015, The rising value of carers' support. 2015, Carers UK: London.

17. Sinha M. Portrait of Caregivers, 2012: Spotlight on Canadians: Results from the General Social Survey. 2012; Statistics Canada Catalogue no. 89-652-No. 001.

18. Anderson LA. Edwards VJ, Pearson WS, Talley RC, McGuire LC, Andresen EM. Adult Caregivers in the United States: Characteristics and Differences in Well-being, by Caregiver Age and Caregiving Status. Preventing Chronic Disease. 2013; 10:E135. doi: 10.5888/pcd10.130090 Accessed 17 September 2015. PMID: 23948336

19. Trivedi R, Beaver K, Bouldin ED, Eugenio E, Zeliadt SB, Nelson K et al. Characteristics and well-being of informal caregivers: Results from a nationally-representative US survey. Chronic Illness. 2014; 10 (3)167–179. doi: 10.1177/1742395313506947 PMID: 24154869

20. Australian Bureau of Statistics (ABS). Disability, Ageing and Carers, Australia. Summary of Findings, 2012. Australian Bureau of Statistics. Cat. no. 4430.0. Canberra.

21. Australian Bureau of Statistics (ABS), Disability, Ageing and Carers, Australia. Summary of Findings. 2009. Australian Bureau of Statistics. Cat. no. 4430.0. Canberra.

22. Reither EN, Hauser RM, Yang Y. (2009) Do birth cohorts matter? Age-period-cohort analyses of the obesity epidemic in the United States. Social Science & Medicine. 69:1439–1448. doi: 10.1016/j.socscimed.2009.08.040

23. SA Health, Health Omnibus Survey. Methodology. Brief Report of the South Australian Health Omnibus Survey on the SA Health Website. Available: http://www.dh.sa.gov.au/pehs/pros/hos.html. 2002–2004.

24. Twigg J, Atkin K. Carers Perceived. Policy and practice in informal care. 1996, Milton Keynes, UK: Open University Press.

25. Schofield H, Bloch S, Herrman H, Murphy B, Nankervis J, Singh B. (Eds). Family caregivers: disability, illness and ageing. 1998, St Leonards, NSW, Australia: Allen and Unwin in Association with VicHealth, the Victorian Health Promotion Foundation.

26. Australian Bureau of Statistics. Census of Population and Housing. Socio-economic Indexes for Areas (SEIFA). Australia, 2011 (cat. no. 2033.0.55.001).

27. Rutherford MJ, Lambert PC, Thompson JR. Age-period-cohort modelling. Stata Journal. 2010; 606–627.

28. Australian Institute of Health and Welfare (AIHW). Disability and ageing. Australian Population patterns and implications. Chapter 2: Population ageing in Australia. Disability Series. 2000. AIHW Cat. No. DIS 19; ISBN 9781 74024 0901. Canberra.

29. Borowski A, Hugo G. Demographic trends and policy implications. In Borowski A, Engel S, Ozanne E (eds.) Ageing and Social Policy in Australia. 1997:37. United Kingdom: Cambidge University Press.

30. Hugo G, Luszcz M, Carson E, Hinsliff J, Edwards P, Barton C, King P. State of Ageing in South Australia. A report to the South Australian Office for the Ageing. In Section 8: Older Carers. Carers in South Australia. 2009:233, Department for Families and communities, Government of South Australia. Adelaide. ISBN: 9781920983819

31. Australian Institute of Health and Welfare (AIHW). Australia's welfare 2015: in brief. Cat. no. AUS 193. Canberra: AIHW. 2.4. Informal Carers.

32. Hui-Chuan Hsu Chin-Yin Lew-Ting, Shwu-Chong Wu. Age Period, and Cohort Effects on the Attitude Toward Supporting Parents in Taiwan. The Gerontologist. 2001. 41(6):742–750. PMID: 11723342

33. Lin S-F, Beck AN, Finch BK, Hummer RA, Master RK. Trends in US Older Adult Disability: Exploring Age, Period, and Cohort Effects. American Journal of Public Health November. 2012. 102;(11)2157–2163.

34. Taylor AW, Shi Z, Montgomerie A, Dal Grande E, Campostrini S. The use of a chronic disease and risk factor surveillance system to determine the age, period and cohort effects on the prevalence of obesity and diabetes in South Australian Adults– 2003–2013. PLos One. 2015. 10(4):e0125233. doi: 10.137/journal.pone.0125233 PMID: 25923664

35. Hirst M. Carer Distress: A prospective population based study. Social Science & Medicine. 2005; 61: 697–708.

36. Jowsey T, McRae I, Gillespie J, Banfield M, Yen L. Time to care? Health of informal older carers and time spent on health related activities: an Australian survey. BMC Public Health. 2013; 13:374. doi: 10.1186/1471-2458-13-374 PMID: 23607727
37. Hosseinpoor AR, Bergen N, Chatterji S. Socio-demographic determinants of caregiving in older adults of low- and middle income countries. Age and Ageing. 2013; 42: 330–338. doi: 10.1093/ageing/afs196 Accessed 17 October 2015. PMID: 23612865
38. Lutomski JE, Baars MAE, Schalk BWM, Boter H, Buurman BM, den Elzen WPJ et al. The Development of the Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS): A Large-Scale Data Sharing Initiative. PLoS One. 2013; 8(12):e81673. doi: 10.1371/journal.pone.0081673 PMID: 24324716
39. Australian Bureau of Statistics (ABS). Australian Demographic Statistics, Country of Birth. 24/09/2015. March 2015. Canberra.
40. Hugo G. The Demographic Facts of Ageing in Australia. Patterns of Growth. Australian Population and Migration Centre. March/April 2014.2(2). Policy Brief. The University of Adelaide.
41. Knight BG, Sayegh P. Cultural values and caregiving: the updated sociocultural stress and coping model. Journal of Gerontology. Psychological Sciences. 2010; 65B(1):5–13.
42. Kaambwa B, Lancsar E, McCaffrey N, Chen G, Gill L, Cameron ID, Crotty M, Ratcliffe J. Investigating consumers' and informal carers' views and preferences for consumer directed care: A discrete choice experiment. Social Science & Medicine. 2015; 140:81–94. http://dx.doi.org/10.1016/j.socscimed.2015.06.034
43. Brehaut JC, Garner RE, Miller AR, Lach LM, Kissen AF, Rosenbaum PL. Health among caregivers of children with health problems: Findings from a Canadian population-based study. American Journal of Public Health. 2009; 99(7):1254–1262. doi: 10.2105/AJPH.2007.129817 PMID: 19059861
44. Schofield D, Cunich M, Shrestha R, Passey M, Kelly S, Tanton R, Veerman L. The impact of chronic conditions of care recipients on the labour force participation in Australia: which conditions are associated with higher rates of non-participation in the labour force? BMC Public Health. 2014; 14(1):561.
45. Deloitte Access Economics: The economic value of informal care in Australia in 2015. Carers Australia, June 2015.
46. Turcotte M. Family caregiving: what are the consequences? Insights on Canadian Society, Statistics Canada. Available: http://www5.statcan.gc.ca/olc-cel/olc.action?ObjId=89-652-X2013001&ObjType=46&lang=en&limit=0. Accessed 12 May 2016.
47. Public Policy Institute. Caregiving in the US, Research Report, June 2015. Available: http://www.caregiving.org/caregivig2015/. Accessed 12 May 2016.
48. Yeandle S, Bennett C, Buckner L, Fry G, Price C. Managing Caring and Employment. CES Report No. 2, 2007. London: Carers UK.
49. Jenkins A, Rowland F, Angus P, Hales C. The future supply of informal care, 2003 to 2013: alternative scenarios. 2003, Australian Institute of Health and Welfare: Canberra.
50. Levine C, Gibson HG, Halper D, Hart AY, Lautz J, Gould DA. Young Adult Caregivers: A First Look at an Unstudied Population. American Journal of Public Health. 2005; 95(11):2071–2075. PMID: 16195506
51. Day C. Young adult carers: a literature review informing the reconceptualisation of young adult caregiving in Australia. Journal of Youth Studies. 2015; 18(7):855–866.
52. Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish a general population. Health and Quality of Life Outcomes. 2015; 13(102). doi: 10.1186/s12955-015-0309-2
53. van den Berg B, Fiebig DG, Hall J. Well-being losses due to care-giving. Journal of Health Economics. 2014; 35:123–131. doi: 10.1016/j.jhealeco.2014.01.008 PMID: 24662888

Appendix C: Reprint of published paper- BMJ Open

Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia

BMJ Open

Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia

Anne F Stacey,[1] Tiffany K Gill,[1] Kay Price,[2] Anne W Taylor[1]

To cite: Stacey AF, Gill TK, Price K, *et al.* Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia. *BMJ Open* 2018;**8**:e020173. doi:10.1136/bmjopen-2017-020173

- Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2017-020173).

Received 25 October 2017
Revised 26 May 2018
Accepted 30 May 2018

[1]Population Research & Outcome Studies, Discipline of Medicine, The University of Adelaide, Adelaide, South Australia, Australia
[2]School of Nursing and Midwifery, University of South Australia, Adelaide, South Australia, Australia

Correspondence to
Ms Anne F Stacey;
anne.stacey@adelaide.edu.au

ABSTRACT

Background There is growing discussion on the impact of informal caregiving on the health status and morbidity of family carers. Evidence suggests a proportion of carers may be at risk of poor health outcomes. However, there are limited population-based studies that provide representative data on specific risk factors among carers (eg, blood pressure, cholesterol, smoking status, activity and body mass index) and major chronic conditions (eg, asthma, diabetes and arthritis). This study aimed to redress that imbalance.

Method Self-reported data were from the South Australian Monitoring and Surveillance System (SAMSS), a representative cross-sectional state-wide population-based survey of 600 randomly selected persons per month. SAMSS uses computer-assisted telephone interviewing (CATI) to monitor chronic health-related problems and risk factors and to assess health outcomes. In total, 2247 family carers were identified from 35 195 participants aged 16 years and older for the 5-year period from 2010 to 2015. Logistic regression analyses examined associations of being a carer with self-reported chronic diseases and health risk factors. In addition, the population attributable risk (PAR) of being a carer was examined for selected chronic conditions.

Results The prevalence of carers was 6.4%, and peak age group for carers was 50–59 years. Adjusted ORs for chronic conditions in carers were significant for all chronic conditions examined. Although there is a high prevalence of self-reported risk factors and chronic conditions among carers compared with non-carers at the population level, PAR findings suggest that caregiving is associated with a small to moderate increased risk of having these chronic conditions.

Conclusions Monitoring of carer health and morbidity particularly 'at risk' individuals such as female carers with asthma or diabetes remains important and provides an ongoing baseline for future surveys. To achieve this, caregiver-based studies need to become part of mainstream biomedical research at both epidemiological and clinical levels.

Strengths and limitations of this study

- This study used population attributable risk analysis to determine the contribution of caregiving to major chronic conditions in carers. To our knowledge, PAR has not been undertaken using carer data on health risk factors and chronic conditions before.
- As the study uses cross-sectional data, it describes associations between carers and major chronic illnesses and risk factors.
- The sampling process was part of ongoing representative state-wide surveys over a 5-year period so it did not limit the recruitment of carers to a specific type of caregiving or care recipient condition.
- The survey using telephone and computer-assisted telephone interviewing protocols was not conducive to in-depth interviewing of each participant; therefore, it limited information about the cared for persons, their diagnosis and disability or the duration or intensity of care provided.
- Questions about the carers' relationships (to the care recipient), carer lifestyles and environments were also limited.

BACKGROUND

Increasing demands for home-based informal care during the closing years of the 20th century have seen the transition of family members and close friends taking on increasingly demanding long-term physical caregiving roles in the home.[1–3] Some of these complex caring activities include tasks that medical and nursing professionals would normally perform in healthcare settings.[4–6] Multidisciplinary research has stimulated discussion on the impact of informal caregiving on carers' lives, health and well-being, morbidity and mortality, which has been comprehensively reviewed over recent years.[7–11]

International and national evidence suggests that due to the protracted periods and intensity of caring for young or older persons with severe disability, chronic illness or dementia, a proportion of carers may be at risk of negative health outcomes.[12–16] Caregiving has been shown to be a risk factor for a range of chronic physical and mental health conditions, such as cardiovascular disease (CVD), coronary heart disease (CHD), psychological distress, stress and depression, which have been extensively investigated throughout the caregiving literature.[17–20] Lifestyle and health risk factors impacting on carer health have included hypertension, overweight, smoking and disturbed sleep.[19 21] Diabetes and other chronic health conditions have also been identified and investigated among carer populations.[22]

From these many examples of negative physical and psychological health outcomes reported to be linked to informal caregiving, most relate to well-established theoretical pathways of chronic stress or conceptual models of caregiving based on a stress-coping frameworks.[9 15 23 24] Other studies have reported carer morbidity in terms of the impacts of caring for longer hours per week, the greater intensity of caring activities and more years as a carer.[14] Kenny *et al*[25] also focused on the duration of caregiving that could exacerbate pre-existing (chronic) conditions in some carers. Another Australian study of older carers revealed most had a chronic illness themselves and was linked to the time they spent on caring activities.[26] This trend was not restricted to particular age groups. In a large population-based Canadian survey of caregivers of children with chronic health problems, the parent carers were shown to be twice as likely to report chronic conditions. They also had greater odds of experiencing poorer general health than carers of healthy children.[27]

Despite the predominance of literature highlighting deleterious consequences of caregiving, positive outcomes have been reported, acknowledging that a proportion of informal caregivers provide ongoing care and support without any detriment to their well-being.[28] For example, some studies show that carers can experience positive benefits and maintain an adequate quality of life and health status during their caregiving.[29 30] This may be influenced by what authors have referred to as 'the healthy carer effect'.[7 31 32] Focusing on mortality and the caring role, Roth *et al*[33] highlighted the need for a more balanced view when reporting the impact of caregiving on carer health with greater rigour in research methodology and definition of caregivers.

Rationale, research question and objective

Many studies, particularly earlier research, are limited by non-representative samples as described by Taylor *et al.*[34] As such, the rationale of this study was to assess self-reported health characteristics and status of adult carers from a large, population-based, random sample of South Australian adults. The research question for this study was: is there an association between the caregiving role as a risk factor for chronic disease and the health status of informal/family carers? Therefore, the study objective was to compare carer health status with adults who did not identify as carers in a population, adjusting for age and gender and determining population attributable risk (PAR) to ascertain the contribution of caring to major chronic conditions. The rationale for examining gender differences was considered important as research consistently shows up to two-thirds more carers are females than males, who may not necessarily share the same health profiles.

METHODS

This representative cross-sectional study obtained data from an ongoing state-wide population-based survey (the South Australian Monitoring and Surveillance System (SAMSS)). SAMSS is an epidemiological monitoring system established in 2002 to detect and facilitate understanding of trends in the prevalence of chronic conditions, risk and protective factors and other determinants of health within the state of South Australia (SA).[35]

Sampling frame and recruitment

SAMSS is based on self-reported data, which is systematically collected from a minimum of 600 randomly selected people each month on persons of all ages in the SA community. This risk factor surveillance system uses computer-assisted telephone interviewing (CATI) to monitor chronic health-related problems and risk factors that can assess health outcomes and provide programme and policy information.[36] All households in SA with a telephone number listed in the electronic white pages of the telephone directory are eligible for selection in the sample. Additional information is available on sampling issues in telephone surveys.[37]

A letter introducing SAMSS is sent to the household of each selected telephone number. The letter informs people of the purpose of the survey and indicates that they can expect a telephone call within the time frame of the survey. Data are collected by a contracted agency, and interviews are conducted in English. At least six call-backs are made to the telephone number selected to interview household members. Where a refusal is encountered, another interviewer generally (at the discretion of the supervisor) calls later, in an endeavour to obtain the interview(s). Replacement interviews for persons who cannot be contacted or interviewed are not permitted. Additional details on SAMSS methodology are available.[36] This study used aggregated data from January 2010 to December 2015. Response rates over the period of 2010–2015 varied between 54.1% and 64.4% (mean 59.8%). Family carers were identified from adults aged 16 years and over for the period 2010–2015. The question asked was 'Do you provide long-term care at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness?'.

Outcome variables

The selection of SAMSS outcome variables related to national determinants of health, namely diet, blood pressure, cardiac, respiratory and metabolic diseases and a range of chronic conditions.[36] During interviews, all respondents were asked if a doctor had ever told them they had diabetes, CVD (heart attack, angina, heart disease and/or stroke), arthritis and osteoporosis. Asthma was defined as self-reported doctor-diagnosed asthma and had experienced asthma symptoms in the previous 12 months. In addition, respondents were asked if they had ever been diagnosed by a doctor in the last 12 months with depression, anxiety, a stress-related or other mental health problem.

Respondents were also asked if a doctor had ever told them they have and/or were currently receiving treatment or medication for high blood pressure (HBP) or high cholesterol. They were asked to provide the time they spent undertaking walking, moderate or vigorous physical activity over the past week. The time was summed, with the time spent undertaking vigorous activity multiplied by a factor of two to account for its greater intensity. This provided an indication as to whether respondents are undertaking a sufficient level of physical activity to provide a health benefit. This is defined as 150 min or more of activity each week and has been categorised into insufficient inactivity (no activity and active but not sufficient) and sufficient activity.[38] Body mass index (BMI) was derived from self-reported weight and height and classified as underweight ($<18.5\,kg/m^2$), normal ($\geq 18.5<25.0\,kg/m^2$), overweight ($\geq 25.0<30.0\,kg/m^2$) and obese ($\geq 30\,kg/m^2$).[39] Data were also collected on smoking status (current ex or non), short-term and long-term alcohol risk (derived from the number of alcoholic drinks per day and the number of times per week alcohol was consumed)[40] and how many serves of fruit and how many serves of vegetables they ate each day with the recommendation being at least two serves of fruit and five serves of vegetables per day.[41]

An indicator of overall health status, the Short Form (SF-1) was determined by asking how they would rate their overall health (excellent, very good, good, fair and poor).[42] Psychological distress was determined using the Kessler 10 (K10) scale, which consists of 10 questions, all of which have the same response categories.[43] To score the K10, 'all of the time' was scored as a 5 and none of the time as 1. The 10 items were summed to provide a score of between 10 and 50, with scores over 22 indicating levels of psychological distress. Disability was defined as physical, mental or emotional problems or limitations that the respondent reported having in their daily life.[44 45]

Data analysis

Demographic variables included in the analyses were age, gender, educational attainment, income and work status. Frequencies and χ^2 tests were determined using SPSS V.24. Univariable and multivariable regression was undertaken using the 'svy' commands in STATA V.14 to determine crude and adjusted ORs. In the univariable analyses, carer status was assessed in association with gender, age, health status, risk factors and chronic conditions variables. Multivariable logistic regression was undertaken to determine the OR associated with carer status and the range of health-related variables adjusted for age and gender.

PAR was calculated using STATA and the '*punaf*' add-in command to examine risk of caregiving to six chronic conditions (diabetes, asthma, CVD, arthritis, osteoporosis and mental health).[46] For each of the chronic conditions, five models were created to determine the relative risk (RR) and subsequently calculate the Population Attributable Risk (PAR) of being a carer. Model 1 was unadjusted, model 2 controlled for gender and age, model 3 additionally controlled for educational attainment, income and work status, model 4 additionally controlled for HBP and high cholesterol and model 5 further adjusting for sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity. The PAR analysis was repeated for both males and females separately.

Weighting was used to correct for disproportionality of the sample with respect to the population of interest. Data were weighted using raking, by area (metropolitan/rural), age, gender, marital status, country of birth, educational attainment and dwelling status (rented property vs other) to the most recent SA population data and probability of selection in the household so that the results are representative of the SA population.[47]

Patient and public involvement statement

This population-based survey is conducted based on the health priorities identified by the South Australian Department of Health and Ageing (SA Health). Patients are not involved in the design of the study. Results are disseminated using publications and policy development, where applicable by SA Health (www.sahealth.sa.gov.au).

RESULTS

Of the 35 195 participants, 6.4% (95% CI 6.0% to 6.8%) identified as carers. Overall, 64.1% of carers were female. The peak age group for carers was 50–59 years with rates declining after this age.

Table 1 presents overall carer/non-carer prevalence comparisons for health status, risk factors and chronic disease variables. The overall health status of carers was lower than non-carers, with 10.2% more carers reporting their health as only fair or poor. The prevalence for disability was 9.9% and psychological distress 5.0% higher in carers than non-carers. Comparing carer health risk factors with non-carers, the prevalence estimates for HBP and high cholesterol were higher in carers, and more carers were current smokers. Carers were less likely to be at risk from alcohol-related risk or injury. Carers were also more likely to have all chronic conditions except osteoporosis.

Table 2 highlights the unadjusted and adjusted OR comparing carers with non-carers on their health status, health risks and chronic conditions. After adjustment for

Table 1 Demographic and health variable comparison between carers and non-carers

	Non-carers	Non-carers	Carers	Carers	P values
Demographic variables	**n**	**%**	**n**	**%**	**χ^2 test**
Gender					
Males	15 998	48.6	806	35.9	
Females	16 949	51.4	1441	64.1	<0.001
Age group (years)					
16–39	12 758	38.7	474	21.1	
40–49	5823	17.7	468	20.9	
50–59	5511	16.7	513	22.8	
60–69	4341	13.2	395	17.6	
70–79	2766	8.4	242	10.8	
80 and over	1746	5.3	153	6.8	<0.001
Health status					
Short Form (SF-1)					
Excellent, very good, good	27 466	83.4	1644	73.2	
Fair or poor	5481	16.6	602	26.8	<0.001
Disability					
No	25 510	77.4	1515	67.5	
Yes	7437	22.6	731	32.5	<0.001
Psychological distress (K10)					
No	29 496	90.1	1898	85.1	
Yes	3249	9.9	333	14.9	<0.001
Health risk factors					
Alcohol-related lifetime risk					
Does not drink	7562	23	657	29.4	
No risk	14 257	43.4	1077	48.2	
Lifetime risk of harm	11 005	33.5	499	22.4	<0.001
Alcohol-related injury					
Does not drink	7562	23	657	29.4	
No risk	20 538	62.6	1376	61.6	
Alcohol-related injury risk	4725	14.4	200	9	<0.001
Body mass index					
Underweight	621	2.1	59	2.9	
Normal	11 252	38.2	649	31	
Overweight	10 235	34.8	701	33.5	
Obese	7323	24.9	381	32.6	<0.001
Fruit					
1 or less serves/day	17 238	52.3	1158	51.5	
2 or more serves/day	14 059	42.7	965	42.9	
None/does not eat fruit	1585	4.8	119	5.3	
Don't know	64	0.2	4	0.2	0.714
Vegetables					
1 or less serves/day	7946	24.1	444	19.8	
2–4 serves/day	21 072	64	1488	66.2	
5 or more serves/day	3441	10.4	272	12.1	
None/does not eat vegetables	259	0.8	23	1	

Continued

Table 1 Continued

Demographic variables	Non-carers n	Non-carers %	Carers n	Carers %	P values χ^2 test
Don't know	227	0.7	18	0.8	<0.001
Physical activity					
No activity	4245	16.4	322	19.2	
Activity – not sufficient	7663	29.6	591	35.3	
Sufficient activity	14004	54	761	45.5	<0.001
High blood pressure					
No	26258	79.7	1600	71.2	
Yes	6689	20.3	647	28.8	<0.001
High cholesterol					
No	27604	83.8	1701	75.7	
Yes	5343	16.2	545	24.3	<0.001
Smoking status					
Non/ex	27792	84.4	1797	80	
Current	5151	15.6	449	20	<0.001
Chronic conditions					
Arthritis					
No	26279	79.8	1542	68.7	
Yes	6668	20.2	704	31.3	<0.001
Asthma					
Don't know/no	28638	86.9	1832	81.5	
Yes	4309	13.1	414	18	<0.001
Chronic obstructive pulmonary disease					
Don't know/no	31543	95.7	2093	93.2	
Yes	1404	4.3	153	6.8	<0.001
Cardiovascular disease (CVD)					
Don't know/no	30487	93.8	2002	6.2	
Yes, CVD	2460	7.5	245	10.9	<0.001
Diabetes					
Don't know/no	30274	91.9	1953	86.9	
Yes	2673	8.1	294	13.1	<0.001
Osteoporosis					
Don't know/no	31481	95.5	2099	93.4	
Yes	1467	4.5	147	6.6	<0.001
Mental health problems					
No	27082	82.2	1723	76.7	
Yes	5865	17.8	523	23.3	<0.001

Data source: South Australian Monitoring and Surveillance System 2010–2015.
K10, Kessler 10.

age and sex, the prevalence of fair/poor health status (SF-1), disability, psychological distress, HBP, raised cholesterol and current smoking all remained significant. Carers were less likely to have lifetime risk of alcohol-related harm and risk of alcohol-related injury. Adjusted ORs for all the selected chronic conditions in carers were significant (arthritis, asthma, COPD, CVD, diabetes, mental health and osteoarthritis, except for osteoporosis).

Table 3 presents the PAR of being a carer for six chronic conditions for each of the five different models described above. In the unadjusted model, being a carer was associated with higher RR for all the chronic conditions.

Table 2 Unadjusted and adjusted associations between carers and non-carers health-related variables

	Carers	Carers				
Health variables	**n**	**%**	**Unadjusted OR**	**P values**	**Adjusted OR**	**P values**
Health status						
Short Form (SF-1)						
Excellent/very good/good	1644	5.7	1		1	
Fair/poor	603	9.9	1.84 (1.59–2.12)	<0.001	1.62 (1.39–1.89)	<0.001
Disability						
No/don't know	1516	5.6	1		1	
Yes	732	9	1.65 (1.45–1.89)	<0.001	1.44 (1.25–1.66)	<0.001
Psychological distress (K10)						
No	1898	6.1	1		1	
Yes	334	9.3	1.60 (1.32–1.92)	<0.001	1.63 (1.35–1.98)	<0.001
Risk factors						
Alcohol-related lifetime risk						
Does not drink alcohol	657	8	1		1	
No risk	1078	7	0.87 (0.75–1.00)	0.056	0.82 (0.71–0.95)	0.009
Lifetime risk of harm	499	4.3	0.52 (0.43–0.63)	<0.001	0.64 (0.52–0.78)	<0.001
Alcohol-related injury risk						
Does not drink alcohol	657	8	1		1	
No risk	1376	6.3	0.77 (0.67–0.89)	<0.001	0.77 (0.66–0.88)	<0.001
Risk of alcohol related injury	201	4.1	0.49 (0.37–0.64)	<0.001	0.71 (0.53–0.95)	0.019
Body mass index						
Underweight	60	8.8	1		1	
Normal	650	5.5	0.60 (0.38–0.96)	0.033	0.60 (0.37–0.96)	0.035
Overweight	701	6.4	0.71 (0.45–1.14)	0.156	0.69 (0.43–1.12)	0.134
Obese	682	8.5	0.97 (0.60–1.54)	0.886	0.87 (0.54–1.41)	0.582
Vegetables						
1 or less	445	5.3	1		1	
2 or more	1488	6.6	1.26 (1.07–1.49)	0.005	1.17 (1.00–1.38)	0.056
5 or more	272	7.3	1.41 (1.13–1.77)	0.002	1.23 (0.99–1.54)	0.065
None	24	8.3	1.62 (0.81–3.26)	0.176	1.68 (0.82–3.42)	0.156
Don't know	19	7.6	1.47 (0.80–2.70)	0.209	1.26 (0.69–2.29)	0.456
Fruit						
1 or less	1158	6.3	1		1	
2-4	965	6.4	1.02 (0.90–1.15)	0.742	0.95 (0.84–1.08)	0.425
5 or more	119	7	1.12 (0.81–1.54)	0.483	1.16 (0.85–1.59)	0.349
None	5	6.5	1.03 (0.33–3.26)	0.954	0.92 (0.29–2.86)	0.88
Don't know	4					
Physical activity						
No activity	322	7.1	1		1	
Activity but not sufficient	591	7.2	1.02 (0.82–1.26)	0.886	1.07 (0.86–1.33)	0.549
Sufficient activity	762	5.2	0.72 (0.58–0.88)	0.001	0.87 (0.70–1.07)	0.176
High blood pressure						
No/don't know	1600	5.7	1		1	
Yes	647	8.8	1.59 (1.40–1.79)	<0.001	1.22 (1.06–1.40)	<0.001
High cholesterol						

Continued

Table 2 Continued

Health variables	Carers n	Carers %	Unadjusted OR	P values	Adjusted OR	P values
No/don’t know	1702	5.8	1		1	
Yes	546	9.3	1.66 (1.46–1.88)	<0.001	1.29 (1.13–1.47)	<0.001
Smoking status						
Non/ex	1798	6.1	1		1	
Current	450	8	1.35 (1.14–1.60)	0.001	1.43 (1.20–1.71)	<0.001
Chronic conditions						
Arthritis						
No/don’t know	1543	5.6	1		1	
Yes	705	9.6	1.80 (1.59–2.04)	<0.001	1.34 (1.16–1.55)	<0.001
Asthma						
No/don’t know	1833	6	1		1	
Yes	414	8.8	1.50 (1.27–1.78)	<0.001	1.49 (1.26–1.76)	<0.001
Chronic obstructive pulmonary disease						
No/don’t know	2094	6.2	1		1	
Yes	154	9.9	1.65 (1.27–2.14)	<0.001	1.40 (1.07–1.83)	0.014
Cardiovascular disease						
No/don’t know	2002	6.2	1		1	
Yes	245	9.1	1.52 (1.28–1.80)	<0.001	1.29 (1.06–1.56)	0.009
Diabetes						
No/don’t know	1953	6.1	1		1	
Yes	294	9.9	1.71 (1.43–2.03)	<0.001	1.43 (1.19–1.72)	<0.001
Osteoporosis						
No/don’t know	2100	6.3	1		1	
Yes	148	9.1	1.51 (1.26–1.81)	<0.001	1.02 (0.84–1.23)	0.835
Mental health conditions						
No	1724	6	1		1	
Yes	523	8.2	1.40 (1.21–1.63)	<0.001	1.34 (1.15–1.56)	<0.001

Adjusted for age and sex.
Data source: South Australian Monitoring and Surveillance System 2010–2015.
K10, Kessler 10.

After adjustment for demographic and health risk factors (model 5), only asthma (RR=1.26) and diabetes (RR=1.19) remained statistically significant (p<0.05). The PAR associated with being a carer for each condition was low.

To determine if there were any differences for males and females, the PAR analysis was then stratified by sex (tables 4 and 5). In the unadjusted model, being a male carer was associated with diabetes (RR=1.79), CVD (RR=1.87), arthritis (RR=1.69) and mental health conditions (RR=1.32). After adjustment (model 5), all associations for male carers disappeared. In table 5, in the unadjusted model, being a female carer was associated with all the selected chronic conditions: diabetes (RR=1.53), asthma (RR=1.42), CVD (RR=1.26), arthritis (RR=1.39), osteoporosis (RR=1.30) and mental health (RR=1.23). After adjustment (model 5), all associations for female carers disappeared except for asthma (RR=1.33) and diabetes (RR=1.21). For both males and females, the PAR associated with being a carer in relation to the range of chronic conditions remained small.

DISCUSSION

This representative population-based study of carer health characteristics estimated there were 6.4% (95% CI 6.0 to 6.8) of the SA population aged 16 years and older, who were informal carers. It shows that carers were more likely to report chronic conditions, psychological distress and disability and to perceive their health status as poor to fair. In terms of their risk factor status, after controlling for age and sex, carers were more likely to

Table 3 PAR of being a carer associated with six chronic conditions, unadjusted, and four multivariable models

	Model 1: unadjusted		Model 2		Model 3		Model 4		Model 5	
	RR (95% CI)	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**
Diabetes	1.61 (1.38 to 1.88)	3.77 (2.29 to 5.22)	1.32 (1.14 to 1.52)	2.35 (0.98 to 3.69)	1.23 (1.07 to 1.42)	1.86 (0.46 to 3.23)	1.19 (1.02 to 1.38)	1.58 (0.12 to 3.01)	1.19 (1.02 to 1.39)	1.67 (0.09 to 3.22)
Asthma	1.41 (1.23 to 1.62)	2.55 (1.37 to 3.72)	1.41 (1.23 to 1.62)	2.58 (1.38 to 3.77)	1.32 (1.15 to 1.52)	2.16 (0.94 to 3.36)	1.30 (1.13 to 1.49)	2.02 (0.84 to 3.18)	1.26 (1.10 to 1.46)	1.94 (0.64 to 3.22)
Cardio vascular disease	1.46 (1.25 to 1.70)	2.85 (1.50 to 4.19)	1.13 (1.00 to 1.29)	1.02 (−0.10 to 2.12)	1.12 (0.96 to 1.30)	0.96 (−0.37 to 2.28)	1.07 (0.93 to 1.24)	0.61 (−0.71 to 1.91)	1.05 (0.91 to 1.22)	0.47 (−0.91 to 1.83)
Arthritis	1.55 (1.42 to 1.69)	3.39 (2.59 to 4.17)	1.19 (1.10 to 1.30)	1.55 (0.77 to 2.33)	1.13 (1.04 to 1.22)	1.07 (0.29 to 1.85)	1.12 (1.03 to 1.21)	1.00 (0.22 to 1.76)	1.08 (0.99 to 1.18)	0.71 (−0.10 to 1.52)
Osteoporosis	1.48 (1.25 to 1.75)	2.95 (1.44 to 4.43)	1.06 (0.90 to 1.24)	0.51 (−0.94 to 1.95)	0.99 (0.84 to 1.17)	−0.05 (−1.57 to 1.45)	0.99 (0.84 to 1.17)	−0.10 (−1.62 to 1.40)	0.98 (0.82 to 1.17)	−0.16 (−1.87 to 1.52)
Mental health	1.31 (1.17 to 1.47)	1.93 (1.00 to 2.85)	1.25 (1.12 to 1.41)	1.65 (0.71 to 2.58)	1.10 (0.98 to 1.23)	0.72 (−0.23 to 1.67)	1.08 (0.96 to 1.21)	0.62 (−0.32 to 1.55)	1.03 (0.90 to 1.19)	0.28 (−0.93 to 1.47)

Data source: South Australian Monitoring and Surveillance System 2010–2015.
PAR was deemed to be significant when the CI for the RR does not include 1.00.
For each of the six chronic conditions listed above, five models were created.
Model 1: unadjusted PAR.
Model 2: adjusted PAR controlling for sex and age.
Model 3: adjusted PAR controlling for age, sex, educational attainment, income and work status.
Model 4; adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP and high cholesterol.
Model 5: adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP, high cholesterol, sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity.
BMI, body mass index; HBP, high blood pressure; PAR, population attributable risk; RR, relative risk.

Table 4 PAR of being a carer associated with six chronic conditions, unadjusted and four multivariable models, males

	Model 1: unadjusted		Model 2		Model 3		Model 4		Model 5	
	RR (95% CI)	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**	**RR (95% CI)**	**PAR % (95% CI)**
Diabetes	1.79 (1.41 to 2.72)	3.64 (1.71 to 5.53)	1.35 (1.08 to 1.67)	2.10 (0.36 to 3.82)	1.22 (0.98 to 1.52)	1.49 (−0.29 to 3.25)	1.16 (0.93 to 1.46)	1.17 (−0.71 to 3.02)	1.18 (0.93 to 1.50)	1.33 (−0.70 to 3.32)
Asthma	1.17 (0.89 to 1.55)	0.83 (−0.73 to 2.35)	1.25 (0.94 to 1.66)	1.11 (−0.47 to 2.66)	1.13 (0.86 to 1.50)	0.66 (−0.91 to 2.20)	1.13 (0.86 to 1.48)	0.63 (−0.91 to 2.14)	1.07 (0.80 to 1.44)	0.38 (−1.29 to 2.02)
Cardiovascular disease	1.87 (1.51 to 2.32)	4.01 (2.21 to 5.77)	1.20 (1.01 to 1.43)	1.36 (−0.04 to 2.74)	1.18 (0.96 to 1.45)	1.33 (−0.44 to 3.07)	1.10 (0.97 to 1.34)	0.79 (−0.97 to 2.52)	1.11 (0.90 to 1.37)	0.86 (−0.98 to 2.67)
Arthritis	1.69 (1.43 to 2.01)	3.21 (1.90 to 4.51)	1.20 (1.04 to 1.39)	1.25 (0.21 to 2.29)	1.15 (0.98 to 1.36)	1.03 (−0.26 to 2.31)	1.14 (0.97 to 1.34)	0.96 (−0.34 to 2.24)	1.11 (0.94 to 1.32)	0.79 (−0.52 to 2.08)
Osteoporosis	1.19 (0.75 to 1.89)	0.90 (−1.73 to 3.46)	0.83 (0.53 to 1.30)	−1.18 (−3.80 to 1.37)	0.70 (0.44 to 1.13)	−2.39 (−5.27 to 0.41)	0.69 (0.43 to 1.12)	−2.51 (−5.42 to 0.31)	0.47 (0.15 to 1.53)	−5.36 (−12.55 to 1.37)
Mental health	1.32 (1.04 to 1.66)	1.50 (0.07 to 2.91)	1.37 (1.09 to 1.74)	1.70 (0.25 to 3.13)	1.08 (0.86 to 1.35)	0.44 (−0.98 to 1.84)	1.07 (0.86 to 1.34)	0.42 (−0.98 to 1.80)	1.01 (0.77 to 1.31)	0.04 (−1.70 to 1.74)

Data source: South Australian Monitoring and Surveillance System 2010–2015.
PAR was deemed to be significant when the CI for the RR does not include 1.00.
For each of the six chronic conditions listed above, five models were created.
Model 1: unadjusted PAR.
Model 2: adjusted PAR controlling for sex and age.
Model 3: adjusted PAR controlling for age, sex, educational attainment, income and work status.
Model 4: adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP and high cholesterol.
Model 5: adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP, high cholesterol, sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity.
BMI, body mass index; HBP, high blood pressure; PAR, population attributable risk; RR, relative risk.

Table 5 PAR of being a carer associated with six chronic conditions, unadjusted and four multivariable models, females

	Model 1: unadjusted		Model 2		Model 3		Model 4		Model 5	
	RR (95% CI)	PAR % (95% CI)	RR (95% CI)	PAR % (95% CI)	RR (95% CI)	PAR % (95% CI)	RR (95% CI)	PAR % (95% CI)	RR (95% CI)	PAR % (95% CI)
Diabetes	1.53 (1.25 to 1.87)	3.97 (1.73 to 6.16)	1.32 (1.09 to 1.59)	2.70 (0.59 to 4.77)	1.27 (1.04 to 15.4)	2.38 (0.22 to 4.50)	1.22 (1.01 to 1.47)	2.06 (–0.11 to 4.17)	1.21 (1.00 to 1.47)	2.16 (–0.16 to 4.43)
Asthma	1.42 (1.22 to 1.66)	3.21 (1.56 to 4.83)	1.46 (1.24 to 1.71)	3.39 (1.71 to 5.04)	1.38 (1.18 to 1.63)	3.00 (1.30 to 4.68)	1.36 (1.16 to 1.59)	2.83 (1.17 to 4.46)	1.33 (1.13 to 1.56)	2.84 (1.02 to 4.63)
Cardiovascular disease	1.26 (1.02 to 1.55)	1.97 (–0.03 to 3.94)	1.09 (0.90 to 1.31)	0.75 (–1.04 to 2.51)	1.09 (0.88 to 1.34)	0.78 (–1.25 to 2.77)	1.05 (0.86 to 1.29)	0.48 (–1.52 to 2.44)	1.01 (0.82 to 1.24)	0.12 (–1.96 to 2.15)
Arthritis	1.39 (1.26 to 1.53)	2.96 (1.95 to 3.96)	1.15 (1.05 to 1.26)	1.39 (0.42 to 2.34)	1.11 (1.02 to 1.22)	1.09 (0.12 to 2.05)	1.10 (1.01 to 1.21)	1.00 (0.04 to 1.95)	1.06 (0.97 to 1.17)	0.65 (–0.39 to 1.67)
Osteoporosis	1.30 (1.09 to 1.55)	2.29 (0.53 to 4.01)	1.09 (0.93 to 1.29)	0.86 (–0.73 to 2.42)	1.05 (0.88 to 1.26)	0.51 (–1.24 to 2.23)	1.05 (0.88 to 1.25)	0.48 (–1.28 to 2.20)	1.01 (0.70 to 1.46)	0.17 (–4.59 to 4.71)
Mental health	1.23 (1.07 to 1.40)	1.74 (0.51 to 2.95)	1.22 (1.06 to 1.39)	1.68 (0.44 to 2.91)	1.11 (0.97 to 1.27)	0.92 (–0.34 to 2.17)	1.09 (0.95 to 1.24)	0.77 (–0.48 to 1.99)	1.05 (0.89 to 1.23)	0.43 (–1.18 to 2.02)

Data source: South Australian Monitoring and Surveillance System 2010–2015.
PAR was deemed to be significant when the CI for the RR does not include 1.00.
For each of the six chronic conditions listed above, five models were created.
Model 1: unadjusted PAR.
Model 2: adjusted PAR controlling for sex and age.
Model 3: adjusted PAR controlling for age, sex, educational attainment, income and work status.
Model 4: adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP and high cholesterol.
Model 5: adjusted PAR controlling for age, sex, educational attainment, income, work status, HBP, high cholesterol, sufficient fruit consumption, sufficient vegetable consumption, smoking status, BMI and sufficient physical activity.
BMI, body mass index; HBP, high blood pressure; PAR, population attributable risk; RR, relative risk.

report smoking, raised cholesterol and HBP than the non-carer population. The PAR of being a carer was minimal suggesting that informal caregiving does not appear to have contributed to the proportion of chronic disease in the sampled population, indicating that if there were no carers in the population, there would only be a small reduction in the number of cases of those with the specified chronic conditions. However, in the SA sample, carers reported more chronic illness than found in other large international studies.[48 49]

Despite much published literature discussing chronic illness in carers, there remains a lack of details about specific chronic conditions among carers, except for CVDs and psychological conditions like stress and depression. Our current study of self-reported carer health in SA included a range of major chronic conditions in adult carers of all ages. The presence of asthma or other respiratory conditions is rarely demonstrated in other studies, although it is acknowledged that carers in this survey are living in Australia, which has one of the highest rates of asthma in the world.[50] Other chronic conditions such as diabetes have been evident in a small number of population and clinical studies about informal caregivers.[22] In the biomedical literature, authors have described the link between long-term informal caregiving, chronic stress and physiological changes including the metabolic syndrome and other endocrine and immune conditions.[24 51] Some of these studies have investigated the impact of caring for a spouse with dementia or a child with a disability where carers were seen to be more at risk of serious chronic physical conditions (such as CHD) or mental health conditions.[52]

There are interesting similarities and contrasts between SA and international surveys of carers. For example, two large population-based surveys exploring the characteristics of informal carers have some relevance to our research.[48 49] The 2011/2012 Spanish population-based national survey, although limited to informal carers in households with a disabled resident, explored associations between the carers, disease and risk factors and compared them with matched controls.[48] Variables included diabetes, HBP, cholesterol, smoking, physical activity and drinking alcohol. Results indicated there was some evidence of depression and anxiety among female carers, but it was gender and the caring role that was seen to mediate chronic diseases in the Spanish carers.[48] Our survey results showed carers were more likely to have diabetes, asthma and arthritis, plus major risk factors such as smoking, raised cholesterol and HBP.

A Swedish population survey collected self-reported data between 2004 and 2013, with the aim of analysing associations between caregiving and health outcomes. The study also investigated carer self-rated health, the presence of long-term illness in carers and their psychological well-being.[49] Comparisons with non-carers showed that carers had lower psychological well-being, which was also reported in the Spanish Survey.[48] The self-rated perceptions of health in Swedish carers were worse than non-carers and adversely associated with carer health.[49]

Psychological distress has been consistently reported in caregiver research spanning at least three decades.[53 54] A British survey found there was a progressive increase of distress in carers as the amount of caregiving increased each week.[14] There are also well-documented links between psychological distress and lower perceived health status, as well as associations between distress and the presence of chronic illness.[54 55] Although it is reported that women are statistically more likely to experience high psychological distress than men, the large volume of caregiving literature showing gender associated with distress may have more to do with the fact that more women are in caregiving roles. As two-thirds of carers from our survey were female, it may explain the finding of higher distress, which supports that trend. Previous research undertaken by the current authors highlighted major demographic trends in SA carers.[56]

The greater likelihood of carers in our sample reporting risk factors of smoking, raised cholesterol and HBP when compared with non-carers is interesting and highlights important issues for assessment of carer morbidity. Despite the wealth of information generated over past decades on the health impacts of smoking within various populations, discussions linking caregiving stress with smoking are few. Like the Spanish study and our own SAMSS surveys, some population surveys in recent years have included caregiving and smoking status in their questionnaires, for example, the Behavioral Risk Factor Surveillance System (BRFSS) state-based surveys being conducted across the USA.[57] Their results showed some similar characteristics to the SA survey in terms of gender and age distribution, but more of our carers reported disability or were current smokers.

In relation to smoking characteristics, studies were mostly limited to the smoking habits of caregivers of patients with Alzheimers Disease. For example, one project was part of the REACH II study (Resources for Enhancing Alzheimer's Caregiver Health, 2002–2004 in the USA). It showed that 40% of caregivers smoked which was higher than smoking in the general population (22%).[58] Findings indicated that nearly a quarter of the informal carers of patients with Alzheimer's disease reported increased smoking over the previous month, which was linked with age, ethnicity and employment. Younger carers were more likely to be smokers, with depression as the main stressor. The study suggested that the smoking increase in carers could be explained by less caregiving skills and fewer coping resources of the carers.[58] Evidence cited from other studies linked the caregiver role with higher distress and to smoking behaviours with subsequent impact on heart disease.[59]

Strengths and limitations

The strengths of this study are the large sample size, the use of standardised validated instruments and a well-established definition of carers that have not altered over the period of data collection and also the stability of the methodology over the research period. Our sample of carers was selected from part of a large representative state-wide surveys over a 5-year period, and therefore, results are applicable to the wider population. The use of PAR analysis to determine the contribution of caregiving to major chronic conditions in carers, to our knowledge, has not been undertaken using carer data before. Specific variables for this study included some of the major health risk factors and chronic conditions; however, as data were cross-sectional, only associations between carers and chronic illnesses and risk factors could be reported. The self-reported nature of the data collection is also acknowledged as a weakness of the study with the known subtleties associated with persons over-reporting or under-reporting their behaviours. For example, measurements to confirm the accuracy of each person's height and weight, blood pressure and cholesterol were not undertaken and so these may be underestimated.[60 61]

The structure of the data base and methodology also limits data collected to demographic questions and health indicators that are suited to telephone and CATI protocols.[62] We acknowledge that the relationship between caregiving and physical health is complex, bidirectional and can be mediated by several factors. For example, pre-existing health problems of the carers, diagnosis of the cared for person, duration and intensity of the caregiving and type of caring role (whether more physically oriented or emotionally demanding). Questions about carer lifestyles and environments, cultural, family and social characteristics were also very limited as the survey was not conducive to in-depth interviewing of each participant. Hence, it was not possible to gather additional information about the cared for persons, their diagnosis and disability or the duration or intensity of care provided. Despite that, the sampling process did allow for carer heterogeneity within the population as it did not limit the recruitment of carers to any one type of caregiving or care recipient condition. Additional information from carers on specific somatisation symptoms like sleeping disorders, musculoskeletal conditions, injuries, pain and general discomfort would have been valuable, but these would require a separate study. There may be opportunity for this research in the future. Lastly, it is acknowledged that the scope of health issues investigated in this study was limited partly due to lack of evidence between informal caring and health status after adjustments for various variables.

CONCLUSION

The profiles of carer health in this study highlight several aspects of caregiving in the South Australian population. This study shows that informal carers, now recognised as the partners in care, were in terms of their own health status, reporting a range of diagnosed diseases such as asthma, diabetes, arthritis, as well as risk factors of smoking, cholesterol and blood pressure. However, although carers in this sample had higher prevalence of almost all conditions, this higher prevalence disappeared for male carers in the process of statistical adjustments. For female carers after adjustments, all associations with chronic conditions disappeared except for diabetes. Therefore, any excess prevalence of chronic conditions in the population that results from people providing care is small. The estimation of PAR associated with caregiving for these selected physical health conditions was not expected to be large, and this is indeed what was found. Overall, we concluded that our findings of small effect size differences in physical health outcomes between carers and non–carers was associated with small to moderate risk of informal carers having these chronic conditions.

This study is novel and useful, not just for demonstrating these differences in carer health status and morbidity, but rather to show that major health disorders are present within the carer population. These findings offer more detailed information on types of chronic physical health problems such as asthma, diabetes, arthritis and hypertension that need more appropriate disease management strategies that are specific to carers. Our results also provide a baseline for assessing and comparing trends across a range of chronic conditions and risk factors among future carers.

Therefore, monitoring of carer health and morbidity, particularly ‘at risk’ individuals such as female carers with asthma or diabetes, is important to track trends in chronic health conditions, distress and disability in informal caregivers. To achieve this, caregiver-based studies need to become part of mainstream biomedical research at both epidemiological and clinical levels.

Acknowledgements SAMSS is owned by Department for Health and Ageing, South Australia, Australia. All collected source data are maintained and managed by Population Research and Outcome Studies, The University of Adelaide.

Contributors AFS and AWT conceptualised the study. AWT supervised the study, and AFS drafted the manuscript. TKG and AFS conducted the statistical analyses. AWT, TKG and KP contributed to writing and critical review of the manuscript. All authors read and approved the final manuscript.

Funding This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Disclaimer The opinions expressed in this work are those of the authors and may not represent the position or policy of SA Department for Health and Ageing.

Competing interests None declared.

Patient consent Not required.

Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethics approval was obtained from the ethics committee of the Department of Health and Ageing, South Australia (SA) (436.02.2014 and HREC/14/SAH/200).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The data that support the findings of this study are available from SA Department of Health and Ageing, but restrictions apply to the availability of these data, which were used under licence for the current study and so are not publicly available. Data are, however, available from the authors on reasonable request and with permission of SA Department of Health and Ageing.

REFERENCES

1. Navaie-Waliser M, Feldman PH, Gould DA, *et al*. When the caregiver needs care: the plight of vulnerable caregivers. *Am J Public Health* 2002;92:409–13.
2. Viana MC, Gruber MJ, Shahly V, *et al*. Family burden related to mental and physical disorders in the world: results from the WHO World Mental Health (WMH) surveys. *Rev Bras Psiquiatr* 2013;35:115–25.
3. Cummins R, Hughes J, Tomyn A, *et al*. Australian Unity Wellbeing Survey:17.1. The wellbeing of Australians: Carer health and wellbeing. (Special Report). 2007. Melbourne: Deakin University. Carers Australia and Australian Unity. http://www.acqol.com.au/reports/auwbi.php.
4. Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Chronic Care. AARP Public Policy Institute and the United Hospital Fund. 2012 www.aarp.org/family/caregiving/info-10-2012.
5. McDonald J, McKinlay E, Keeling S, *et al*. How family carers engage with technical health procedures in the home: a grounded theory study. *BMJ Open* 2015;5:e007761.
6. Stajduhar K, Funk L, Toye C, *et al*. Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliat Med* 2010;24:573–93.
7. Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2007;62:P126–P137.
8. Saria MG, Nyamathi A, Phillips LR, *et al*. The Hidden Morbidity of Cancer: Burden in Caregivers of Patients with Brain Metastases. *Nurs Clin North Am* 2017;52:159–78.
9. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129:946–72.
10. Vitaliano PP, Young HM, Zhang J. Is Caregiving a Risk Factor for Illness? *Curr Dir Psychol Sci* 2004;13:13–16.
11. van den Berg B, Fiebig DG, Hall J. Well-being losses due to caregiving. *J Health Econ* 2014;35:123–31.
12. Richardson TJ, Lee SJ, Berg-Weger M, *et al*. Caregiver health: health of caregivers of Alzheimer's and other dementia patients. *Curr Psychiatry Rep* 2013;15:367.
13. Edwards B, Higgins DJ. Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia. *Med J Aust* 2009;190:S61–S65.
14. Smith L, Onwumere J, Craig T, *et al*. Mental and physical illness in caregivers: results from an English national survey sample. *Br J Psychiatry* 2014;205:197–203.
15. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs* 2008;108(9 Suppl):23–7.
16. Legg L, Weir CJ, Langhorne P, *et al*. Is informal caregiving independently associated with poor health? A population-based study. *J Epidemiol Community Health* 2013;67:95–7.
17. Miyawaki A, Tomio J, Kobayashi Y, *et al*. Impact of long-hours family caregiving on non-fatal coronary heart disease risk in middle-aged people: Results from a longitudinal nationwide survey in Japan. *Geriatr Gerontol Int* 2017;17:2109–15.
18. Phillips AC, Gallagher S, Hunt K, *et al*. Symptoms of depression in non-routine caregivers: the role of caregiver strain and burden. *Br J Clin Psychol* 2009;48:335–46.
19. Laks J, Goren A, Dueñas H, *et al*. Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. *Int J Geriatr Psychiatry* 2016;31:176–85.
20. Hussain R, Wark S, Dillon G, *et al*. Self-reported physical and mental health of Australian carers: a cross-sectional study. *BMJ Open* 2016;6:e011417.
21. Capistrant BD, Moon JR, Glymour MM. Spousal caregiving and incident hypertension. *Am J Hypertens* 2012;25:437–43.
22. Lebrec J, Ascher-Svanum H, Chen YF, *et al*. Effect of diabetes on caregiver burden in an observational study of individuals with Alzheimer's disease. *BMC Geriatr* 2016;16:93.
23. Luecken LJ, Lemery KS. Early caregiving and physiological stress responses. *Clin Psychol Rev* 2004;24:171–91.
24. Vitaliano PP, Scanlan JM, Zhang J, *et al*. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosom Med* 2002;64:418–35.

25. Kenny P, King MT, Hall J. The physical functioning and mental health of informal carers: evidence of care-giving impacts from an Australian population-based cohort. *Health Soc Care Community* 2014;22:646–59.
26. Jowsey T, McRae I, Gillespie J, *et al*. Time to care? Health of informal older carers and time spent on health related activities: an Australian survey. *BMC Public Health* 2013;13:374.
27. Brehaut JC, Kohen DE, Garner RE, *et al*. Health among caregivers of children with health problems: findings from a Canadian population-based study. *Am J Public Health* 2009;99:1254–62.
28. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002;17:184–8.
29. Ratcliffe J, Lester LH, Couzner L, *et al*. An assessment of the relationship between informal caring and quality of life in older community-dwelling adults - more positives than negatives? *Health Soc Care Community* 2013;21:35–46.
30. O'Reilly D, Rosato M, Maguire A, *et al*. Caregiving reduces mortality risk for most caregivers: a census-based record linkage study. *Int J Epidemiol* 2015;44:1959–69.
31. Vlachantoni A, Evandrou M, Falkingham J, *et al*. Informal care, health and mortality. *Maturitas* 2013;74:114–8.
32. Buyck JF, Bonnaud S, Boumendil A, *et al*. Informal caregiving and self-reported mental and physical health: results from the Gazel Cohort Study. *Am J Public Health* 2011;101:1971–9.
33. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist* 2015;55:309–19.
34. Taylor R, Ford G, Dunbar M. The effects of caring on health: a community-based longitudinal study. *Soc Sci Med* 1995;40:1407–15.
35. Adelaide: Department of Health. SAMSS Brief Report No. 2002-20. 2002 http://www.health.sa.gov.au/ pros.
36. *SAMSS Technical Paper 1 – Method. Population Research and Outcomes Studies Unit. South Australian Monitoring and Surveillance System (SAMSS). Survey Methodology. SAMSS Technical Paper Series No.1/04*. Adelaide: Department of Health 2004.
37. Dal Grande E, Taylor AW. Sampling and coverage issues of telephone surveys used for collecting health information in Australia: results from a face-to-face survey from 1999 to 2008. *BMC Med Res Methodol* 2010;10:77.
38. BeActive Australia. Commonwealth of Australia May 1999. National Physical Activity Guidelines for Adults, Department of Health and Aged Care. Canberra. Reprinted 2005. 1999. Available at http://www.beactive.com.au/downloads/National%20Guidelines/Adult%20Brochure%20Final.pdf.
39. World Health Organization (WHO). (2010). BMI classification. Geneva, Switzerland: World Health Organization. 2013 http://apps.who.int/bmi/index.jsp?introPage=intro_3.html.
40. National Health and Medical Research Council. *Australian Guidelines to Reduce Health Risks from Drinking Alcohol, Canberra, Australia*: National Health and Medical Research Council, 2009.
41. National Health and Medical Research Council). (NHMRC). Food for health, dietary guidelines for Australians: a guide to healthy eating. 2005; Australian Government, Canberra (2005). http://www.nhmrc.gov.au/publications/synopses/_files/n31.pdf.
42. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30:473–83.
43. Kessler RC, Mroczek DK. *Final versions of our non-specific psychological distress scale*. Survey Research Centre of the Institute for Social Research: University of Michigan, Ann Arbor, 1994.
44. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. *Psychol Med* 1979;9:139–45.
45. Goldney RD, Dal Grande E, Fisher LJ, *et al*. Population attributable risk of major depression for suicidal ideation in a random and representative community sample. *J Affect Disord* 2003;74:267–72.
46. Rockhill B, Newman B, Weinberg C. Use and misuse of population attributable fractions. *Am J Public Health* 1998;88:15–19.
47. Dal Grande E, Chittleborough CR, Campostrini S, *et al*. Health Estimates Using Survey Raked-Weighting Techniques in an Australian Population Health Surveillance System. *Am J Epidemiol* 2015;182:544–56.
48. González-de Paz L, Real J, Borrás-Santos A, *et al*. Associations between informal care, disease, and risk factors: A Spanish country-wide population-based study. *J Public Health Policy* 2016;37:173–89.
49. Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish general population. *Health Qual Life Outcomes* 2015;13:109.
50. To T, Stanojevic S, Moores G, *et al*. Global asthma prevalence in adults: findings from the cross-sectional world health survey. *BMC Public Health* 2012;12:204.
51. Roepke SK, Mausbach BT, Patterson TL, *et al*. Effects of Alzheimer caregiving on allostatic load. *J Health Psychol* 2011;16:58–69.
52. Lovell B, Moss M, Wetherell M. The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD. *Psychoneuroendocrinology* 2012;37:534–42.
53. Vitaliano PP, Schulz R, Kiecolt-Glaser J, *et al*. Research on physiological and physical concomitants of caregiving: Where do we go from here? *Annals of Behavioral Medicine* 1997;19:117–23.
54. Hirst M. Carer distress: a prospective, population-based study. *Soc Sci Med* 2005;61:697–708.
55. Price K, Gill T, Winefield H, *et al*. *Administrative Assistant. Determinants of Psychological Distress – A Literature Review. The Assessment of the Determinants and Epidemiology of Psychological Distress (ADEPD) Study*: Discipline of Psychiatry, University of Adelaide, 2008.
56. Stacey AF, Gill TK, Price K, *et al*. Unpaid Informal Caregivers in South Australia: Population Characteristics, Prevalence and Age-Period-Cohort Effects 1994–2014. *PLoS One* 2016;11:e0161994.
57. Crawford A, DeFries E, Brumback B, *et al*. Characteristics of caregivers and care recipients: Results from 2007 Kansas Behavioral Risk Factor Surveillance System. Kansas Department of Health and Environment Office of Health Promotion. 2009.www.kdheks.gov/brfss/PDF/ BRFSS_2007_CaregiverModule_Rpt.pdf
58. Salgado-García FI, Zuber JK, Graney MJ, *et al*. Smoking and Smoking Increase in Caregivers of Alzheimer's Patients. *Gerontologist* 2015;55:780–92.
59. von Känel R, Mausbach BT, Patterson TL, *et al*. Increased Framingham Coronary Heart Disease Risk Score in dementia caregivers relative to non-caregiving controls. *Gerontology* 2008;54:131–7.
60. Taylor AW, Dal Grande E, Gill TK, *et al*. How valid are self-reported height and weight? A comparison between CATI self-report and clinic measurements using a large cohort study. *Aust N Z J Public Health* 2006;30:238–46.
61. Taylor A, Dal Grande E, Gill T, *et al*. Comparing self-reported and measured high blood pressure and high cholesterol status using data from a large representative cohort study. *Aust N Z J Public Health* 2010;34:394–400.
62. Dal Grande E, Fullerton S, Taylor AW. Reliability of self-reported health risk factors and chronic conditions questions collected using the telephone in South Australia, Australia. *BMC Med Res Methodol* 2012;12:1–10.

Appendix D: Reprint of published paper- PLoS One

Biomedical health profiles of unpaid family carers in an urban population in South Australia

PLOS ONE

RESEARCH ARTICLE

Biomedical health profiles of unpaid family carers in an urban population in South Australia

Anne F. Stacey[1]*, **Tiffany K. Gill**[2], **Kay Price**[3], **Anne W. Taylor**[1]

1 Population Research & Outcome Studies, Discipline of Medicine, The University of Adelaide, Adelaide, South Australia, Australia, **2** Adelaide Medical School, The University of Adelaide, Adelaide, South Australia, Australia, **3** School of Nursing and Midwifery, University of South Australia, Adelaide, South Australia, Australia

* anne.stacey@adelaide.edu.au

Citation: Stacey AF, Gill TK, Price K, Taylor AW (2019) Biomedical health profiles of unpaid family carers in an urban population in South Australia. PLoS ONE 14(3): e0208434. https://doi.org/10.1371/journal.pone.0208434

Editor: Yuka Kotozaki, Iwate Medical University, JAPAN

Received: May 1, 2018

Accepted: March 14, 2019

Published: March 28, 2019

Data Availability Statement: The North West Adelaide Health Study (NWAHS) data is an ongoing cohort study that includes sensitive and potentially identifiable information, and our ethical approval for the study is subject to stringent protection of these individual-level data. External requests for NWAHS data can be directed to the NWAHS Management Committee (email: pros.nwahs@adelaide.edu.au).

Funding: The authors received no specific funding for this work.

Abstract

Objectives

To compare the biomedical health profile and morbidity of adult carers with non-carers.

Methods

The North West Adelaide Health Study (NWAHS) is a representative population-based longitudinal biomedical cohort study of 4056 participants aged 18 years and over at Stage One. Informal (unpaid) carers were identified in Stage 3 of the project (2008–2010). Risk factors, chronic medical conditions and biomedical, health and demographic characteristics using self-report and blood measured variables were assessed. Data were collected through clinic visits, telephone interviews and self-completed questionnaires. Risk factors included blood pressure, cholesterol/lipids, body mass index (BMI), smoking and alcohol intake. Chronic medical conditions included cardiovascular and respiratory diseases, diabetes, and musculoskeletal conditions. Blood measured variables were routine haematology, biochemistry, Vitamin D, and the inflammatory biomarkers high sensitivity C-Reactive Protein (hs-CRP), Tumor Necrosis Factor alpha (TNFα) and Interleukin-6 (Il-6).

Results

The prevalence of carers aged 40 years and over was 10.7%, n = 191. Carers aged 40 years and over were more likely to assess their health status as fair/poor and report having diabetes, arthritis, anxiety and depression. They also reported insufficient exercise and were found to have higher BMI compared with non-carers. Significant findings from blood measured variables were lower serum Vitamin D and haemoglobin. Male carers had raised diastolic blood pressure, higher blood glucose, lower haemoglobin and albumin levels and slightly elevated levels of the inflammatory biomarkers TNFα and hs-CRP.

Competing interests: The authors have declared that no competing interests exist.

Abbreviations: BMI, Body Mass Index; CATI, Computer Assisted Telephone Interview; CI, Confidence interval; CRP, C-Reactive Protein; CVD, Cardiovascular Disease; e-Sel, e-Selectin; FEV1, Forced Expiratory Volume in one second; Hb, Haemoglobin; HbA1c, Glycosylated haemoglobin; HDL, High Density Lipoprotein; hs-CRP, high sensitivity C-Reactive Protein; Il-6, Interleukin-6; LDL, Low Density Lipoprotein; MPO, Myeloperoxidase; NWAHS, North West Adelaide Health Study; RR, Relative risk; SF1, Short Form 1 (Question 1); SF36, Short Form 36 (Questionnaire); SPSS, Statistical Package for Social Sciences; TNFα, Tumor Necrosis Factor alpha; WHR, Waist Hip Radio.

Discussion and conclusions

This study confirms informal carers had different biomedical profiles to non-carers that included some chronic physical illnesses. It identifies that both female and male carers showed a number of risk factors which need to be considered in future caregiver research, clinical guidelines and policy development regarding carer morbidity.

Introduction

Although research findings in the caregiving literature have been mixed and at times contradictory, providing long-term care of persons with disability, physical, mental health illnesses and frailty, has been associated with higher rates of hypertension, heart disease, arthritis and other chronic conditions in informal family carers [1–7]. The psychological impact of informal caregiving on carer health, which has received greater emphasis than chronic conditions in the caregiving literature, has indicated that carers frequently experience stress, distress, anxiety and depression, particularly female carers who usually represent the majority of carers [2,8–13]. Published research has mostly been based on self-reported data, while biomedical profiles of carer health that include clinic measured physical and physiological data have been slower to emerge, especially those using well-designed population studies.

Population studies based on self-report data

National surveys of family carers from the United Kingdom, Europe, Canada, Australia and other countries have described some international trends of carer morbidity at the population level [14–19]. They have found independent associations of chronic exposure to informal caregiving and self-reported poor health even at the extremes of the age range, in both younger and older carers [20]. In recent years surveys of the public health impacts of caregiving in the United States of America (USA) indicate family carers have had a slight to modest decline in their health [21,22]. Carers also reported chronic medical conditions such as diabetes, and joint pain was identified as a recurrent health problem. Assessing risk factors among carers revealed responsible health behaviours in relation to taking exercise and checking cholesterol levels, and those carers surveyed were less likely to be current smokers [23].

Biomedical measures of carer health: Inflammatory biomarkers

Biomedical studies in the caregiver literature examining inflammatory, immunological and metabolic profiles of carers include mainly small clinical studies. Some of these demonstrated associations between informal caregiving and altered biomarkers in carers of persons with stroke, cancer or the frail aged [4,24]. More detailed physiological assessments of carers' health have revealed elevated levels of pro-inflammatory biomarkers, in particular plasma cytokines such as Interleukin (IL-6), high sensitivity C-Reactive Protein (hs-CRP) and Tumor Necrosis Factor alpha (TNFα) [25–27]. There have been mixed results from other studies of biomarkers among carer participants. For example a recent review of the literature (2017) found only weak associations between caregiving, stress and increased pro-inflammatory biomarkers, such as IL-6 and CRP among spousal and female home based relatives caring for older persons. The carers themselves were often aged sixty years and over [28]. Another systematic review that was specific to the psychobiological impact of dementia caregiving had a focus on chronic stress and incorporated a broad range of biological markers [29]. An overview of risk factors in carers confirmed differences in blood pressure and heart rate between carers and non-carers, also Body Mass Index (BMI) and weight gain were reported to be different between male and female carers [30]. Caregiving stress was found to be moderated by gender [30] while an earlier study had reported that the negative impact of caregiving on health was not observed in individuals who did not find caregiving to be stressful. [7]. As much past research has been based on dementia caregiving and stress in carers, there is a lack of population research which can provide a broader profile of carer health characteristics and offer a different perspective of the distribution of chronic disease among informal carers.

This study therefore aimed to compare general and biomedical health status of informal carers with non-carers from the same population with an emphasis on gender differences. Access to comprehensive self-reported and biomedical data from the North West Adelaide Health Study (NWAHS) made our investigation possible and provided a wider selection of haematological and biochemical blood variables rarely featured in carer projects. Research objectives were to analyse a range of risk factors and selected chronic medical conditions, using both self-report and clinically measured blood and other biomedical variables, including a selection of inflammatory biomarkers. The research questions were: *Do informal family carers show different biomedical profiles in terms of blood and other measured variables than non-carers*? and secondly; *Is there an association between the caregiving role, risk factors and chronic conditions amongst South Australian informal carers*?

Methods

Study design and setting

The NWAHS is a representative population based longitudinal cohort study set in the north and western suburbs of Adelaide, which is the capital of South Australia. The northern and western regions of Adelaide number approximately half of the city's population and one quarter of South Australia's population. These regions reflected the demographic profile of the state's population at the time of the initial data collection. The study was designed to investigate the prevalence of a number of chronic conditions and health-related risk factors along a continuum, from not at risk, to at risk, to diagnosed, to co-morbidity to death. Stage 1 occurred between 1999 and 2003, Stage 2: 2004–6 and Stage 3: 2008–10. The full methodology of the NWAHS, including original sample selection procedure, entry and exclusion criteria, original interview schedules and biomedical measurements have been comprehensively described and published elsewhere [31,32].

Study population and participants

Initially 4,056 participants aged 18 years were randomly selected and recruited by telephone interview in Stage 1. The analysis for this paper focuses on data collected from Stage 3 only (2008–2010). Stage 3 was the most recent relevant data collected which included both biomedical data and carer status. Data collection at Stage 3 included (1) a Computer Assisted Telephone Interview (CATI); (2) a self-completed questionnaire; (3) a biomedical examination at a clinic. Overall 2,487 (67%) of the eligible sample completed all of these assessments.
The main focus of our study compared health risk factors, chronic medical conditions and biomedical health characteristics with non-carers, using self-report, clinic and blood measured variables. Those aged over 40 years were included in this study as testing for all of the inflammatory biomarkers was only conducted on this group.

Self-reported variables

In order to determine the prevalence of carers within the cohort, participants were asked as part of the self-complete questionnaire:

> *Do you provide long-term care at home for a parent, partner, child, other relative or friend, who has a disability, is frail, aged or who has a chronic mental or physical illness?*

Demographic characteristics selected for this study included age, sex, marital status, work status, educational status, annual household income, and employment status (including whether participants received government support from age, carer or disability pensions). Participants self-reported if they had ever been diagnosed by a doctor for arthritis, cardiovascular (CVD) (ie heart attack, stroke, angina, transient ischaemic attack), or a mental health condition (i.e. anxiety, depression, stress related problem).

Smoking was assessed using standard questions which related to current smoking and the frequency of smoking and alcohol consumption was determined from questions based on the National Heart Foundation Risk Factor Prevalence Study undertaken in 1989 [33]. Physical activity was determined from the amount of walking, moderate and/or vigorous activity undertaken over a one week period, which was then categorized into "No activity", "Insufficient activity" (less than 150 minutes of walking, moderate and/or vigorous activity) and "Sufficient" (150 minutes or more per week) [34]. General health was assessed using the SF1, which is the first question of the Short Form 36 (SF36) [35].

Clinic measured variables

The presence of diabetes was derived from a self-reported doctor diagnosis of diabetes and/or a fasting plasma glucose level of greater than or equal to 7.0 mmol/L. The presence of asthma was determined using self-reported, doctor diagnosed asthma and spirometry measures following administration of salbutamol. For example a change in Forced Expiratory Volume in one second, (FEV1) $> =$ 12% & $>$200ml, or absolute change greater or equal to 400ml from baseline measurements [36,37].

Other clinically measured risk factors included blood pressure readings, height and weight for calculation of BMI, and waist and hip circumference measurements to determine waist/hip ratio (WHR) using standardized measurement techniques. Details of procedures for measuring and techniques have been described and published elsewhere [38–40]. BMI was categorized according to the World Health Organization (WHO) criteria and a high WHR was defined as $>$ 1.0 for males and $>$0.85 for females [41,42].

A fasting blood sample was collected by venipuncture from all participants who were able to provide an adequate amount of blood sample at the clinic visit. Samples were transported to an accredited National Association of Testing Associations (NATA) laboratory for analysis. Biochemical measurements of hs-CRP, glucose and albumin levels were determined using an Olympus AU5400 (Beckman Coulter, USA) and glycosylated haemoglobin (HbA1c) using a Bio-Rad Variant II (HPLC) (Bio-Rad, USA). High density lipoprotein (HDL) and total cholesterol were analysed using an Olympus AU5402. Both low density lipoprotein (LDL) and the total cholesterol/HDL ratio were calculated from these results. Haemoglobin (Hb) levels were determined using a Sysmex XE (Japan). Vitamin D levels to April 2010 were determined using and enzyme Immunoassay method from Immunodiagnostic Systems (IDS, UK) and performed on a BEST 2000 automated enzyme-linked immunosorbent assay (ELISA) system from Biokit. From April 2010, Vitamin D was measured using and automated Chemiluminescent assay from IDS and performed on an iSYS Automated Immunoassay system from IDS.

The patient comparison during the change over gave a Passing-bablock regression equation of y = -1.61 + 1.07x with a bias of -1.9nmol/L indicating good agreement.

The fasting blood sample measured a series of inflammatory biomarkers in study participants aged 40 years and over. IL-6, TNFα, e-Selectin (e-Sel) and Myeloperoxidase (MPO) levels were measured with an ELISA and Cobas autoanalyzer (Roche Diagnostics US).

Data weighting

In Stage 1, data were weighted by region (western and northern health regions), age group, sex and probability of selection in the household to the Australian Bureau of Statistics 1999 Estimated Resident Population and the 2001 Census data [43,44]. Weighting was undertaken to reflect the population of interest and to correct for potential non-response bias in which some demographic groups of respondents may be over- or under-represented. Stage 3 was reweighted using the 2009 Estimated Resident Population for South Australia and incorporated participation in the three components (CATI), self-complete questionnaire, clinic), whilst retaining the original weight from Stage 1 in the calculation. All analyses in this paper, where applicable, are weighted to the population of the northern and western suburbs of Adelaide.

Data analysis

Statistical analysis was conducted using SPSS version 24 (IBM, Armonk, NY, USA) and STATA version 14 (StataCorp, College Station, TX, USA). Descriptive analysis (proportions, means, medians where applicable) were determined for all of the predictor variables (demographic characteristics, chronic conditions and health risk factors). Bivariable analysis using chi-square tests and including post hoc tests using the adjusted residuals, were used to determine which categories were significantly different from the other categories, combined for both carers and non-carers. All continuous data were tested for normality using Kolmogorov-Smirnov and Shapiro-Wilk tests (both tests were used to obtain a more in depth understanding of whether data were normally distributed), and data that were not normally distributed were analysed using non-parametric tests (Mann-Whitney U).

Generalised linear models using the binary outcome variable of presence carer or not a carer were used with the “svy” estimators in STATA and weighted data to determine the relative risks (RR) of each of the predictors, in association with the outcome variable. Separate multivariable models were created for males and females which included all possible predictors.

Ethical approval

All protocols and procedures were approved by the Human Research Ethics Committee of The Queen Elizabeth Hospital, in Adelaide, South Australia, and all participants provided written informed consent.

Results

The prevalence of carers aged 40 and over was 10.7% (95% CI 9.3–12.3), n = 191. Table 1 presents the demographic characteristics for carers aged 40 years and over compared to non-carers. Carers were more likely to be female, married and have a lower education level. They were also more likely to be retired, undertake home duties or were unable to work. Carers had higher levels of uptake of carer pensions, age pension and disability pension. Carers were also

Table 1. Demographic characteristics of carers compared to non-carers, aged 40 years and older.

Variable	Carers			Non-carers			p value
	n	%	95% CI	n	%	95% CI	X^2
Gender							
Male	78	9.1 ↓	7.3–11.3	779	90.9 ↑	88.7–92.7	
Female	113	12.1 ↑	10.1–14.5	818	87.9 ↓	85.5–89.9	0.038
Age Group (years)							
40–59	92	9.1 ↓	7.3–11.3	921	90.9 ↑	88.7–92.7	
60 years and over	99	12.8 ↑	10.7–15.2	676	87.2 ↓	84.8–89.3	0.011
Marital status							
Married/de facto	150	11.8 ↑	10.1–13.8	1122	88.2 ↓	86.2–89.9	
Divorced/Separated	9	5.3 ↓	3.2–8.7	160	94.7 ↑	91.3–96.8	
Widowed	10	6.1	2.7–13.2	146	93.9	86.8–97.3	
Never Married	11	12.6	6.8–22.2	73	87.4	77.8–93.2	0.015
Employment status							
Self/ Full time / Part time	63	6.6 ↓	5.1–8.6	883	93.4 ↑	91.4–94.9	
Unemployed	5	19.4	7.9–40.2	21	80.6	59.8–92.1	
Home duties	13	19.3 ↑	11.3–31.0	53	80.7 ↓	69.0–88.7	
Retired	74	13.3 ↑	10.8–16.3	482	86.7 ↓	83.7–89.2	
Student/Volunteer	2	13.0	3.4–38.9	12	87.0	61.2–96.6	
Unable to work	14	21.6 ↑	12.6–34.5	52	78.4 ↓	65.5–87.4	
Carer	8	100.0 ↑	-	-	-	-	<0.001
Educational status							
High school	122	13.3 ↑	11.2–15.8	795	86.7 ↓	84.2–88.8	
Trade/ Certificate/ Diploma	42	8.0 ↓	5.9–10.7	482	92.0 ↑	89.3–94.1	
Bachelor degree or higher	15	6.3 ↓	3.7–10.4	226	93.7 ↑	89.6–96.3	<0.001
Annual household income ($Aus)							
Up to $20,000	22	10.8	7.2–15.8	180	89.2	84.2–92.8	
$20,000-$40,000	75	18.3 ↑	14.9–22.3	332	81.7 ↓	77.7–85.1	
$40,000-$60,000	16	5.9 ↓	3.8–9.1	259	94.1 ↑	90.9–96.2	
$60,000-$80,000	20	9.4	5.8–14.8	193	90.6	85.2–94.2	
$80,000-$100,000	15	8.5	4.7–15.0	157	91.5	85.0–95.3	
More than $100,000	12	4.2 ↓	2.3–7.6	272	95.8 ↑	92.4–97.7	
Not stated	20	15.3	9.7–23.3	112	84.7	76.8–90.3	<0.001
Carer Payment							
No	63	6.2 ↓	4.7–8.0	959	93.8 ↑	92.0–95.3	
Yes	26	86.7 ↑	64.7–95.9	4	13.3 ↓	4.1–35.3	<0.001
Age Pension							
No	63	6.2 ↓	4.7–8.0	959	93.8 ↑	92.0–95.3	
Yes	64	15.1 ↑	12.1–18.8	357	84.9 ↓	81.2–87.9	<0.001
Disability Pension							
No	63	6.2 ↓	4.7–8.0	959	93.8 ↑	92.0–95.3	
Yes	14	16.8 ↑	10.1–26.5	69	83.2 ↓	73.5–89.9	<0.001

Chi square post hoc tests ↑↓ indicates statistically significantly difference in categories using adjusted standardised residual

https://doi.org/10.1371/journal.pone.0208434.t001

more likely to be over 60 years of age and have an annual income of between $20,000 and $40,000 per year.

Table 2 presents bivariable analysis of general health, risk factor and chronic conditions of carers aged 40 years and over, compared to non-carers. Carers were more likely to have higher

Table 2. Risk factor and chronic condition profile of carers compared with non-carers, aged 40 years and over.

Variable	Carers			Non-carers			p-value
	n	%	95% CI	n	%	95% CI	X^2
Body Mass Index							
Underweight/ normal	29	7.1 ↓	5.0–10.0	381	92.9 ↑	90.0–95.0	
Overweight	76	11.1	8.9–13.9	602	88.9	86.1–91.1	
Obese	72	12.2	9.8–15.2	515	87.8	84.8–90.2	0.027
Waist-to-hip ratio							
Normal	102	9.1 ↓	7.5–11.0	1025	90.9 ↑	89.0–92.5	
High	76	13.6 ↑	11.0–16.8	481	86.4 ↓	83.2–89.0	0.004
Smoking status							
Non smoker	91	11.7	9.0–13.6	733	88.9	86.4–91.0	
Ex-smoker	73	10.4	8.4–12.8	625	89.6	87.2–91.6	
Current smoker	27	10.7	7.3–15.5	224	89.3	84.5–92.7	0.919
Alcohol Risk							
Non drinker, no risk	112	12.2	10.2–14.6	807	87.8	85.4–89.9	
Low risk	60	9.9	7.7–12.6	551	90.1	87.4–92.3	
Intermediate to very high	3	3.6 ↓	1.2–9.8	72	96.4 ↑	90.2–98.8	0.041
Physical Activity							
No activity	49	14.1 ↑	10.5–18.7	295	85.9 ↓	81.3–89.5	
Activity but not sufficient	71	12.5	10.0–15.6	498	87.5	84.4–90.0	
Sufficient activity	58	7.6 ↓	5.9–9.7	704	92.4 ↑	90.3–94.1	0.001
Asthma							
No	134	9.9	88.3–91.6	1218	90.1	88.3–91.6	
Yes	44	13.2	82.5–90.1	288	86.8	82.5–90.1	0.079
Cardiovascular disease							
No	158	10.3	8.9–12.0	1370	89.7	88.0–91.1	
Yes	22	13.8	8.7–21.1	135	86.2	79.0–91.3	0.185
Diabetes							
No	149	10.0 ↓	8.5–11.6	1344	90.0 ↑	88.4–81.5	
Yes	29	15.3 ↑	10.8–21.3	162	84.7 ↓	78.7–89.2	0.022
Arthritis							
No	95	9.1 ↓	7.4–11.2	945	90.9 ↑	88.8–92.6	
Yes	75	13.7 ↑	11.1–16.8	471	86.3 ↓	83.2–88.9	0.005
Anxiety							
No	140	9.9 ↓	8.4–11.7	1271	90.1 ↑	88.3–91.6	
Yes	18	19.2 ↑	12.0–29.2	76	80.8 ↓	70.8–88.0	0.005
Depression							
No	133	9.8 ↓	8.3–11.6	1222	90.2 ↑	88.4–91.7	
Yes	25	16.5 ↑	10.8–24.5	125	83.5 ↓	75.5–89.2	0.011
Stress							
No	145	10.2	8.6–11.9	1288	89.8	88.1–91.4	
Yes	12	17.1	10.3–27.1	58	82.9	72.9–89.7	0.062
SF1							
Ex/very good/good	133	9.3 ↓	7.9–11.0	1287	90.7 ↑	89.0–92.1	
Fair/poor	57	16.2 ↑	12.5–20.7	293	83.8 ↓	79.3–87.5	<0.001

Chi square post hoc tests ↑↓ indicates statistically significantly difference in categories using adjusted standardised residual

https://doi.org/10.1371/journal.pone.0208434.t002

Table 3. Clinic measured variables, carers compared with non-carers, aged 40 years and over.

	Carer				Non-carers				
	n	**Mean**	**SD**	**Median**	**n**	**Mean**	**SD**	**Median**	**p-value**
Systolic BP	178	129.5	16.8	128.0	1505	129.4	19.2	127.0	0.568
Diastolic BP	178	78.0	8.6	78.0	1505	77.7	8.7	77.5	0.594
CRP	173	4.6	7.8	2.3	1490	3.4	4.7	2.0	0.015
HbA1c	176	6.0	0.8	5.8	1490	5.8	0.8	5.7	0.007
LDL	176	3.1	1.0	3.1	1473	3.1	1.0	3.0	0.405
HDL	176	1.5	0.4	1.4	1492	1.5	0.4	1.4	0.191
Total cholesterol	176	5.2	1.1	5.2	1492	5.3	1.1	5.2	0.755
Total cholesterol/HDL ratio	176	3.7	0.9	3.6	1492	3.7	1.1	3.6	0.076
Glucose	176	5.4	1.2	5.1	1490	5.3	1.2	5.1	0.125
Hb	175	139.4	14.3	139.9	1489	142.8	13.3	143.0	0.014
Vitamin D	176	64.7	25.5	62.0	1466	70.1	27.9	66.0	0.009
Albumin	175	39.4	3.2	39.5	1491	39.8	3.2	40.0	0.111
Il6	152	1.9	1.8	1.4	1220	1.7	1.6	1.2	0.352
MPO	152	218.6	229.4	143.4	1219	202.4	237.2	118.8	0.172
TNFα	152	2.2	3.8	1.6	1220	1.8	2.6	1.4	0.106
E-selectin	152	32.8	11.8	31.9	1219	32.9	16.7	30.2	0.796

Non-parametric tests undertaken for non-normally distributed data

https://doi.org/10.1371/journal.pone.0208434.t003

BMI and WHR than non-carers, were less likely to undertake a sufficient level of physical activity but had a lower alcohol risk. Carers were also more likely to have diabetes, arthritis, anxiety, depression and fair/poor health status compared to non-carers.

Table 3 presents a comparison between carers and non-carers for clinic measured variables (blood pressure and blood measured tests). Significant differences were evident between carers and non-carers for the blood measured variables hs-CRP, HbA1c, Hb, and Vitamin D (Table 3). There were no significant differences with regard to the other inflammatory biomarkers IL-6, MPO, TNFα, and e-Sel.

Table 4 presents the results of the multivariable models for males and females. Pension type (carer, aged, disability) was excluded from the analysis, as were total cholesterol and total cholesterol/HDL ratio due to collinearity. Male carers compared with non-carer males were more likely not to be employed (RR 2.52, 95% CI 1.19–5.31; p = 0.015); undertake some activity (RR 2.21, 95% CI 1.22–4.00; p = 0.009); have lower systolic (RR 0.96, 95% CI 0.94–0.99; p = 0.011) but higher diastolic blood pressure (RR 1.13, 95% CI 1.07–1.20; p = <0.001). Male carers were also more likely to have higher levels of blood glucose (RR 1.40, 95% CI 1.03–1.89; p = 0.03), raised hs-CRP (RR 1.03, 95% CI 1.00–1.06; p = 0.023) and TNFα (RR 1.12, 95% CI 1.06–1.20; p = <0.001) but lower levels of HbA1c (RR 0.54, 95% CI 0.33–0.89; p = 0.016) and albumin (RR 0.90, 95% CI 0.82–1.00; p = 0.040). Female carers were less likely to be widowed, separated or divorced and to have lower levels of income below $40,000 when compared with non-carer females.

Discussion

Reviewing our research questions, we examined whether informal family carers showed different biomedical profiles in terms of blood and other measured variables than non-carers. Overall our carers aged 40 years and over had only slightly elevated levels of the inflammatory biomarkers TNFα, hs-CRP, and HbA1c but they showed lower Vitamin D and Hb levels. The

Table 4. Relative risk of predictor variables associated with being a carer compared to non-carers, male and female aged 40 and over.

	Male		Female	
	RR (95% CI)	*p*-value	RR (95% CI)	*p*-value
Marital status				
Never married	1.00		1.00	
Widowed	1.10 (0.08–15.39)	0.941	0.23 (0.07–0.77)	0.017
Separated/divorced	1.62 (0.16–16.27)	0.684	0.19 (0.06–0.64)	0.007
Married/ de facto	2.88 (0.32–26.13)	0.347	0.85 (0.36–2.01)	0.714
Annual household income				
More than $100,000	1.00		1.00	
$80,000-$100,000	1.16 (0.27–4.92)	0.842	3.09 (0.52–18.51)	0.217
$60,000-$80,000	1.05 (0.28–3.93)	0.938	3.80 (0.66–21.77)	0.134
$40,000-$60,000	0.59 (0.17–2.08)	0.411	1.56 (0.25–9.88)	0.638
$20,000-$40,000	1.49 (0.49–4.53)	0.478	6.64 (1.29–33.18)	0.024
Up to $20,000	3.24 (0.74–14.25)	0.119	7.59 (1.29–44.76)	0.025
Not stated	0.96 (0.16–5.65)	0.966	5.65 (1.07–29.78)	0.041
Employment status				
Self/ Full time employed/Part time employed	1.00		1.00	
Not employed	2.52 (1.19–5.31)	0.015	1.55 (0.84–2.86)	0.159
Educational status				
Bachelor degree or Higher	1.00		1.00	
Trade/ Certificate/ Diploma	0.92 (0.37–2.33)	0.862	1.18 (0.36–3.90)	0.780
High school	1.17 (0.42–3.23)	0.763	1.58 (0.52–4.85)	0.420
Body Mass Index				
Underweight/normal	1.00		1.00	
Overweight	1.20 (0.41–3.53)	0.734	1.51 (0.74–3.05)	0.780
Obese	1.54 (0.53–4.48)	0.427	1.18 (0.54–2.60)	0.420
Waist:Hip ratio				
Normal	1.00		1.00	
High	0.65 (0.29–1.47)	0.304	1.23 (0.77–1.97)	0.379
Smoking status				
Non smoker	1.00		1.00	
Ex smoker	0.90 (0.47–1.72)	0.747	1.11 (0.71–1.74)	0.650
Current smoker	1.46 (0.46–4.69)	0.522	1.14 (0.51–2.56)	0.746
Alcohol Consumption Risk				
High risk	1.00		1.00	
Low risk	7.01 (0.85–57.47)	0.070	2.17 (0.57–8.17)	0.254
Non drinkers / no risk	6.06 (0.75–48.62)	0.090	3.29 (0.86–12.59)	0.082
Recreational physical activity				
Sufficient	1.00		1.00	
Activity but not sufficient	2.21 (1.22–4.00)	0.009	1.04 (0.6–1.78)	0.875
No activity	1.75 (0.73–4.16)	0.206	1.36 (0.78–2.38)	0.273
Diabetes				
No	1.00		1.00	
Yes	1.47 (0.63–3.39)	0.371	0.70 (0.22–2.21)	0.537
Asthma				
No	1.00		1.00	
Yes	0.84 (0.40–1.78)	0.653	1.12 (0.63–1.98)	0.701
Arthritis				

(*Continued*)

Table 4. (Continued)

	Male		Female	
	RR (95% CI)	*p*-value	RR (95% CI)	*p*-value
No	1.00		1.00	
Yes	1.80 (0.81–3.99)	0.146	1.03 (0.64–1.63)	0.915
Cardiovascular disease				
No	1.00		1.00	
Yes	1.61 (0.76–3.41)	0.218	1.23 (0.57–2.65)	0.604
Anxiety				
No	1.00		1.00	
Yes	0.35 (0.05–3.41)	0.307	1.67 (0.69–4.06)	0.255
Depression				
No	1.00		1.00	
Yes	0.79 (0.29–2.10)	0.630	0.98 (0.43–2.27)	0.970
Stress				
No	1.00		1.00	
Yes	2.19 (0.94–5.72)	0.109	1.24 (0.42–3.67)	0.702
General health				
Excellent/very good/good	1.00		1.00	
Fair/poor	0.82 (0.34–1.94)	0.645	1.24 (0.73–2.11)	0.418
Systolic blood pressure	0.96 (0.94–0.99)	0.011	0.99 (0.97–1.00)	0.133
Diastolic blood pressure	1.13 (1.07–1.20)	<0.001	1.02 (0.98–1.05)	0.357
CRP	1.03 (1.00–1.06)	0.023	1.00 (0.94–1.06)	0.971
HbA1c	0.54 (0.33–0.89)	0.016	1.11 (0.67–1.84)	0.681
HDL	1.03 (0.36–2.92)	0.963	1.40 (0.81–2.40)	0.226
LDL	1.09 (0.81–1.46)	0.576	1.15 (0.90–1.47)	0.257
Glucose	1.40 (1.03–1.89)	0.031	0.90 (0.64–1.27)	0.551
Hb	0.98 (0.95–1.00)	0.087	1.00 (0.97–1.02)	0.715
Vitamin D	1.00 (0.99–1.01)	0.516	0.99 (0.99–1.00)	0.138
Albumin	0.90 (0.82–1.00)	0.040	0.97 (0.89–1.05)	0.419
IL-6	0.75 (0.57–1.00)	0.051	0.97 (0.83–1.14)	0.707
TNFα	1.12 (1.06–1.20)	<0.001	1.03 (0.98–1.07)	0.242
MPO	1.00 (1.00–1.00)	0.895	1.00 (1.00–1.00)	0.657
eSel	0.99 (0.97–1.00)	0.140	1.02 (1.00–1.03)	0.115

https://doi.org/10.1371/journal.pone.0208434.t004

second research question investigated if there was an association between the caregiving role, risk factors and chronic conditions amongst informal carers. Our findings indicate that when carers were compared with non-carers, they were more likely to have higher BMI and WHRs, report less than optimal physical activity and describe their health status as fair/ poor. In terms of chronic conditions carers were more likely to report diabetes, arthritis, anxiety and depression than non-carers. However stress-related conditions were not evident amongst carers in our study and they reported significantly lower or no alcohol consumption risk (p = 0.041). They were also less likely to be current smokers.

Vitamin D and other blood measured variables

Comparing the large number of haematological and biochemical variables of carers with non-carers in the NWAHS, yielded a few differences in blood pictures, for instance, levels of Vitamin D, Hb, HbA1c, TNFα and hs-CRP. Most of these results were within acceptable ranges, but of the five blood measured variables of interest, 25(OH)D (Vitamin D) was the most notable result showing that carers had lower median levels when compared with non-carers. Despite a large body of research on Vitamin D in the biomedical literature, of the studies collated, no comparable clinical research and population surveys could be identified reporting any association of Vitamin D with carer health outcomes in the context of informal caregiving. One previous project involving Stage 3 participants of the NWAHS, although not specific to carers, does provide an insight into Vitamin D and associated characteristics of that population [45]. Obesity (indicating higher BMI), physical activity, gender and seasonality all appeared to have a strong association with Vitamin D levels. For instance participants had lower Vitamin D levels even with seasonal variations during summer / spring months [45]. In our study based on participants from the same NWAHS population, carers had lower levels of Vitamin D in comparison to non-carers. This finding is important as Vitamin D can prevent conditions such as osteoporosis, particularly in post-menopausal women who represent up to half of all the female carers. Although osteoporosis was not significant amongst carers in our study, if carers were to develop osteoporosis related to low Vitamin D and nutritional deficiencies, they could be more at risk of injuries from frequently moving and lifting the persons being cared for [3]. Haemoglobin was found to be statistically different between the NWAHS carers and non-carers. Albumin, another blood measured variable, was lower amongst male carers who were more at risk of lower levels than non-carers (RR = 0.90, CI 95% 0.82–1.00; p = 0.040) however these levels were not of clinical significance. Again, of the studies reviewed in the literature, none specifically highlighted haemoglobin or albumin in carer populations. Several studies reported measuring haematological and serum chemistry in carers as part of larger projects but, found few notable differences between the full blood counts with non-carers, other than variables specific to their own studies [46,47].

Inflammatory biomarkers: TNFα and hs-CRP

In our study there were only slight statistically significant differences in blood measured inflammatory biomarkers amongst NWAHS carers aged 40 years and over. Namely, the immune regulatory cytokines hs-CRP and TNFα. These are acute phase markers of inflammation, especially hs-CRP which is used as a non-specific but very sensitive biomarker for detecting systemic inflammatory conditions, tissue damage and infection, as well as early onset cardiovascular disease [48]. Although inflammatory biomarkers are not as frequently assessed in biomedical studies of caregivers, previous studies have identified male carers as more vulnerable to physiological and pathological changes as predicted by the presence of hs-CRP [25,49,50]. Our NWAHS male carers had minimally raised plasma levels of inflammatory biomarkers TNFα and to a lesser extent, hs-CRP when compared to non-carer male but the cytokine IL-6 levels were much lower in male carers when compared with male non-carers (RR 0.75, 95% CI 0.75–1.00; p = 0.051) (See Table 4). Von Kanel et al (2012) had observed that being a carer did not necessarily show increased hs-CRP levels, but rather hs-CRP increased over time as the caregiving burden continued. The longer duration of caregiving with elevated biomarkers (TNFα and hs-CRP) suggested a pro-inflammatory state [25]. As we did not have equivalent carer details in our own study we were unable to examine biomarkers in terms of the duration of caring to make a comparison.

HbA1c, Type II diabetes and related chronic conditions

Blood measured HbA1c levels were inconsistent in our study. Glycated Haemoglobin (HbA1c) is a measure that provides information on long-term glucose control. HbA1c, is a recognised biomarker used to establish the prevalence or presence of Type 2 diabetes. Our findings showed significant but minimal differences in HbA1c blood levels in our sample of carers. However self-report data suggested carers were at greater risk of Type 2 diabetes than non-carers. This was a similar finding to a previous state-wide population survey also using self-report data from South Australian carers which we conducted between 2010–2015 [51]. Few published Australian population surveys that included carers have featured specific chronic conditions such as diabetes [20], while self-report health surveys conducted in Brazil, the USA and other countries have reported Type 2 diabetes in informal carers. In the biomedical literature there has been limited attention given to investigating diabetes-related characteristics in carers, and with the exception of one study [52], the emphasis has usually been on Type 2 diabetes in the person being cared for, rather than the carer.

Risk factors: Physical activity and BMI

Carers in our study were more likely to report insufficient activity or "no activity" than non-carers, but how participants interpreted the questions about their own physical activity may have been a factor in their responses. For example, carers might be physically active but have a different type and level of activity associated with demanding caregiving duties. Older carers in particular and those with their own disabilities may not be able to participate in recreational exercise or sport. This was partly investigated in a population based study which included community dwelling informal carers aged 40 years and over (n = 1380) from the German Ageing Survey [53]. They found decreased sporting activities and higher BMI amongst carers could lead to adverse health outcomes for carers. It was also concluded that time spent caregiving performing regular personal care activities and nursing care services for persons in a poor state of health could be associated with stress and depression, which can in turn be linked with higher BMI [53]. These results are in keeping with trends from our own research confirming higher BMI in carers [54].

Stress and anxiety

In the caregiving literature, parent carers, dementia and mental health carers have reported lower perceived health status [55,56]. NWAHS carers were also more likely to state their health was fair/poor. From a large British study of over 8000 middle aged men and women, carers rated their physical or mental health as fair/poor however it was further suggested that the rating of *poor* health could be 'proxy markers of perceived stress' [57]. Our findings from NWAHS carers overall did not specifically indicate carer-related stress which was unexpected, but anxiety and depression were two other aspects of psychological morbidity identified amongst our carers. Sherwood et al had found a significant association between anxiety in male carers of spouses with cancer and anxiety was seen as a risk factor for higher levels of inflammation in male carers [58].

Female carers when compared with female non-carers in our study had fewer significant risk factors or chronic conditions, but male carers presented quite a mixed biomedical profile when compared with non-carer males. The female carers in our study tended towards more metabolic and anthropometric manifestations that suggested a stronger association with BMI and adiposity. Kang et al however had found that while there was an association of metabolic dysfunction with family caregiving, no gender differences emerged from their large national study [59].

Strengths and limitations

The main strengths of this study are that both biomedical and self-report data were obtained from a large sample of metropolitan residents. It included a substantial number of blood tested and measured variables which were collected at clinics and during interviews. Clinically accessed information was a central part of this study which included a wide range of observed and measured variables for major risk factors, seven chronic conditions, inflammatory and other biomarkers. Carers in this study were more heterogeneous than recruited participants as they did not represent any one particular group of people living with specific disabilities or medical conditions. This type of large population study is usually cost prohibitive and requires the collaboration of a consortium of academic and government groups. It therefore offers a more comprehensive review of carer health characteristics than is usually possible.

There were limitations however in relation to the assessment of carer participants identified and grouped as a subset of this cohort study so they could be compared with the non-carers within the same population. The definition of *informal carer* chosen to identify carers was the standard used within Australia, however other carer specific questions were not included to further classify the type of caregiving. Within this study therefore we do not have details of the cared for person's age, diagnosis, health, disability or disease status, and their level of dependency, all of which have been reported as impacting on the role as informal carer. Nor was information collected on duration of caring—for example how long spent caring; how many hours per day or per week they were providing care and the level of intensity of their caring role. Further we do not have information on whether the participant was the main carer; if they were co-resident with the person being cared for; what other caregiving demands were put on the carers and which carers were combining personal caregiving with paid employment. Another weakness of this study is that we do not know which conditions reported by the carers, were pre-existing and therefore whether the risk factors and chronic conditions could be actual health outcomes of the caregiving experience. Also we do not know the severity of carers' illnesses and if they had multiple health problems as not all potential chronic conditions were included in this research. The lack of biomedical data on those aged less than 40 years is also a weakness of the study.

Conclusions and recommendations

Our study has demonstrated that in terms of blood and other clinic measured variables the NWAHS carers did show some differences in their biomedical health profiles when compared with non-carers. In contrast to other published studies our findings suggest carers may be at risk of lower Vitamin D and Hb levels thus revealing a possible gap in current knowledge of carer morbidity. It is acknowledged that the differences in other blood measured variables were minimal when compared with non-carers, but the significance of lower Hb, raised TNFα as well as hs-CRP in male carers highlights the need for ongoing assessments of their biomedical health status [60].

From a population perspective, urban carer participants' results indicated that there are carers providing care in less than optimum health, reporting chronic conditions of diabetes, arthritis, anxiety and to a lesser extent, depression. These cross-sectional analysis results provide only weak associations between the caregiving role, risk factors and chronic conditions. In contrast to previous studies, stress was not a significant finding. Higher BMI amongst carers generally, and particularly in female carers, combined with other risk factors such as insufficient physical activity, warrants closer scrutiny. Carers may have less opportunities to undertake physical activity, have less time outdoors and consequently less exposure to Vitamin D and less opportunity to maintain a healthy weight. Public health strategies targeting carers and addressing these factors may be worthy of consideration. Our research therefore recommends closer monitoring of carer health and morbidity trends across populations over time with special attention to the choice of health variables requiring ongoing measurement and assessment.

This would contribute to the development of more balanced health policies and clinical guidelines for chronic diseases that are carer specific and age sensitive. Policymakers and health professionals therefore need to take into account the differences in carer health status, risk factors and morbidities for male and female carers.

Acknowledgments

We wish to acknowledge all participants of the North West Adelaide Health Study.

Author Contributions

Conceptualization: Anne F. Stacey, Anne W. Taylor.

Formal analysis: Tiffany K. Gill.

Methodology: Tiffany K. Gill, Anne W. Taylor.

Project administration: Kay Price, Anne W. Taylor.

Supervision: Anne W. Taylor.

Writing – original draft: Anne F. Stacey.

Writing – review & editing: Anne F. Stacey, Kay Price, Anne W. Taylor.

References

1. Vitaliano PP, Schulz R, Kiecolt-Glaser J, Grant I. Research On Physiological And Physical Concomitants Of Caregiving: Where Do We Go From Here? Annals of Behavioural Medicine. 1997; 19(2):117–123.
2. Pinquart M, Sorensen S. Differences Between Caregivers and Non caregivers in Psychological Health and Physical Health: A Meta-Analysis. Psychology and Aging. 2003; 18(2):250–267. Accessed 30.08.2015 http://www.researchgate.net/publication/10691251. PMID: 12825775
3. Australian Institute of Health and Welfare 2010. Primary carers of people with arthritis and osteoporosis. Arthritis series no. 12. Cat. no. PHE 124. Canberra: AIHW.
4. Bevans M, Sternberg EM. Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients. Journal of the American Medical Association. 2012; 307(4):398–403. https://doi.org/10.1001/jama.2012.29 PMID: 22274687
5. van Ryn M, Sanders S, Kahn K, van Houtven C, Griffin JM, Martin M, et al. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? Psycho-Oncology. 2011; 20:44–52. https://doi.org/10.1002/pon.1703 PMID: 20201115
6. Hori Y, Hoshino J, Suzuki K. Physical and Psychological Health Problems Among Japanese Family Caregivers. Nagoya Journal of Medical Science. 2011; 73:107–115. PMID: 21928692.
7. Schulz R, Beach SR. Caregiving as a risk factor for mortality. The caregiver health effects study. Journal of the American Medical Association. 1999; 282(23):2215–2219. PMID: 10605972
8. Vitaliano PP, Young HM, Zhang J. Is Caregiving a Risk Factor for Illness? Current Directions in Psychological Science. 2004; 13(1):13–16.
9. Hirst M. Carer distress: A prospective, population-based study. Social Science and Medicine. 2005; 61:697–708. https://doi.org/10.1016/j.socscimed.2005.01.001 PMID: 15899327
10. Smith L, Onwumere J, Craig T, McManus S, Bebbington P, Kuipers E. Mental and physical illness in caregivers: results from an English national survey sample. British Journal of Psychiatry. 2014; 205:197–203. https://doi.org/10.1192/bjp.bp.112.125369 PMID: 25061119
11. Cooper C, Balamurali TBS, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. International Psychogeriatrics. 2007; 19(2):175–195. PMID: 17005068
12. Torres Á, Blanco V, Vázquez FL, Díaz O, Otero P, Hermida E. Prevalence of major depressive episodes in non-professional caregivers. Psychiatry Research. 2015; 226(1):333–9. https://doi.org/10.1016/j.psychres.2014.12.066 PMID: 25667119

13. Pinquart M, Sorensen S. Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. Journals of Gerontology, Series B, Psychological Sciences and Social Sciences. 2006; 61(1), P33–P45.
14. Legg L, Weir CJ, Langhorne P, Smith LN, Stott DJ. Is informal caregiving independently associated with poor health? A population-based study. Journal of Epidemiology and Community Health. 2013; 67:95–97. https://doi.org/10.1136/jech-2012-201652 PMID: 22875077
15. Verbakel E, Tamlagsrønning S, Winstone L, Fjær EL, Eikemo TA. Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. European Journal of Public Health. 2017; 27(suppl.1):90–95. https://doi.org/10.1093/eurpub/ckw229 PMID: 28355645
16. Sinha M. Portrait of Caregivers, 2012: Spotlight on Canadians: Results from the General Social Survey. 2012; Statistics Canada Catalogue no. 89-652-No. 001.
17. Health Quality Ontario. The Reality of Caring: Distress among the caregivers of home care patients. Toronto: Queen's Printer for Ontario; 2016. ISBN 978-1-4606-7761-2.
18. Australian Bureau of Statistics (ABS). Disability, Ageing and Carers, Australia. Summary of Findings, 2012. Australian Bureau of Statistics. Cat. no. 4430.0. Canberra.
19. Laks J, Goren A, Duenas H, Novick D, Kahle-Wrobleski K. Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. International Journal of Geriatric Psychiatry. 2016; 31:176–185. https://doi.org/10.1002/gps.4309 PMID: 26011093
20. Doran T, Drever F, Whitehead M. Health of young and elderly informal carers: analysis of UK census data. British Medical Journal. 2003; 327:1388. https://doi.org/10.1136/bmj.327.7428.1388 PMID: 14670886
21. Trivedi R, Beaver K, Bouldin ED, Eugenio E, Zeliadt SB, Nelson K, et al. Characteristics and well-being of informal caregivers: Results from a nationally-representative US survey. Chronic Illness. 2014; 10 (3):167–179. https://doi.org/10.1177/1742395313506947 PMID: 24154869
22. Neugaard B, Andresen E, McKune SL, Jamoom EW. Health-Related Quality of Life in a National Sample of Caregivers: Findings from the Behavioral Risk Factor Surveillance System. Journal of Happiness Studies. 2008; 9(4):559–575.
23. DeFries E, Bouldin ED, Andresen E. Caregiving Across the United Sates. Caregivers of Persons with Alzheimer's Disease or Dementia in Illinois, Louisiana, Ohio, and the District of Columbia. Data from the 2009 Behavioral Risk factor Surveillance System. Report 2009; Florida Office on Disability and Health, Department of Epidemiology and Biostatistics, College of Public Health and Health Professions, University of Florida. http://fodh.phhp.ufl.edu.
24. Lovell B, Wetherell MA. The cost of caregiving: endocrine and immune implications in elderly and non-elderly caregivers. Neuroscience and Biobehavioral Reviews. 2011; 35;1342–1352. https://doi.org/10.1016/j.neubiorev.2011.02.007 PMID: 21333674
25. von Kanel R, Mills PJ, Mausbach BT, Dimsdale JE, Patterson TL, Ziegler MG, et al. Effect of Alzheimer Caregiving on Circulating Levels of C-Reactive Protein and other biomarkers Relevant to Cardiovascular Disease Risk: A longitudinal Study. Gerontology. 2012; 58:354–356. https://doi.org/10.1159/000334219 PMID: 22133914
26. Kiecolt-Glaser JK, Preacher KJ, MacCallum RC, Atkinson C, Malarkey WB, Glaser R. Chronic Stress and age-related increases in the proinflammatory cytokine IL-6. Proceedings of the National Academy of Sciences of the United States of America. 2003; 100(15):9090–9095. https://doi.org/10.1073/pnas.1531903100 PMID: 12840146
27. Johnson TV, Abbasi A, Master VA. Systematic Review of the Evidence of a Relationship Between Chronic Psychosocial Stress and C-Reactive Protein. Molecular Diagnosis and Therapy, 2013; 17:147–164. https://doi.org/10.1007/s40291-013-0026-7 PMID: 23615944
28. Potier F, Degryse J-M, de Saint-Hubert M. Impact of caregiving for older people and pro-inflammatory biomarkers among caregivers: a systematic review. Aging Clinical and Experimental Research. 2017; https://doi.org/10.1007/s40520-017-0765-0 (Published online: 04 May 2017). PMID: 28474314
29. Allen AP, Curran EA, Duggan A, Cryan JF, Chorcoráin AN, Dinan TG, et al. Biological markers of chronic stress in informal caregivers for patients with dementia: a systematic review. PROSPERO 2015:CRD42015020828. http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42015020828.
30. Allen AP, Curran EA, Duggan A, Cryan JF, Chorcoráin AN, Dinan TG, et al. A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience and Biobehavioral Reviews. 2017; 73:123–164. https://doi.org/10.1016/j.neubiorev.2016.12.006 PMID: 27986469

31. Grant JF, Chittleborough CR, Taylor AW, Dal Grande E, Wilson DH, Phillips PJ, et al. North West Adelaide Health Study Team: The North West Adelaide Health Study: methodology and baseline segmentation of a cohort along a chronic disease continuum. Epidemiologic Perspectives & Innovations. 2006; 3:4.

32. Grant JF, Taylor AW, Ruffin RE, Wilson DH, Phillips PJ, Adams RJT et al. North West Adelaide Health Study Team: Cohort profile: The North West Adelaide Health Study. International Journal of Epidemiology. 2008; 1–8.

33. Australian Institute of Health and Welfare and National Heart Foundation. Risk factor prevalence study: Survey no 3. 1989. Canberra: AIHW.

34. Armstrong T, Bauman A, Davies J. Physical activity patterns of Australian adults. 2000. Australian Institute of Health and Welfare, Canberra.

35. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). Medical Care. 1992; 30(6):473–483. PMID: 1593914

36. National Heart Lung and Blood Institute Global Initiative for Asthma. National Institutes of Health, Bethesda (MD). 2003. Publication no. 02–3659.

37. Chronic Obstructive Pulmonary Disease. National clinical guideline on management of chronic obstructive pulmonary disease in adults in primary and secondary care. Thorax. 2004; 59(suppl 1):1–232.

38. Taylor AW, Dal Grande E, Gill TK, Chittleborough CR, Wilson DH, Adams RA, et al. How valid are self-reported height and weight? A comparison between CATI self-report and clinic measurements using a large representative cohort study. Australian and New Zealand Journal of Public Health. 2006; 30:238–46. PMID: 16800200

39. Taylor A, Dal Grande E, Gill T, Pickering S, Grant J, Adams R, et al. Comparing self-reported and measured high blood pressure and high cholesterol status using data from a large representative cohort study. Australian and New Zealand Journal of Public Health. 2010; 34:394–400. https://doi.org/10.1111/j.1753-6405.2010.00572.x PMID: 20649780

40. Gill T, Chittleborough C, Taylor A, Ruffin R, Wilson D, Phillips P. Body mass index, waist hip ratio, and waist circumference: which measure to classify obesity? Sozial-und Praventivmedizin. 2003; 48 (3):191–200. PMID: 12891871

41. WHO. Obesity: preventing and managing the global epidemic 2000 WHO Geneva Switzerland. http://www.who.int/nutrition/publications/obesity/WHO_TRS_894/en/.

42. Australasian Society for the Study of Obesity. Healthy Weight Australia: A National Obesity Strategy. Australasian Society for the Study of Obesity. 1995.

43. Australian Bureau of Statistics: Population by age and sex. South Australia Canberra: Australian Bureau of Statistics. 2000; 30 June 1999.

44. Australian Bureau of Statistics: Census of Population and Housing Selected Social and Housing Characteristics for Statistical Local Areas South Australia, 2001. In Australian Bureau of Statistics, Cat No. 2015.4 Canberra: Australian Bureau of Statistics; 2002.

45. Gill TK, Hill CL, Shanahan EM, Taylor AW, Appleton SL, Grant JF, et al. Vitamin D levels in an Australian population. BMC Public Health, 2014; 14:1001. https://doi.org/10.1186/1471-2458-14-1001 PMID: 25256413

46. Bauer ME, Vedhara K, Perks P, Wilcock GK, Lightman SL, Shanks N. Chronic stress in caregivers of dementia patients is associated with reduced lymphocyte sensitivity to glucocorticoids. Journal of Neuroimmunology. 2000; 103(1):84–92. https://doiorg/10.1016/SO165-5728(99)00228-3. PMID: 10674993

47. Torimoto-Sasai Y, Igarashi A, Wada T, Ogata Y, Yamamoto-Mitani N. Female family caregivers face a higher risk of hypertension and lowered estimated glomerular filtration rates: a cross sectional, comparative study. BMC Public Health. 2015; 15:177. https://doi.org/10.1186/s12889-015-1519-6 PMID: 25927998

48. Koenig W, Sund M, Fröhlich M, Fischer H-G, Löwel H, Döring A, et al. C-reactive protein, a sensitive marker of systemic inflammation, predicts future risk of coronary heart disease in initially healthy middle-aged men. Results from the MONICA-Augsburg cohort study 1984–92. Circulation. 1999; 99:237–242. PMID: 9892589

49. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler IC. A Path Model of Chronic Stress, the Metabolic Syndrome, and coronary Heart disease. Psychosomatic Medicine. 2002; 64:418–435. PMID: 12021416

50. Mills PJ, Ancoli-Israel S, vonKanel R, Mausbach BT, Aschbacher K, Patterson TL, Ziegler MG, et al. Effects of gender and dementia severity on Alzheimers Disease caregivers' sleep and biomarkers of coagulation and inflammation. Brain, Behaviour and Immunity. 2009; 23(5):605–610. https://doi.org/10.1016/j.bbi.2008.09.014 PMID: 18930805

51. Stacey AF, Gill TK, Price K, Taylor AW. Differences in risk factors and chronic conditions between informal (family) carers and non-carers using a population-based cross-sectional survey in South Australia. BMJ Open 2018; 8:e020173. https://doi.org/10.1136/bmjopen-2017-020173 PMID: 30037861

52. Lebrec J, Ascher-Svanum H, Chen YF, Reed C, Kahle-Wrobleski K, Hake AM, et al. Effect of diabetes on caregiver burden in an observational study of individuals with Alzheimer's disease. BMC Geriatrics. 2013; 16(1):93. https://doi.org/10.1186/s12877-016-0264-8 PMID: 27142529

53. Hajek A, Bock J-O, König H-H. Association of informal caregiving with body mass index and frequency of sporting activities: evidence of a population-based study in Germany. BMC Public Health. 2017; 17:755. https://doi.org/10.1186/s12889-017-4786-6 PMID: 28962607

54. Finucane MM, Stevens GA, Cowan MJ, Danaei G, Lin JK, Paciorek CJ, et al. (2011). National, regional, and global trends in body-mass index since 1980: Systematic analysis of health examination surveys and epidemiological studies with 960 country-years and 9.1 million participants. Lancet; 377;557–567. https://doi.org/10.1016/S0140-6736(10)62037-5 PMID: 21295846

55. Gupta S, Isherwood G, Jones K, Van Impre K. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. BMC Psychiatry. 2015; 27(3):292–297. https://doi.org/10.1186/s12888-015-0547-1 PMID: 26194890

56. Ho SC, Chan A, Woo J, Chong P, Sham A. Impact of Caregiving on Health and Quality of Life: A Comparative Population-Based Study of Caregivers for Elderly Persons and Noncaregivers. Journal of Gerontology: Medical Sciences. 2009; 64A(8): 873–879. https://doi.org/10.1093/gerona/glp034 PMID: 19351695

57. Buyck JF, Ankri J, Dugravot A, Bonnaud S, Nabi H, Kivimäki M, et al. Informal Caregiving and the risk for Coronary Heart Disease: The Whitehall II Study. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences. 2013; 68(10):1316–1323. https://doi.org/10.1093/gerona/glt025 PMID: 23525476

58. Sherwood PR, Price TJ, Weimer J, Ren D, Donovan HS, Given CW, et al. Neuro-oncology family caregivers are at risk for systemic inflammation. Journal of Neuro-Oncology. 2016; 128:109–118. https://doi.org/10.1007/s11060-016-2083-3 PMID: 26907491

59. Kang SW, Marks NF. Filial caregiving is associated with greater neuroendocrine dysfunction: Evidence from the 2005 National Survey of Midlife in the United States. SAGE Open Medicine. 2014; 2:2050312113520152. https://doi.org/10.1177/2050312113520152 PMID: 25309742

60. Baker KL, Robertson N. Coping with caring for someone with dementia: Reviewing the literature about men. Aging & Mental Health. 2008; 12(4): 413–422. https://doi.org/10.1080/13607860802224250 PMID: 18791888