

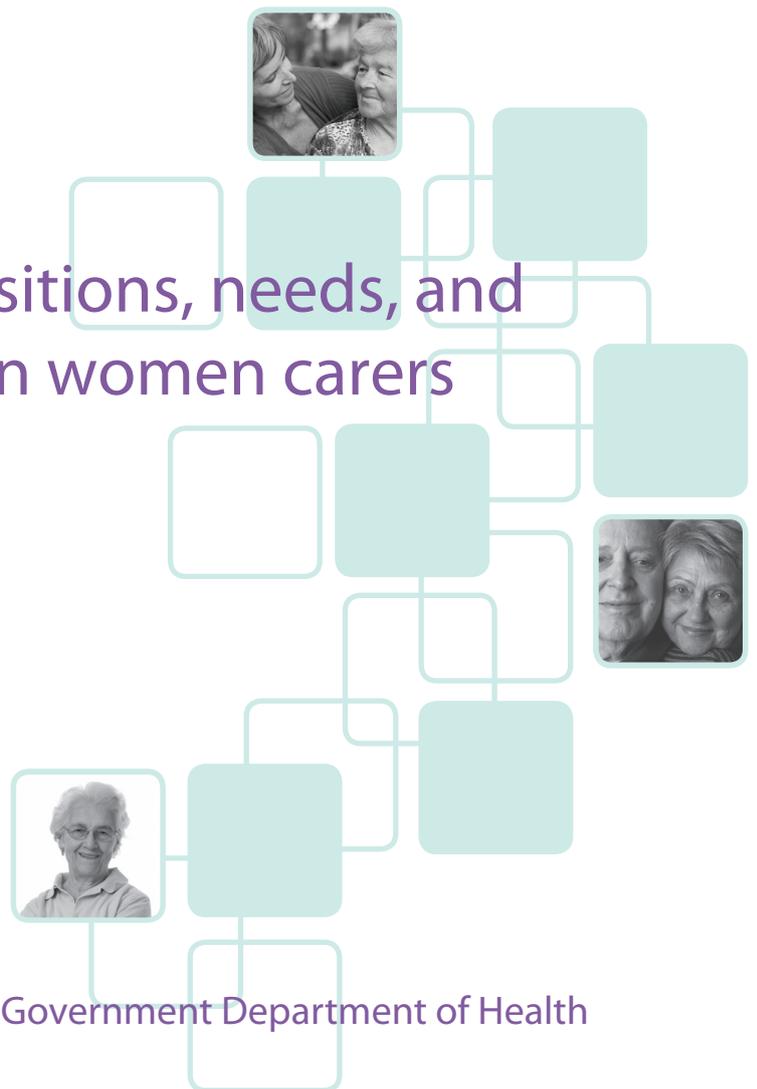
women's health *a u s t r a l i a*



the australian longitudinal
study on women's health

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Carrying the load: Transitions, needs, and service use of Australian women carers



Stage 2 Project Report for the Australian Government Department of Health
and Ageing Carers Project

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Summary of findings for Stage 2

The Research on Caring Stage 2 investigated the transitions into and out of caring, carer needs, and use of interventions and services for women born between 1946 and 1951, and 1921 and 1926. Stage 2 involved three phases of research each with its own methodology and participant sample.

Phase 1

The first report (Phase 1) examined caring and use of services in women born between 1946 and 1951 (McKenzie et al. 2009a). The study was a pilot substudy of the Australian Longitudinal Study on Women's Health (ALSWH) and included 296 women (97 carers, 199 noncarers) that participated in pilot surveys for the 1946-1951 cohort. We found that while carers were similar to noncarers on most demographic characteristics (age, marital status, residence, language spoken at home and level of education), they were less likely to be in the workforce than noncarers. Carers also had poorer mental health and less social support than noncarers. The detailed report also showed that carers were not a homogenous group. Women who were live-in carers reported higher carer strain and were more likely to be the main care provider, have been caring for a longer time, care for younger recipients (who were typically their husbands/ partners), perform more activities of daily living (particularly the more intensive activities of daily living) and work part-time, if in the labour force. However, carers who did not live with their care recipient were more likely to care for older recipients (who were typically their parents), perform only instrumental activities of daily living and work full-time, if in the labour force.

Phase 2

The second report (Phase 2) examined caring and use of services in women carers born between 1921 and 1926 (McKenzie et al. 2009b). The study was a nested cross-sectional substudy of the ALSWH, involving data from 280 carers who cared for someone who may have used community services. The detailed report showed that carers had poorer mental and physical health compared to the entire 1921-1926 cohort of the ALSWH. The carers who completed the survey provided the majority of the help for the care recipients compared to other unpaid carers or paid services. Use of services was low. However, when the services were used, the carers reported that they were easy to access, they were of a good quality, and that they received as much as they wanted. The use of services, particularly respite care, was strongly driven by care recipient preference. The most common themes of the positive aspects of caring were 'characteristics of the relationship between the carer and care recipient,' such as companionship, and 'personal concerns or attitudes of the carers,' such as the carers' outlook on life and an appreciation for what they do have. The most discussed theme for the negative aspects of caring was 'practicalities of the situation' which included restrictions on everyday life and dissatisfaction with the present situation and repetitious routine.

Phase 3

The third report (Phase 3) described exploratory and longitudinal analysis of data from Surveys 2, 3, 4, and 5 of the 1921-1926 cohort of the ALSWH to examine carer needs and transitions (McKenzie et al. 2009c). Of the women who responded, 60% of them did not provide care at any survey from Survey 2 (1999) to Survey 5 (2008). The remaining women included those who provided care at all four surveys (2%) and women who provided care at some point across the four surveys (38%). Therefore, of the women who provided care at some point during the surveys, the majority (95%) transitioned into or out of their caring roles. The effect of ten factors (including transition groups, time of survey and sociodemographic and health factors), on seven health and community service outcomes (mental health, physical health, number of visits to the general practitioner (GP) and use of nursing or community health services, respite services, homemaking services and home maintenance services) was investigated. Women who never provided care typically had better outcomes compared to carers who lived with their care recipients but worse outcomes compared to carers who lived elsewhere. Generally, women who used the services or had poorer health outcomes transitioned into or out of providing care for a care recipient who lived with them and women who had better mental health were more likely to have transitioned into or out of providing care for a care recipient who lived elsewhere. The combination of factors that was related to poorer health, visiting the GP five or more times and use of services, is:

- Transitioning into or out of providing care for a live-in care recipient,
- Reporting difficulties managing on available income,
- Not providing care for grandchildren,
- Needing care themselves,
- Reporting sleep difficulties, and
- More memory decline.

Conclusions of Stage 2

While carers may have willingly entered into a caring relationship, their lives were still impacted by their caring role and they had poorer mental health and less social support than noncarers. The reports of Stage 2 also highlighted the importance of knowing if the carer lived with the care recipient: women who provided care for recipients who lived with them had poorer health outcomes and were more burdened than women who provided care for someone who lived elsewhere.

Carers across all three phases reported minimal financial difficulties. However, women of the 1921-1926 cohort who did report financial difficulties were at risk of poorer outcomes. In addition, older women who were carers were at risk of poorer outcomes if they also did not provide care for grandchildren, needed care themselves, and reported sleep difficulties and memory decline. Therefore, while service use was generally low, carers of the 1921-1926 cohort who were using the services were more likely to have that combination of risk factors. Women with these characteristics would be potential candidates for appropriate policies and services. Furthermore, care recipient preferences associated with using services may have hindered women from using them. Improving acceptability of services for older care recipients may improve the use of services.

Carers' satisfaction with their social support may provide a buffer to their strain and burden. The good aspects of caring that were highlighted in Phase 2, such as companionship and an appreciation for what they do have, may have also moderated the

burden and strain of caring. Further investigation is needed to determine the causality of these relationships.

Caring is transient in women born between 1921 and 1926. The majority of these women who were carers at some point across the four surveys from 1999 to 2008 did not provide care at all surveys. Instead, most women transitioned into or out of providing care. This has policy implications for timely services.

Possible policy implications

- Policies need to recognise that carers and their situations are different and may change over time.
- Due to the transient nature of caring, services should be provided in a timely manner.
- Results indicate that carers who provided care for a care recipient who lived with them, or transitioned into or out of this live-in caring role, had poorer health outcomes than carers who lived elsewhere. Policies should consider the particular needs of carers who live with the person for whom they care. As these carers may experience difficulty leaving their care recipient at home, adequate respite services to allow carers to visit health services, or in-home health visits, may be necessary to ensure adequate access to services.
- In particular, older women who are carers are at risk of poorer outcomes if they also have difficulties managing on their available income, do not provide care for grandchildren, need care themselves, and report sleep difficulties and memory decline. This finding emphasises the importance of adequate financial provision and health services for carers.
- Care recipient preference strongly drove the use of services, particularly respite care. Therefore, services should aim to improve acceptability and use of services by older care recipients.
- Framing the needs of the carer(s) and care recipient as a system where each affects the other may assist health services to provide for the needs of both in an efficient manner.
- Carers who were provided with services through the Department of Veterans' Affairs commended them highly. Other non-veterans service providers may be able to model their service delivery and availability after the Department of Veterans' Affairs.

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Chapter 1 Background

1.1 Introduction

This project report provides a summary of findings from the Research on Caring Stage 2. In Stage 2, the Ageing and Aged Care Division of the Department of Health and Ageing contracted researchers in the ALSWH team at the University of Queensland to provide further detailed analyses of caring by women born between 1946 and 1951, and 1921 and 1926, in three phases of research. The research investigated transitions into and out of caring, carer needs, and use of interventions and services.

This final report presents an overview of the ALSWH from which the research was based, the methodology and findings from each of the three phases of Stage 2 and patterns that are present across the three phases. In addition, at the request of the Department, comparisons are made to other data from the ALSWH and the Department's 2008 Community Care Census. The representativeness and generalizability of the results of Stage 2 are discussed and possible policy implications of these are presented.

1.2 Overview of the Australian Longitudinal Study on Women's Health

The ALSWH explores social, behavioural, and economic factors and their relationship to health outcomes and use of health and related services. In addition, the study investigates how these factors influence lifestyle choices around family and workforce participation at key points in women's lives. The ALSWH advances understanding of the factors that enhance or inhibit good health in women.

In 1994, the Australian Government Department of Health and Ageing awarded the contract to a team of researchers based at the Universities of Newcastle and Queensland to design and conduct the study. The ALSWH began in 1995 and it is projected to run for at least 20 years. It provides information on trends in areas such as healthy ageing, chronic conditions, partner violence, health service use, weight, physical activity, alcohol consumption, tobacco and other drugs, mental health, paid work, and planning for retirement, on women in metropolitan, rural, and remote areas of Australia. The ALSWH also collects information about caring for family members or friends. Linkage with the Medicare and Pharmaceutical Benefits Scheme datasets provides additional information on the health service use of women.

In 1995, the ALSWH commenced and recruited over 40,000 Australian women. The women were randomly selected from the Australian Medicare database with intentional oversampling of rural and remote areas. The Medicare database includes all permanent residents and citizens. There are approximately 12,000 women in each of three age cohorts: women born between 1973 and 1978 who are aged 31-36 years in 2009; women born between 1946 and 1951 who are aged 58-63 years in 2009; and women born between 1921 and 1926 who are aged 83-88 years in 2009.

In 2008, the ALSWH Steering Committee adopted a new naming convention for the three cohorts of women to better reflect the generations that are represented. The new names for cohorts (and the names replaced) are:

- 1921-1926 cohort (older cohort),
- 1946-1951 cohort (mid-aged cohort), and
- 1973-1978 cohort (younger cohort).

Each cohort has a similarly aged pilot study group of women, not included in the main sample, who pilot test the main survey. Each cohort group is surveyed every three years and substudies may be conducted each year for the two groups not involved in a main survey. There are now 14 years of data available. The women born between 1973 and 1978 are being surveyed in 2009 for the fifth time.

1.3 Research on Caring Stage 1

In 2006 and 2007 researchers in the ALSWH team at the University of Queensland were contracted by the Department of Health and Ageing to provide detailed analyses of caring by women born between 1946 and 1951, with particular emphasis on the impact of employment and other life roles and to develop and pilot a substudy focusing on support needed for mid-aged women who provide care for someone who is frail or disabled. This research is referred to as Stage 1. The results of Stage 1 were delivered in three reports:

- Report 1: Preliminary report. Employed carers in mid-life: Findings from the Australian Longitudinal Study on Women's Health (Lucke et al. 2006),
- Report 2: Detailed report. Changes in caring roles and employment in mid-life: Findings of the Australian Longitudinal Study on Women's Health (Berecki et al. 2007), and
- Report 3: Pilot study report. Service use and the impact of family caregiving on Mid-aged women from the Australian Longitudinal Study on Women's Health (Watson, Lucke & Dobson 2007).

1.4 Research on Caring Stage 2

In 2008 researchers in the ALSWH team at the University of Queensland, were contracted by the Ageing and Aged Care Division of the Department of Health and Ageing to provide further detailed analyses of caring by women born between 1946 and 1951, and 1921 and 1926. These analyses were to examine the influence of factors such as where carers lived (both in relation to the care recipient and in terms of area of residence) and care recipient needs (such as functional dependency levels) and the frequency and amount of care. The research was to provide evidence to address the following questions:

1. Transitions:
 - a. What are the transitions into and out of caring over the lifespan?
 - b. What factors contribute to deciding to care for a family member or friend?

- c. How do women manage the transition to caring, particularly in relation to labour force participation?
- d. What factors contribute to the decision to decrease working?
2. Carer needs:
 - a. What is the broad impact of caring on women's lives?
 - b. What needs, unmet or under met, can be identified for carers?
3. Interventions / services:
 - a. What types of interventions / services do carers use?
 - b. What patterns of health or community service use are demonstrated?
 - c. What information can be provided on access, information, and perception of services that carers use?
 - d. What interventions / services lessen the impact of caring?
 - e. What interventions / services are effective?
 - f. What carer support strategies and interventions assist or could assist employed carers?
 - g. What type / dose / timing of respite interventions are effective in maintaining a caring relationship for the different carer types and settings?

The results of Stage 2 were delivered in three reports:

- Phase 1. Detailed report. Caring and use of services in women born between 1946 and 1951: Findings from the Australian Longitudinal Study on Women's Health (McKenzie et al. 2009a),
- Phase 2: Detailed report. Caring for carers: Caring and use of services in women carers born between 1921 and 1926 (McKenzie et al. 2009b), and
- Phase 3: Detailed report. Transitions into and out of caring and their effects on health and use of community services in women born between 1921 and 1926 (McKenzie et al. 2009c).

1.5 Methods and data collection for Stage 2

Each phase of research for Stage 2 had its own methodology and participant sample. These methodologies are presented in the following three sections. A discussion of the generalizability of the results from the three phases is presented in the *Data limitations, representativeness, and generalizability* section.

1.5.1 Methodology of Phase 1. Caring and use of services in women born between 1946 and 1951: Findings from the Australian Longitudinal Study on Women's Health

Every three years, the pilot group of women test the main ALSWH surveys for the 1946-1951 cohort. These 1946-1951 pilot women are a convenience sample of women that predominantly live in the Wollongong and Bathurst areas and they are not included in the main 1946-1951 cohort. In 2007, researchers in the ALSWH team at the University of

Queensland conducted a cross-sectional¹ pilot substudy of the 355 women in the 1946-1951 pilot group. The substudy of Phase 1 was originally designed to pilot test the survey procedure and instruments before administration to the full 1946-1951 cohort.

The substudy was conducted as a postal survey and data were collected over three months. The survey consisted of two sections. The first section contained 42 questions that applied to all participants and asked about their general health, wellbeing, and access to services. The second section contained 22 questions and was only relevant to women who were currently providing care to someone with a long-term illness, disability, or frailty. The second section asked about caring activities and access to services for the care recipient. If a participant cared for more than one person, the participant completed the survey for the person she had cared for the longest. Of the 355 women invited to participate, 296 participated (an 83.4% response rate). Of these, 97 were carers and 199 were noncarers. While the small sample was intended to pilot the survey and measures for a larger study with the full 1946-1951 cohort, it was still worthwhile analysing the data for the pilot women.

The main surveys of the ALSWH have all been approved by the University of Newcastle Ethics Committee (Approval number: H-076-0795) and University of Queensland Medical Research Ethics Committee (Approval number: 200400224). The Phase 1 pilot substudy was covered under the main ethics approval number for the University of Queensland Medical Research Ethics Committee, but the University of Newcastle Ethics Committee provided separate ethical clearance for this project (Approval number: H-421-0407).

The results of Phase 1 are presented in detail in the Phase 1 report (McKenzie et al. 2009a) and are summarised in Section 2.1 of this report.

1.5.2 Methodology of Phase 2. Caring for carers: Caring and use of services in women carers born between 1921 and 1926

Phase 2 was a nested cross-sectional substudy² of the ALSWH. Participants were selected based on their responses to Survey 3 of the 1921-1926 cohort (2002). The intention of the original project was to select women who cared for recipients with neurodegenerative disorders. However, to obtain an adequate sample size for statistical analysis, all women who indicated that they were providing care for someone living with them, either from a specific survey item or in-text responses, and who had not been selected for other ALSWH substudies, were invited to participate (n=674, aged 78-83 years).

The women were sent a written invitation and the survey. Overall, 201 (29.8%) of the women invited to participate reported being ineligible (i.e. they did not or no longer provided care), 86 (12.8%) did not want to participate, no response was received from 78 (11.6%), 3 had died and 306 (45.4%) returned surveys, of which one was not complete.

Of the 305 returned completed surveys, 276 (91%) were from carers who lived with their care recipients, 4 (1%) were from carers who lived elsewhere and 25 (8%) were from

¹ In a cross-sectional study design, participants are sampled at just one point in time.

² A nested study design is one in which the study's participants are selected from participants of another study. In a cross-sectional study design, participants are sampled at just one point in time. Therefore, in Phase 2, the carers were selected from the 1921-1926 cohort and completed the survey just one time.

carers whose recipients lived in care facilities. Women who cared for someone living in a care facility were excluded from analysis because access to health and community services was not relevant to nursing home participants in the same way as for those living in the community. Therefore, there were data available from 280 women who cared for someone who may have used community services.

Those who did not respond initially were contacted by phone and encouraged to complete the survey if they were eligible. Those unwilling to complete the postal survey were offered the option of completing it over the phone. This only occurred for 5 of the 280 (1.8%) women.

The survey consisted of 53 closed-response questions (some with open-ended components) and 5 open-ended questions. Both the statistical analyses of the quantitative data (from the closed-response questions) and summaries of the text of the open-ended questions were presented in the Phase 2 report (McKenzie et al. 2009b). The survey was constructed in 14-point font and was written at a grade seven to eight reading level, consistent with the educational levels of Australian women now in their 70s and 80s. The survey content was informed by focus groups and pilot tested.

The Phase 2 substudy was approved by the University of Queensland Medical Research Ethics Committee (Approval number: 2003000293) and the University of Newcastle Ethics Committee (Approval number: H-548-0303).

The results of Phase 2 are presented in detail in the Phase 2 report (McKenzie et al. 2009b) and are summarised in Section 2.2 of this report.

1.5.3 Methodology of Phase 3. Transitions into and out of caring and their effects on health and use of community services in women born between 1921 and 1926

Sample

Phase 3 involved analysis of data from the 1921-1926 cohort of the ALSWH. The data were collected according to standard ALSWH procedures, which have been fully described elsewhere (Brown et al. 1998; Lee et al. 2005). ALSWH data collection was approved by the University of Queensland Medical Research Ethics Committee (Approval number: 2004000224) and the University of Newcastle Ethics Committee (Approval number: H-076-0795).

Surveys 2, 3, 4, and 5 were conducted in 1999, 2002, 2005, and 2008, respectively. These four surveys were examined because the question about providing care was asked consistently across these surveys and it provided information about where the carer lived relative to the care recipient. In Surveys 2-5, participants were asked about providing care in the following question: "Do you regularly provide care or assistance (eg personal care, transport) to any other person because of their long-term illness, disability, or frailty? (*Mark all that apply*)". The response options were 'yes, for someone who lives with me', 'yes, for someone who lives elsewhere', and 'no, I do not provide care'. Previous reports from both Stage 1 and Stage 2 have highlighted the importance of knowing if the carer lived with the care recipient. Therefore, Survey 1 was not examined because the question about caring only included the response options 'yes' or 'no' which meant that the data could not be combined with data from other surveys to examine transitions into and out of caring over time.

Therefore, in the Phase 3 report, carers were classified into three caring status groups at each survey for Surveys 2, 3, 4, and 5:

- Not: Women who did not provide care
- With: Women who cared for a care recipient who lived with them
- Elsewhere: Women who cared for a care recipient who lived elsewhere.

Transitions

To examine the transitions into and out of caring across Surveys 2, 3, 4, and 5, transition groups were created. First, women whose caring status did not change across the four surveys were categorized into three groups:

- Always With carers: Women who provided live-in care for a care recipient who lived with them at all four surveys
- Always Elsewhere carers: Women who provided care for a care recipient who lived elsewhere at all four surveys
- Never Carers: Women who did not provide care at any of the four surveys.

The remaining women transitioned into and out of caring at some point across the surveys. Therefore, for these women, transition groups were created for each consecutive pair of surveys: Surveys 2-3, Surveys 3-4, Surveys 4-5. For instance, transitions groups for Survey 3 were determined by combining the caring status groups (Not, With, or Elsewhere as described previously) at Survey 2 and Survey 3. Therefore, for example, participants who were not providing care (Not) at Survey 2 and provided live-in care (With) at Survey 3 were classified in the Not-With transition group for Survey 3.

These paired combinations resulted in nine further groups, which were classified under five categories:

Not caring

- Not-Not: Women who did not provide care at both time points

Started caring

- Not-With: Women who started providing live-in care for a care recipient who lived with them
- Not-Elsewhere: Women who started providing care for a care recipient who lived elsewhere

Stopped caring

- With-Not: Women who stopped providing live-in care for a care recipient who lived with them
- Elsewhere-Not: Women who stopped providing care for a care recipient who lived elsewhere

Changed caring

- With-Elsewhere: Women who provided care at both time points, but the carer lived with a care recipient at the first time point and lived elsewhere at the second time point

- Elsewhere-With: Women who provided care at both time points, but the carer lived elsewhere from a care recipient at the first time point and lived with a care recipient at the second time point

Stayed caring

- With-With: Women who provided live-in care for a care recipient who lived with them at both time points
- Elsewhere-Elsewhere: Women who provided care for a care recipient who lived elsewhere at both time points.

Transitions groups were created for Survey 3 (using caring status groups at Surveys 2 and 3), Survey 4 (using caring status groups at Surveys 3 and 4), and Survey 5 (using caring status groups at Surveys 4 and 5). Caring transitions groups could not be created for Survey 2 because the caring question in Survey 1 did not provide information on where the carer lived relative to the care recipient. For a more detailed description of the 12 transition groups, please see the Phase 3 report (McKenzie et al. 2009c).

These 12 transition groups were the main factor explored in the analysis of health and use of community services, i.e., whether there was any association between these different types of care groups, and transitions between them, and health and use of community services. In addition to transition groups, exploratory analysis was used to explore the data to determine other factors that may affect health and use of community services.

Analysis

Exploratory analysis³ was used to determine the variables that had the most important and meaningful relationships with caring. The data were explored by observing patterns in frequencies or median and quartile values across the surveys and eight relevant factors were identified: education, country of birth, area of residence, ability to manage on available income, caring for grandchildren, need for care, sleep difficulty, and memory decline.

The data were then analysed using complex longitudinal analyses⁴ (called “mixed models”) to examine both the effect of the transition groups and the eight relevant factors on health and use of community services across time (Surveys 3, 4, and 5). The health and community services outcomes included mental health, physical health, number of visits to the GP, and use of nursing or community health services, respite services, homemaking services, and home maintenance services.

The results of Phase 3 are presented in detail in the Phase 3 report (McKenzie et al. 2009c) and are summarised in Section 2.3 of this report.

³ Exploratory analysis is a technique in which the data are examined by summarising them in more basic terms, such as means, medians, or frequencies, to gain insight about a set of data.

⁴ The analyses were *longitudinal* because data for the relevant factors were examined *over time* at more than one time (at Surveys 3, 4, and 5). Therefore, the variable ‘time’ (categorized as Surveys 3, 4, and 5) was analysed as a factor in these analyses.

Chapter 2 Summary of findings from each Stage 2 phase

The summary of findings from each phase of Stage 2 is presented in this chapter.

2.1 Phase 1. Caring and use of services in women born between 1946 and 1951: Findings from the Australian Longitudinal Study on Women's Health

2.1.1 Context

Phase 1 examined the transitions into and out of caring, carer needs, and the use of interventions and services by carers and their care recipients (McKenzie et al. 2009a). The study was a pilot substudy of the ALSWH and included 296 women of the 355 pilot women that participated in pilot surveys for the 1946-1951 cohort (an 83.4% response rate). Of the participants, 199 were noncarers and 97 were carers. All participants were asked about their general health, wellbeing, and access to services in the first section of the survey. The second section was relevant only to women who were currently providing care for someone with a long-term illness, disability, or frailty, and asked about caring activities and access to services for the care recipient.

2.1.2 Caring by women

- The mean age of the women was 60 years. Most of the women were married, spoke English at home, and lived in rural areas (62%), particularly Bathurst, or other metropolitan areas (30%), particularly Wollongong.
- Carers were similar to noncarers on demographic characteristics, including age, marital status, residence, language spoken at home, and level of education.
- However, noncarers were more likely to be in the workforce than carers.
- The intensity of caring duties was summarised in a care index that was created by combining answers to questions on the frequency of caring and the amount of care provided at each occasion, with a high care index indicating more intense caring duties. Please see the Appendix for more detailed information on this index.
- Women who were live-in carers, compared to carers who lived elsewhere, were more likely to have a high care index, have been caring for longer, be the main care provider, care for younger recipients (who were typically their husbands / partners), and perform more activities of daily living, particularly basic activities of daily living.
- Carers who lived elsewhere, compared to live-in carers, were more likely to have a medium care index, care for older recipients (who were typically their parents), and their recipients were more likely to use paid services.

2.1.3 Transitions in caring

- Most carers wanted to provide care and started caring gradually.
- On average, the care index remained stable over the previous four years, indicating that the intensity of care was steady.

- On average, involvement in employment decreased over the previous four years.
- Carers with a high and medium care index were least likely to work full-time and most likely to not be in the labour force.
- Live-in carers were more likely to have part-time employment while carers who lived elsewhere were more likely to have full-time employment.

2.1.4 Carer needs and impact of caring

- Carers had poorer mental health and less social support than noncarers.
- Live-in carers, who were likely to have a high care index, were more strained, and were more likely to report that their lives were worse from caring than carers who lived elsewhere.
- Carers showed no evident financial stress according to the Australian Bureau of Statistics financial stress indicators.
- Written comments indicated that more support for care at home, or closer to home, were needs that were not being met.

2.1.5 Interventions and services used, and needed, by women carers

- Service use by carers was low.
- Care recipients used services more than carers did.
- The most highly used services were home maintenance (e.g. odd jobs, gardening) and counselling. Carers who used these services had higher carer strain and poorer mental health than carers who did not use those services.
- Carers who lived elsewhere were more likely to use paid services than live-in carers. Carers who lived elsewhere and used at least one paid service were more strained than carers who lived elsewhere and did not use paid services.
- These results may indicate that using services was not lessening the impact of caring or it may be that carers who were strained were more likely to use services. Further investigation is required to determine the causality of these associations.

2.2 Phase 2. Caring for carers: Caring and use of services in women carers born between 1921 and 1926

2.2.1 Context

Phase 2 was a nested cross-sectional substudy of the ALSWH, involving data from 280 carers who cared for someone who may have used community services. The survey consisted of 53 closed-response questions (some with open-ended components) and 5 open-ended questions. Both the statistical analyses of the quantitative data (from the closed-response questions) and summaries of the text of the open-ended questions are presented in detail in the Phase 2 report (McKenzie et al. 2009b).

2.2.2 Caring by women

- The mean age of the carers was 78 years. Most carers were married, lived in a major city or inner regional area, spoke English at home, had a school or intermediate certificate, and were not having difficulties managing on their income.
- The demographic profile of the carers in the Phase 2 substudy was similar to that of the 1921-1926 cohort from the ALSWH, except that more women were married

in the substudy. This difference was due to most of the older carers in the substudy caring for their husbands. The substudy's carers also had poorer mental and physical health compared to the entire 1921-1926 cohort.

- The Care Activity Index (CAI) classified the 280 carers into three equal groups (lower, middle, higher) according to the level of activities, from the nine activities of daily living in the survey, that they performed for their care recipients. The higher CAI category indicated more frequent caring for more activities. Please see the Appendix for more detailed information on this index.
- The age of the care recipients (mean=83.0 years) was similar across CAI groups.

2.2.3 Carer needs and impact of caring

- In general, carers perceived their lives to be worse due to caring and carers with a higher CAI were most affected.
- The Caregiver Strain Index measured carer strain. Carer strain was related to CAI group: carers with a higher CAI were more likely to be strained than were carers with a lower or middle CAI.
- Developmental burden, as measured by the Caregiver Burden Inventory, describes carers' feelings of being 'out of sync' in their development with respect to their peers. In the substudy, developmental burden was related to CAI group: carers with a higher CAI were more likely to be burdened than were carers with a lower or middle CAI.
- Carers were satisfied with their social support network.
- The carers reported that their needs and those of the people they cared for were generally being met.
- The carers who completed the survey provided the majority of the help for the care recipients compared to other unpaid carers or paid services.

2.2.4 Interventions and services used, and needed, by women carers

- The use of Meals on Wheels, personal home care, domestic home care, and respite care was low. However, when the services were used, the carers reported that they were easy to access, they were of a good quality, and that they received as much as they wanted.
- Personal home care had the highest proportion of carers reporting that they received the service less often than they wanted, followed by domestic home care and respite care in descending order. No carers reported that they received Meals on Wheels less often than wanted. Conversely, out of the four services, Meals on Wheels stood out as the service that had the most carers reporting they received it more frequently than wanted.
- The most difficult health service to access for care recipients was 'house calls by the doctor.'
- Nearly half of the carers wrote that no groups or government services had provided significant support to them as carers.
- Carers whose recipients received health services through the Department of Veterans' Affairs commended their helpfulness and availability of services.
- The survey data informed the possible relationship between use of the four highlighted services and the impact of caring. However, further investigation is required to determine the causality of the associations between use of these services and impact on caring.

- The use of respite care was strongly driven by care recipient preference.
- The most common themes of the positive aspects of caring in the written section were 'characteristics of the relationship between the carer and care recipient' and 'personal concerns or attitudes of the carer.' 'Characteristics of the relationship' included companionship, longevity of marriage and reciprocity within the relationship. 'Personal concerns or attitudes of the carer' referred to the carers' outlook on life, providing care, coping, and religious beliefs.
- The most discussed theme for the negative aspects of caring in the written section was 'practicalities of the caring situation.' 'Practicalities' covered an extensive range of topics including restrictions on everyday life, lack of holidays and travel, and dissatisfaction with the present situation and repetitious routine.

2.3 Phase 3. Transitions into and out of caring and their effects on health and use of community services in women born between 1921 and 1926

2.3.1 Context

Phase 3 examined the transitions into and out of caring among 12,432 women from the 1921-1926 cohort of the ALSWH. It also examined carers' needs for health services. The report described exploratory and longitudinal analysis of data from Surveys 2, 3, 4, and 5. These surveys were examined because the question about providing care was asked consistently across them and it provided information about where the carer lived relative to the care recipient. Survey 1 data were not included in the analysis, as it was not possible to determine whether the carer was living with the care recipient.

2.3.2 Transitions in caring

Women were classified into transition groups according to the pattern of their caring across Surveys 2-5. Three groups included women whose caring roles remained the same. These were carers who consistently cared for someone who lived with them, carers who consistently cared for someone who lived elsewhere, and women who consistently did not provide care for anyone across Surveys 2-5.

There were nine further groups created from the participants' caring status between consecutive surveys for those participants who had caring transitions. These nine groups fell under five broad categories of not providing care, started to provide care, stopped providing care, changed where they lived relative to their care recipient (changed caring), and stayed providing care in the same living relationship to their care recipient.

Of the women who responded, 60% of them did not provide care at any survey from Survey 2 (1999) to Survey 5 (2008). The remaining women included those who provided care at all four surveys (2%) and women who provided care at some point across the four surveys (38%). Therefore, of the women who provided care at some point during the surveys, the majority (95%) transitioned into or out of their caring roles.

The 12 groups (three groups whose roles stayed the same and nine groups who had caring transitions) were the main factor explored in the analysis of health and use of community services, i.e., whether there was any association between these different types of care groups, and transitions between them, and health and use of community services.

In addition to transition groups, exploratory analysis of the data was conducted to determine other factors that may have affected health and use of community services.

2.3.3 Carer needs and impact of caring

Ten factors were examined including transition group, time of survey, education, country of birth, area of residence, ability to manage on available income, caring for grandchildren, need for care, sleep difficulty, and memory decline. The seven health and community services outcomes included mental health, physical health, number of visits to the GP, and use of nursing or community health services, respite services, homemaking services and home maintenance services.

Women who never provided care typically had better outcomes compared to carers who lived with their care recipients but worse outcomes compared to carers who lived elsewhere. Generally, women who used the services or had poorer health outcomes transitioned into or out of providing care for a care recipient who lived with them, and in the case of homemaking services, their use of services was more apparent earlier, at Survey 3. However, women who had better mental health were more likely to have transitioned into or out of providing care for a care recipient who lived elsewhere.

The combination of factors that was related to poorer health, visiting the GP five or more times, and use of services, is:

- Transitioning into or out of providing care for a live-in care recipient,
- Reporting difficulties managing on available income,
- Not providing care for grandchildren,
- Needing care themselves,
- Reporting sleep difficulties, and
- More memory decline.

Women with these characteristics would be potential candidates for appropriate policies and services.

Chapter 3 Patterns

There were constraints in sample size and the cross-sectional design of Phases 1 and 2. However, despite these constraints, there were patterns present in Phases 1 and 2 that were also present in the more representative sample used in Phase 3. In this chapter, patterns in the results across the three phases are presented by the three main areas of requirement: transitions, carer needs, and interventions / services.

3.1 Transitions

Information was reported about transitions in caring for women of the 1946-1951 pilot cohort in Phase 1 and women of the 1921-1926 cohort in Phase 3. Carers in Phase 1 wanted to provide care and started caring gradually. Generally, as these women aged, their involvement in employment decreased. In particular, carers with more intense caring duties were least likely to work full-time and most likely to not be in the labour force.

In Phase 3, women in the 1921-1926 cohort were examined across Surveys 2, 3, 4, and 5 (completed in 1999, 2002, 2005, and 2008, respectively) and they were classified into one of 12 groups (three groups whose roles stayed the same and nine groups who had caring transitions). Of the women who responded, 60% of them did not provide care at any survey from Survey 2 (1999) to Survey 5 (2008). The remaining 40% of women provided care at some point across the four surveys. The remaining women included those who provided care at all four surveys (2%) and women who provided care at some point across the four surveys (38%). Therefore, of the women who provided care at some point during the surveys, the majority (95%) transitioned into or out of their caring roles.

The 12 caring transition groups were statistically significantly related to mental and physical health and the use of nursing or community health, respite, homemaking, and home maintenance services. Women who never provided care typically had better outcomes compared to carers who lived with their care recipients but worse outcomes compared to carers who lived elsewhere. Generally, women who used the services or had poorer health outcomes transitioned into or out of providing care for a care recipient who lived with them. However, women who had better mental health were more likely to have transitioned into or out of providing care for a care recipient who lived elsewhere.

The results on transitions indicate that caring is transient, and while carers may have willingly entered into a caring relationship, their lives were still impacted by their caring role. This is discussed further in the next section.

3.2 Carer needs

3.2.1 Providing live-in care

The reports highlighted the importance of knowing if the carer lived with the care recipient. Women who provided care for recipients who lived with them had poorer health outcomes and were more burdened than women who provided care for someone who lived

elsewhere. This was evident in the 1946-1951 pilot cohort (Phase 1) and the 1921-1926 cohort (Phase 3). Compared to carers who lived elsewhere, live-in carers:

- Were more likely to be the main care provider,
- Assisted their recipients more frequently and for longer periods of time,
- Assisted their recipients with more activities of daily living, particularly the more personal basic activities of daily living, and
- Were more strained and more likely to report that their lives were worse from caring.

Transitioning into or out of caring for someone who lived with them was also related to poorer health and use of community services.

3.2.2 Income

Carers across all three phases reported minimal financial difficulties. This may be contrary to other research on carers. Therefore, to determine the generalizability of this result to the general female population, income data from Survey 4 (2005) of the 1921-1926 cohort were compared to data from similarly aged women from the National Health Survey (2005). The comparison indicated that the 1921-1926 cohort was only slightly biased (by 8%) toward women who were doing better financially.

However, it should also be noted that in Phase 3, poorer health outcomes were related to reporting difficulties managing on available income. Therefore, while the 1921-1926 cohort generally may not have reported difficulties managing on their available income, those women who reported difficulties managing were more likely to visit the GP more often and use community services.

3.2.3 Social support

The carers from the 1921-1926 carers substudy of Phase 2 were satisfied with their social support network. A high proportion of the carers and care recipients had health services coverage provided by the Department of Veterans' Affairs. While there was no consistent statistical link between this and satisfaction of support or ratings of service quality possibly due to sample sizes across the variables, the carers' written comments indicated that the carers liked the Department of Veterans' Affairs. The carers also reported that the support provided by family, friends, and formal services (such as the Department of Veterans' Affairs) was a positive aspect of their caring role.

Possibly, the carers' satisfaction with their social support provided a buffer to their strain and burden, so that the carers' mental and physical health were not affected. The good aspects of caring, such as companionship and an appreciation for what they do have, may have also moderated the burden and strain of caring. Further investigation is needed to determine the causality of these relationships.

3.3 Interventions / services

Information on use of interventions or services was presented in all three phases. In general, service use by carers was low in both the 1946-1951 pilot cohort and the 1921-

1926 carers substudy. Specifically, the use of Meals on Wheels, personal home care, domestic home care, and respite care was low in the 1921-1926 carers substudy in Phase 2. However, when these services were used, the carers reported that they were easy to access, they were of a good quality, and that they received as much as they wanted.

Counselling and home maintenance services (e.g. odd jobs, gardening) were the two most used services in the 1946-1951 pilot cohort. Carers in the 1921-1926 carers substudy used domestic home care (e.g. cleaning, ironing, shopping, gardening) services the most followed by personal home care (e.g. assistance with self care or nurse care), respite care, and Meals on Wheels in descending order of frequency. In this cohort, the care recipients' preferences determined use of services, particularly for respite care, and there was a stigma associated with using services. Therefore, use of services was low and the carer and care recipient beliefs associated with using services may have hindered women from using them.

However, it was found in Phase 3 that women who visited the GP five or more times or used community services (including nursing or community health, respite, homemaking, or home maintenance services) were more likely to have this combination of traits:

- Transitioning into or out of providing care for a live-in care recipient,
- Reporting difficulties managing on available income,
- Not providing care for grandchildren,
- Needing care themselves,
- Reporting sleep difficulties, and
- More memory decline.

Chapter 4 Comparisons

The results of Stage 2 are compared to data from Stage 1 and the 2008 Community Care Census in this chapter. Stage 2 expanded the Research on Caring to include women born between 1921 and 1926 in addition to women born between 1946 and 1951, which were the sole focus of Stage 1. Comparing these two groups of women illustrates how caring status varies for different age groups. The results of Stage 2 are also compared to those of the 2008 Community Care Census, a one-week census of beneficiaries of packaged care, to determine the similarities between the two data sets.

4.1 Comparison between the Research on Caring Stage 1 and Stage 2

Stage 1 involved caring by women born between 1946 and 1951. Phase 1 of Stage 2 involved a pilot substudy of this cohort, while a substudy of carers from the 1921-1926 cohort was examined in Phase 2 and the main 1921-1926 cohort was examined in Phase 3. Caring status frequencies across Surveys 2-5 for the main 1946-1951 and 1921-1926 cohorts are provided in Figure 1.

The 1946-1951 cohort consisted of 13,716 women and the 1921-1926 cohort consisted of 12,432 women. At each survey, most women were noncarers in both cohorts. In both cohorts, more women provided care for someone who lived elsewhere than for someone who lived with the carer and this was more pronounced in the 1946-1951 cohort. Generally, caring status frequencies remained stable across the surveys for the 1946-1951 cohort. However, as reported in Stage 1, more than half of the women providing care at Survey 3 or Survey 4 did not do so at both surveys, indicating that caring roles are transient and changeable.

Caring roles were also transient in the 1921-1926 cohort. Of the women who responded, 38% of the women transitioned into or out of their caring roles and only 2% of the women provided care at all four surveys. Therefore, of the women who provided care at some point during the surveys, the majority (95%) transitioned into or out of their caring roles. Also in the 1921-1926 cohort, the overall number of participants decreased as the women aged due to attrition from death, withdrawal due to frailty, withdrawal due to other reasons, or lost to follow up. In particular, the proportion of carers who lived elsewhere to carers who lived with their care recipients was greatly reduced at Survey 5.

4.2 Comparison with the 2008 Community Care Census data

The Community Care Census was a one-week census in 2008 of beneficiaries of packaged care through one of three Commonwealth-funded programs administered by the Department of Health and Ageing: Community Aged Care Package Program (CACP), Extended Aged Care at Home (EACH), or Extended Aged Care at Home—Dementia

(EACHD). The programs focused on frail older people aged 70 years and over, or 50 years and over for Aboriginal and Torres Strait Islanders.

A comparison between the data from the Census and the data from the 1946-1951 pilot cohort (Phase 1) was requested by the Department to determine the similarities between the two data sets. Data from the 1921-1926 carers substudy (Phase 2) were also compared. Care recipients who were cared for by female carers who were similarly aged to the ALSWH carers of Phases 1 and 2 were selected from the Census data for comparison. In Phase 1, the carers' ages ranged from 57 to 62 years with a mean age of 60 years, while in Phase 2, carers' ages ranged from 75 to 81 years with a mean age of 78 years. Therefore, the Census carer age groups of 55-59, 60-64, 75-79, and 80-84 years old are highlighted in Table 1. Data from Phase 3 were not compared to the Census data because information on care recipients was not collected.

There were differences between the data from the Census and Phase 1 and Phase 2 for care recipient age and relationship to carer, most likely due to differences in sampling methods. Since the Census data were collected for recipients 70 years of age or older, a larger portion of care recipients are in the older age brackets than the recipients of Phase 1 for which *carers* were selected because of their mid-age. However, when the carers' ages (75-81 years) were closer to the ages of recipients selected for in the Census data (70+ years), the proportion of care recipient ages was more similar between the Census and Phase 2.

The difference in sampling methods is also apparent in the relationship of the care recipient to the carer. For instance, because recipients 70 years of age or older, or 50 years and older for Aboriginal and Torres Strait Islanders, were sampled for the Census, it is nearly impossible for carers aged 55-64 years or 75-84 years to have provided care for their sons / daughters. Only 1% of carers aged 80-84 years in the Census provided care for a son or daughter. This figure most likely consists of older Aboriginal and Torres Strait Islander carers who provided care for their sons or daughters who were over 50 years old.

Information on where the carers lived relative to their care recipients was collected in the Census and Phases 1 and 2. The proportions of carers who lived with their care recipients and lived elsewhere are comparable between the Census data and the similarly aged Phases 1 and 2 data. The results indicate that the frequency of carers living with their care recipient increases from mid-age to older age.

The different sampling methods of these three groups of carers preclude any further comparisons. In addition, it cannot be determined whether the women of Phases 1 and 2 used Department funded services. Therefore, comparisons between these groups are limited. However, as discussed in the following section (*Data limitations, representativeness, and generalizability*), the results of the Stage 2 research are still relevant to the caring population.

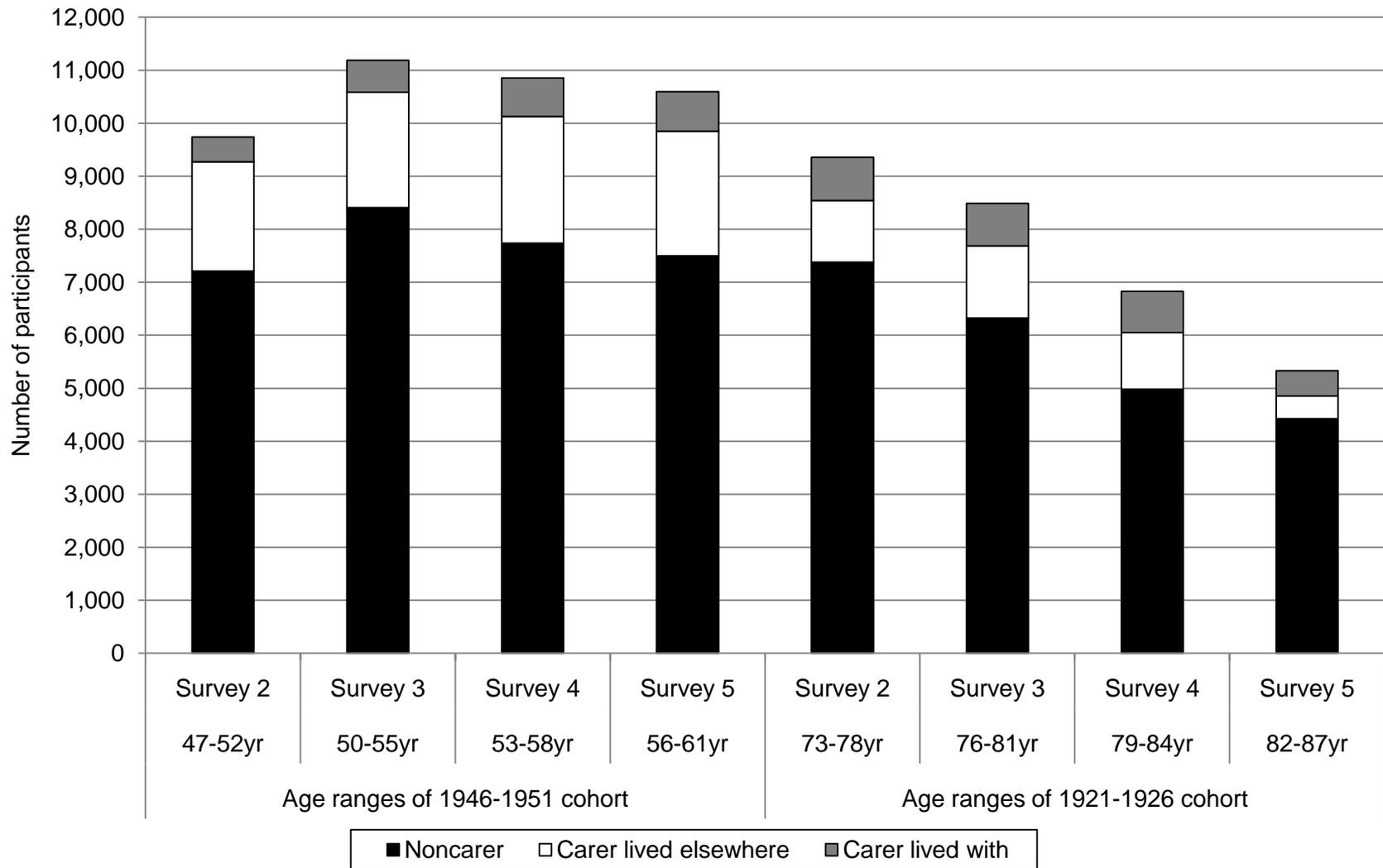


Figure 1 Frequency of noncarers and carers who lived elsewhere from their care recipients or who lived with them for the main 1946-1951 and 1921-1926 cohorts across Surveys 2-5

Table 1 Carer and care recipient information from Phase 1 and Phase 2 of Stage 2 and the Community Care Census, presented by carer age group

	Phase 1 1946-1951 pilot cohort	Community Care Census		Phase 2 1921-1926 carers substudy	Community Care census	
	Carer age group 57-62yr	Carer age groups 55-59yr	60-64yr	Carer age group 75-81yr	Carer age groups 75-79yr	80-84yr
Care recipient age (%)						
0-74	36	9	15	8	8	3
75-79	6	11	6	12	35	10
80-84	23	27	17	45	34	44
85-89	23	35	32	30	15	32
90-94	12	15	23	5	4	9
95+	0	3	7	0	4	2
Recipient relationship to carer (%)						
Parent / parent-in-law	56	83	71	n/a	4	1
Husband / partner	20	6	14	91	82	83
Son / daughter	12	0	0	6	0	1
Other	13	11	15	3	14	15
Where the carer lived (%)						
Lived with recipient	40	38	55	99	91	94
Lived elsewhere	60	62	45	1	9	6

n/a=not available

Data limitations, representativeness, and generalizability

Stage 2 involved three phases of research each with its own methodology and participant sample and resulting generalizability. There were limitations to the data in Phase 1 due to the constraints in sample size and selection of women mainly from Wollongong and Bathurst. Therefore, care should be taken when generalizing the results to the general carer population. In addition, due to the cross-sectional sampling of Phases 1 and 2, only associations, not causality, can be determined from these data.

The results of Phase 2 are more generalizable to the general carer population than those of Phase 1. In Phase 2, all possible carers who reported that they provided live-in care were selected from the 1921-1926 cohort. Further, the areas of residence of this nested sample were more representative of the general population, unlike the women of Phase 1.

The results of Phase 3 are the most generalizable to the general Australian population, including the carer population. Women of the main ALSWH (Phase 3) were randomly selected from Medicare Australia, which includes all permanent residents and citizens. The women who agreed to participate in the ALSWH 1921-1926 cohort were largely representative with a few small differences. For instance, the cohort women were more likely to be married and have a tertiary education and were less likely to report fair or poor self-rated health than the general population. As the women have aged, the ALSWH 1921-1926 cohort is still considered an adequate representation of Australian women born between 1921 and 1926. Some differences are present due to attrition because initially the women were less likely to report fair or poor self-rated health and they currently have better survival.

Therefore, of the three phases of research, the results of Phase 3 are the most generalizable and useful for informing policy.

At this time, the caring indexes used in Phase 1 (Care Index) and Phase 2 (Care Activity Index) could not be used as standardised assessment tools. The surveys from which those indexes were based were not created to assess the indexes' suitability. However, the indexes do have potential, and they would need to be formally developed and tested to determine their suitability as standardised assessment tools in other samples.

Possible policy implications

- Policies need to recognise that carers and their situations are different and may change over time.
- Due to the transient nature of caring, services should be provided in a timely manner.
- Results indicate that carers who provided care for a care recipient who lived with them, or transitioned into or out of this live-in caring role, had poorer health outcomes than carers who lived elsewhere. Policies should consider the particular needs of carers who live with the person for whom they care. As these carers may experience difficulty leaving their care recipient at home, adequate respite services to allow carers to visit health services, or in-home health visits, may be necessary to ensure adequate access to services.
- In particular, older women who are carers are at risk of poorer outcomes if they also have difficulties managing on their available income, do not provide care for grandchildren, need care themselves, and report sleep difficulties and memory decline. This finding emphasises the importance of adequate financial provision and health services for carers.
- Care recipient preference strongly drove the use of services, particularly respite care. Therefore, services should aim to improve acceptability and use of services by older care recipients.
- Framing the needs of the carer(s) and care recipient as a system where each affects the other may assist health services to provide for the needs of both in an efficient manner.
- Carers who were provided with services through the Department of Veterans' Affairs commended them highly. Other non-veterans service providers may be able to model their service delivery and availability after the Department of Veterans' Affairs.

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Appendix

Care Index from Phase 1

In Phase 1, the intensity of caring duties was summarised in a care index which was developed during Stage 1 of the Research on Carers and has been used in previous reports (Berecki et al. 2007; Lucke et al. 2006). The care index was created by combining answers to questions on the frequency of caring (ranging from daily to every few weeks) and the amount of care provided at each occasion (ranging from all day and night to an hour per occasion). The resulting score was grouped into three categories:

Low: For example, caring once per week for one hour at a time; or caring every few weeks for several hours at a time.

Medium: For example, caring several times per week for several hours at a time; or caring every day for about an hour.

High: For example, caring all day, several times a week; or caring everyday for several hours at a time.

A care index was calculated for 83 carers (the other 14 carers had missing data, which means the index could not be calculated). Nineteen carers had a low care index, while 38 had a medium care index and 26 had a high care index.

Carer Activity Index from Phase 2

In Phase 2, the 280 carers were classified into three groups according to the frequency and number of activities with which they helped their care recipients. The tasks that carers may have performed fell into two categories: basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs). BADLs include the personal tasks of daily life and six of these (washing, dressing or grooming, preparing meals, eating or drinking, transfers, toileting and mobility) were included in the survey. IADLs include further life activities and three of these (household management, recreation, and transportation) were included in the survey.

To determine the intensity of caring activities performed by the carer, an index of caring activity for each carer was created by combining the responses to questions that asked whether the care recipient needed help with each activity and how often the carer helped the recipient with the activity (responses ranged from never to every day). Firstly, a score was created for each of the nine activities from the survey.

- If the care recipient did not need help with an activity, it was scored as zero.
- If the care recipient did need help with an activity, the score for that activity was determined from the response to item a (as outlined below).
- “a” items were scored so that a higher number indicated a higher caring intensity:
 - 0=never
 - 1=hardly ever
 - 2=a few times a month

- 3=a few times a week
- 4=every day.

The scores for each activity were then summed to create a total activity score, ranging from 0 to 36, with a higher score indicating a higher intensity of caring. A score could not be created for one carer who had missing data on all activities questions. This score was used to separate carers into one of three equally sized groups:

- **Lower** third: 93 carers with a mean care activity score of 6.1.
- **Middle** third: 93 carers with a mean care activity score of 15.5.
- **Higher** third: 93 carers with a mean care activity score of 26.4.

The carer activity index in Stage 2 Phase 2 was different from the care index used in Stage 2 Phase 1. The carer activity index for Phase 2 was based on the frequency and number of activities out of the nine activities of daily living in the survey, whereas the care index in Phase 1 was based on the frequency and duration of any form of caring assistance. In Phase 2, the carer activity index was referred to as CAI, with the group specification (lower, middle, higher).



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