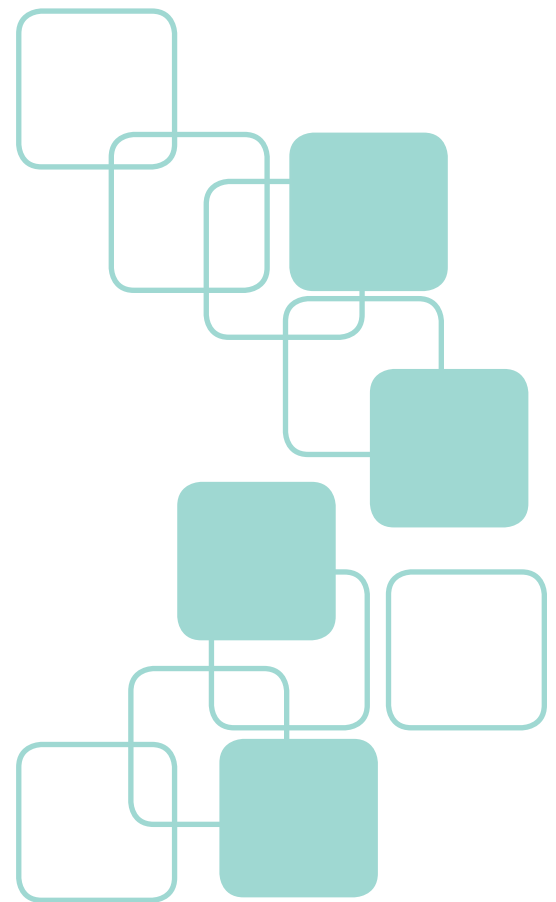


From child care to elder care: Findings from the Australian Longitudinal Study on Women's Health



Authors:

Leigh Tooth
Deborah Loxton
Hsiu-Wen Chan
Joanne Coombe
Annette Dobson
Richard Hockey
Natalie Townsend
Julie Byles
Gita Mishra

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1. Executive summary

The Australian Longitudinal Study on Women's Health (ALSWH) is a longitudinal population-based survey examining the health of over 58,000 Australian women. The study comprises four cohorts of women: three cohorts (born in 1921-26, 1946-51, 1973-78) have been repeatedly surveyed since 1996, and a new cohort (born in 1989-95) was first surveyed in 2013. The ALSWH data have been widely used to assess health status of women in Australia and to investigate the behavioural and socio-demographic characteristics that affect health and the use of health services at different life stages. This major report, the latest in a series for the Department of Health, examines informal caregiving across the life course.

The provision of informal care (that is, unpaid care) to another person is an important and often significant part of women's lives. Statistics from Australia and countries across the OECD show that over two-thirds of primary caregivers, and over half of all caregivers, are women. In Australia, the economic value of informal care in 2015 was estimated to be over \$1 billion per week.

For many women, caregiving roles and responsibilities occur at multiple points along the life course, with these life course variations largely driven by relationships between and within generations. For example, women may care for their own children and grandchildren, care for parents, other family members or friends, and in later decades, care for spouses or partners. Women can provide primary, often higher intensity, care for people living with them or secondary, often lower intensity, care for people living elsewhere. Women often transition in and out of caregiving roles while managing other responsibilities, for example, employment and family life.

This report presents an analysis of the patterns of caregiving by Australian women across the life course using data from women aged from 18 to 97 years, the socio-demographic factors associated with caregiving patterns, and the impact of caregiving on social, employment and health outcomes of caregivers including their health service use. Both quantitative and qualitative data from the ALSWH cohorts have been used.

Provision of care to children in young adult life: Women in the 1973-78 cohort

While less than 10% of women aged 18 to 23 in 1996 had at least one child, by the time they were 31 to 36 years, 79% of women had at least one child. When aged 28 to 33 years, 75% of women used informal and/or formal child care with this percentage dropping to 60% by the ages 37 to 42. Child care use, particularly informal child care, was highest in women who were working (either part-time or full-time) and those with higher levels of education. The percentages of women who used informal child care were similar amongst those who lived in major cities, and inner and outer regional areas with those in remote areas being the least likely to use this type of care. Use of formal and informal care was similar regardless of how well women reported managing on their income.

The majority of women using formal child care considered it to be convenient and available when aged 37 to 42 years. The convenience and availability of formal child care was perceived to be more of a problem by women who did not use formal child care than by women who did. One-third of women using formal child care reported that the cost of this service was a problem. Higher socio-demographic status was associated with the perception that formal child care was more conveniently located and affordable. Overall, the majority of women experienced high levels of satisfaction with their child care arrangements and were happy with their share of child care activities.

In an analysis of the women's own words (free-text comments), flexible employment conditions were important to facilitate returning to paid work for women after having children. However, a better understanding of the types of flexibility that are most useful would be helpful. Some women felt the cost of formal child care negated their potential earnings. An investigation into the costs to families and the economy of this lost productivity would be useful, in order to more fully understand the benefits of high quality affordable child care. Alternatives to formal child care include care by family members and social support networks. However, these are not available to all women. Further investigation of social support, child care and paid employment could illuminate the value of social networks to women with children. Furthermore, support for building networks to assist with child care could provide an affordable alternative to parents who wish to undertake paid work.

Provision of care to children in mid-age and later life: Women in the 1946-51 and 1921-26 cohorts

The percentage of women in the 1946-51 cohort who provided care for their grandchildren or other people's children steadily increased up to 60% by the time they were 62 to 67 years. Women in the 1946-51 cohort who worked full-time or had a university degree were less likely to provide care than women not in the labour force or with lower educational attainment. Women who found it impossible or very difficult to manage on their income were more likely to provide daily child care compared with women who found it easiest to manage on income.

The percentage of women in the 1921-26 cohort who provided child care steadily decreased from 45% when they were aged 73 to 78 to 12% when they were aged 85 to 90. In this cohort, women who had better self-reported health were more likely to provide child care than women who reported their health as being fair or poor.

Provision of care to somebody because of their long-term illness, disability or frailty in mid-age: Women in the 1946-51 cohort

Provision of care for somebody because of their long-term illness, disability or frailty was highest in women in the 1946-51 cohort (who were aged between 45 and 72 years across eight successive surveys). Over the surveys, between 24 and 30% of these women reported

caring for another person. There was a high degree of movement into and out of caregiving over time, with only 4% of women providing this care at every survey. As these women aged, the percentage who cared for someone they lived with increased while the percentage who cared for someone they did not live with decreased after 2004 when they were aged 53 to 58 years. Of the caregivers living with the person they cared for, most were not in the labour force and had less education. Caregivers living with the person they cared for also reported more difficulty managing on their income than non-caregivers.

There was no difference in the percentage of caregivers among women living in major cities, regional, or remote areas.

Table 1-1 below shows a summary of the most common associations between intensity of caregiving, age of caregiver, relationship between caregivers and care recipient, location of the care recipient and conditions of the care recipient. For example, the table shows that high intensity caregiving was most often provided by women when they were aged 56 to 67 (across Surveys 5 to 7) and that this care was usually provided to a spouse/partner who lived with the women and who had a serious medical issue like a mental health condition or cancer.

Table 1-1 Associations between intensity of caregiving, age of caregiver, relationship between caregivers and care recipient, and location and conditions of the care recipient.

| Intensity level | Most prevalent ages | Most prevalent type of care recipient | Most prevalent location of care recipient | Most prevalent condition/s of care recipient |
|---|----------------------------|---|--|---|
| Low: <i>caregiving once per week for one hour at a time; or every few weeks for several hours at a time</i> | 53-64 years | Sibling/sibling-in-law Friend Neighbour | Lives elsewhere to caregiver | Frailty in old age Visual impairment Alzheimer's disease/dementia |
| Medium: <i>caregiving several times per week for several hours at a time; or every day for about an hour</i> | 53-64 years | Parent/Parent-in-law Child Grandchild | Lives elsewhere to caregiver | Frailty in old age Visual impairment |

| Intensity level | Most prevalent ages | Most prevalent type of care recipient | Most prevalent location of care recipient | Most prevalent condition/s of care recipient |
|--|----------------------------|--|--|---|
| High: <i>caregiving all day, several times a week, or every day for several hours at a time</i> | 56-67 years | Spouse/partner Child | Lives with caregiver | Mental health problem Heart condition Alzheimer's disease/dementia Cancer Respiratory condition Stroke |

Overall, the majority of women in the 1946-51 cohort who provided care (66-81%) were happy with their share of caregiving activities and approximately 10% reported at each survey that they would prefer another arrangement.

Provision of care to somebody because of their long-term illness, disability or frailty in early adult life: Women in the 1973-78 cohort

When aged in their 20s and 30s about 6% of women in the 1973-78 cohort provided care for other people, with this prevalence increasing as the women entered their 40s. Similarly to women in the 1946-51 cohort, those caring for other people had poorer socio-demographic status than non-caregivers and those caring for someone who lived elsewhere. No particular trend for caregiving intensity was found in women born in 1973-78 when they were in their mid-30s to early 40s (the question about caregiving intensity was only asked in Surveys 6 and 7 of this cohort).

Provision of care to somebody because of their long-term illness, disability or frailty in later life: Women in the 1921-26 cohort

In the 1921-26 cohort, the percentage of women who were caregivers peaked when they were aged 76 to 84 years before sharply decreasing. In contrast to the 1973-78 and 1946-51 cohorts, there were no differences in socio-demographic indicators between caregivers and non-caregivers. Low and medium intensity care was provided by caregivers in the 1921-26 cohort who did not live with the person they cared for. High intensity care was provided by caregivers who lived with the person they cared for.

Factors influencing transitions in caregiving

A summary of previously published research using data from the ALSWH revealed insights into caregiving transitions in women in the 1973-78 and 1946-51 cohorts. In the 1946-51 cohort, women who provided care when aged 47 to 55 had lower engagement in the labour force compared with non-caregivers, which is possibly due to their poorer health status and greater use of health services. As women aged from their early to late 50s, the percentage of women who provided care increased and, simultaneously, participation in paid employment decreased. Transition into caregiving was not influenced by the number of hours of paid employment undertaken prior to caregiving, however once caregiving commenced, women in the 1946-51 cohort subsequently reduced their hours of employment.

In the 1973-78 and 1946-51 cohorts, women who provided continuous caregiving over time had poorer socioeconomic indicators at baseline; no other socioeconomic or health-related associations were apparent for other types of caregivers or non-caregivers. Turning points in the percentage of different types of caregiving over time by women in the 1946-51 cohort suggest that the women were engaging in a new type of caregiving behaviour, or that factors that influence the decision to be a caregiver had changed.

Caregiving and health, health behaviours and health service use

Overall, women in the 1946-51 cohort who provided care for somebody who lived with them reported poorer health, health behaviours and greater health service use when compared to caregivers who did not live with the person they cared for or non-caregivers, namely, they:

- had poorer self-reported health
- were more likely to be less physically active, to smoke and be obese
- had poorer adherence to guidelines for fruit intake
- were less likely to adhere to pap test recommendations
- reported three or more chronic conditions
- had higher levels of stress, anxiety and depression
- had more visits to the general practitioner and a higher number of prescriptions filled.

Similar findings were found for women in the 1973-78 cohort. Women living with the person they cared for had poorer health and health-related behaviours, and greater use of health services than women caring for someone living elsewhere and non-caregivers. There was however no difference between caregivers and non-caregivers for specific lifestyle behaviours such as smoking, drug use, alcohol consumption and adherence to dietary guidelines.

For women in later life, a different pattern emerged likely reflecting that at these later life stages, only women who were in good health were able to provide care for others. Caregivers

aged 79 to 84 and not living with the person they cared for had better self-rated health and were more physically active than live-in caregivers and non-caregivers. Caregivers who lived with the person they cared for were more likely to be obese than caregivers who lived elsewhere and non-caregivers. There were no differences in self-reported anxiety and depression, and MBS service use between caregivers and non-caregivers. Amongst the women aged 79 to 84 years, non-caregivers were the most likely to require help with their own daily tasks, followed by live-in caregivers, and caregivers living elsewhere.

An analysis of the women's own words (free-text comments) revealed that ensuring they have sufficient personal and emotional care when they become widowed is essential to their ongoing health and ability to live independently. Formal and informal care assists women to not only care for their husbands but also for themselves. Most women reported being able to access the care they required. Many women reported the desire to remain independent and in their own homes as long as possible, and ensuring that there are services available to facilitate this is important. As most women reported that the person they cared for was their spouse, some caregiving burden for these women, who are also in need of assistance, could be alleviated by a coordinated approach. This might include a couple's care plan, rather than individual care plans, potentially provided by different administering bodies (e.g., DVA and State-based community services).

Caring for multiple generations and 'sandwich' caregiving

Many women who provide care do so for more than one person. In the 1973-78 cohort, about 11% of women with children were also caring for another person who was ill, disabled or frail when they were aged 37 to 42. A larger percentage of women in the 1946-51 cohort were providing care for multiple generations (25% at Survey 8, when the women were aged 67-72), while 10% of women in the 1921-26 cohort (when aged 79-84 years) provided care for more than one generation. Associations between providing multi-generational care were influenced by whether the women lived with the person they cared for or elsewhere. A summary is presented in Table 1-2.

Table 1-2 Associations between women in the 1973-78, 1946-51 and 1921-26 cohorts who provided multi-generational care and varied socio-demographic and health indicators

| Cohort | Socio-demographic indicators | Health indicators |
|----------------|--|--|
| 1973-78 | If lived with care recipient - more likely to have more than 3 children | If lived with care recipient – more inactive, depression, higher stress |
| 1946-51 | If lived with care recipient – more likely to also provide daily care for grandchild | If lived with care recipient - more inactive, depression, higher stress, poorer self-rated health, more visits to the GP |
| 1921-26 | | If lived with care recipient - poorer self-rated health, fewer visits to the GP If lived elsewhere to care recipient – higher physical activity |

Note: In this table care recipient refers to someone who is ill, disabled or frail.

In an analysis of the women’s own words (free-text comments from women in the 1946-51 cohort), more accessible and affordable child care options for parents returning to work may reduce the burden on grandparents of caring for their grandchildren. More research is needed to investigate the impact of long-term multigenerational caregiving among those who are reaching retirement age, and who are experiencing their own age-related health issues. While child care and respite care may be available to caregivers, these are rarely, if ever, offered as a coordinated support service. The complex support needs of caregivers in this position warrant assessment at the individual level.

2. Introduction and overview of the ALSWH

Australia has over 2.7 million carers, 12% of the population. The chances are you personally *are* a carer, *need* a carer or *know* a carer.

Carers Australia, 2018

2.1 Caregiving in Australia

Informal unpaid caregiving¹ is a substantial undertaking in Australia, with around 2.7 million unpaid caregivers recorded at the 2015 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (ABS, 2016). While the average age of caregivers in Australia is around 55 years, 1 in 10 (or 272,000 caregivers) in 2015 were under the age of 25, of which 1 in 5 (almost 60,000) were aged under 15 years. However, it is likely that these numbers are an undercount because many people, in particular women, do not formally identify themselves as caregivers due to societal and personal attitudes towards family responsibilities (Colombo et al., 2011). Most informal caregivers in Australia are women, representing 68% of primary caregivers and 55% of all caregivers. These statistics are not unique to Australia, with similar numbers found across the OECD (Colombo et al., 2011). In 2015, Deloitte Access Economics estimated that caregivers in Australia provided 1.9 billion hours of unpaid care, with the replacement value about \$60.3 billion - over \$1 billion per week (Deloitte Access Economics, 2015).

In the ABS Surveys of Disability, Ageing and Carers, and for the analyses conducted by Deloitte Access Economics, informal caregiving is usually defined as providing supervision or help with personal care or basic activities of daily living to people (usually aged 65 or older) with functional limitations or disability. As such, the results of these reports must be interpreted with this narrow definition in mind. To gain a broader picture of the impact of caregiving generally on the women who provide it, it is important to consider the other types of caregiving women provide across the life course, most notably care for children (and grandchildren) who do not have any disability or functional limitations. For example, recent data from the ABS showed that caring for children remained a significant barrier to workforce participation for women. Of the 665,000 women who wanted to do more work or start working in 2016-17, 25% cited the need to look after children as the main barrier (ABS, 2017).

¹ "A carer is defined as a person who provides any informal assistance, in terms of help or supervision, to people with disability or older people (aged 65 years and over). Assistance must be ongoing, or likely to be ongoing, for at least six months". ABS Survey of Disability, Ageing and Caring, 2016.

Further, while the proportion of children in Australia who attend formal child care is increasing, grandparents remain the principal source of informal child care, with around 1 in 5 children aged 0 to 12 years being cared for by their grandparents (AIHW, 2017a) with grandparents found to provide an average of 10 hours of care per week (AIHW, 2017b).

For many women, caregiving roles and responsibilities occur at multiple points along the life course, with these life course variations largely driven by relationships between and within generations. For example, women may care for their own children and grandchildren, care for parents, other family members or friends, and in later decades, care for spouses or partners. Women can provide primary, often higher intensity, care for people living with them or secondary, often lower intensity, care for people living elsewhere. Women often transition in and out of caregiving roles while managing other responsibilities, for example, employment and family life.

The purpose of this report is to use data from the Australian Longitudinal Study on Women's Health to:

- assess the patterns of caregiving by Australian women across the life course using data from women aged from 18 to 97 years;
- assess the socio-demographic factors associated with caregiving patterns; and
- assess the impact of caregiving on social, employment and health outcomes of caregivers including their health service use.

The report uses both quantitative and qualitative data from the 1973-78, 1946-51 and 1921-26 cohorts, and a small amount of qualitative data from the 1989-95 cohort. The analyses of these data aim to assist health care providers to better identify present and future caregivers, based on socio-demographic factors, and to provide recommendations for policy setting.

2.2 Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health (ALSWH) is a long running survey of a large nationally representative sample of Australian women. When it began in 1996, the Study comprised three cohorts of women – 18 to 23 year old women born in 1973-78 (N=14,247 in 1996; aged 40-45 in 2018), 45 to 50 year old women born 1946-51 (N=13,714 in 1996; aged 67-72 in 2018) and 70 to 75 year old women born 1921-26 (N=12,432 in 1996; aged 92-97 in 2018). In 2012-13, to maintain coverage across the adult lifespan, a new cohort of 18 to 23 year old women born 1989-95 (N=17,015 in 2012-13; aged 23-29 in 2018) were recruited. For the three cohorts surveyed in 1996, women in rural and remote areas were purposely sampled at twice the rate of women in urban areas (Lee et al., 2005). However, participants in the 1989-95 cohort were recruited by a different method and are more geographically representative of the Australian population in their age group (Mishra et al., 2014). For more than 20 years, participants have provided information on social, psychological, physical, and

environmental aspects of their health and their use of health services, and survey data have also been linked to administrative records (e.g., Medicare Benefits Scheme (MBS), Pharmaceutical Benefits Scheme (PBS), cancer registries, hospital admissions, perinatal data collections, and aged care datasets).

From this rich dataset, ALSWH provides a unique opportunity to monitor changes over time in the health and well-being of women, their social circumstances, and their health behaviours.

2.3 Caregiving by ALSWH participants:

Caregiving at all stages of the adult life course were examined using data from the 1973-78, 1946-51 and 1921-26 cohorts. Women were defined as caregivers based on responses to the following information provided in the surveys:

- Whether they provided care to a child, grandchild or other person's child.
- Whether they provided unpaid care to someone because of their long-term illness, disability or frailty.
- Women who simultaneously provided care to more than one generation (for example, a child as well as someone who was ill, disabled or frail; often referred to as 'sandwich' caregivers) were also examined.

In addition, responses to questions about the items below were also analysed.

- Use of child care (both formal and informal).
- Perceptions of the convenience, availability and costs of formal and informal child care.
- Perceptions of satisfaction with child care arrangements and activities.
- Perceptions of happiness with share of tasks involving caring for an adult.

2.4 The nature and depth of the caregiving provided by ALSWH participants

Where appropriate, responses to the principal questions about caregiving were further stratified by socio-demographic status, details about the care recipients and the intensity of caregiving provided by the women. These included:

- **Where the women lived in relation to the person they cared for** (in the case of people with a long-term illness, disability or frailty). This was defined as living with the person they cared for or elsewhere.
- **Highest level of education** (less than year 12, year 12 or equivalent, certificate/diploma, university), **labour force participation** (not in the labour force, part-time or full-time work), **ability to manage on available income** (impossible/very

difficult, difficult sometimes, not too bad/easy) **and geographical area of residence** (this was based on the Accessibility and Remoteness Index of Australia (ARIA+) and classified as major city, inner regional, outer regional, and remote ([DoHAC, 2001](#))).

- **The relationship of the caregiver to the care recipient.** This was defined as parent/parent-in-law, spouse/partner, friend, child, sibling/sibling-in-law, neighbour, grandchild, and other.
- **The nature of the condition of the care recipient.** These were classified as frailty in old age, heart condition, mental health problem, Alzheimer’s disease/dementia, visual impairment, cancer, respiratory condition, stroke, and other.
- **The intensity of the caregiving provided.** An index which indicated the level of care provided by the women was created by combining answers to questions about frequency of caregiving (ranging from daily to every few weeks) and duration of caregiving (ranging from all day/night to caring for about an hour at a time). The index had three levels representing low, medium and high intensity caregiving.

2.5 The impact of caregiving on ALSWH participants

Associations between caregiving and health, health behaviours and health service use were examined where appropriate and depending on the cohort data being analysed. These were further examined by whether or not the women lived with the person they cared for.

The self-reported health, health behaviour and health service use outcomes included:

- Self-rated health
- Body mass index
- Physical activity
- Alcohol consumption
- Smoking and illicit drug use
- Use of health screening services (mammography, pap smears)
- Visits to a specialist in the previous 12 months
- Chronic conditions
- Perceived stress
- Depression
- Anxiety
- Adherence to dietary guidelines
- Visits to a general practitioner in the previous 12 months

Health service use outcomes from linked data included:

- Number of Medical Benefit Scheme unreferral visits
- Number of Pharmaceutical Benefit Scheme scripts filled

2.6 Personal stories and reflections about caregiving by ALSWH participants

The ALSWH quantitative data provide population level information about the complexities experienced by women who are caregivers. The ALSWH qualitative data provide context and information about the lived experience of caregiving. Thus, qualitative data in the form of free text comments were analysed and the results included in relevant sections throughout this report. At every survey, the ALSWH participants are invited to respond to a question on the final page of the survey that asks “*Have we missed anything? If you have anything you would like to tell us, please write on the lines below*”. Over the 20 years of the ALSWH study period many women have taken the opportunity to write about the diverse range of factors affecting their lives and health. For this report, we have focused on an analysis of three specific research questions:

1. What are the experiences of women returning to paid work after having children?
(‘Working mothers’)
 - a. What factors facilitate or deter a return to paid work after having children?
 - b. How is caring for children negotiated when women undertake paid work?
2. What are the experiences of women who are providing care for children and adults?
(Multiple generation or ‘sandwich caregivers’)
 - a. How do these experiences influence their health and wellbeing?
 - b. What factors help women to manage these multiple caregiving roles
3. What are the experiences of women who need care and support and also provide care to those who depend on them? **(‘Providing and needing care’)**
 - a. What aspects of both providing and receiving care are problematic?
 - b. What factors facilitate caregiving under these circumstances?

2.7 Previous ALSWH commissioned research on caregiving

From 2006 to 2009, researchers from the ALSWH were contracted by the then Australian Government Department of Health and Ageing to provide three detailed programs of analysis of data from women in the 1946-51 and 1921-26 cohorts who provided care for someone who was ill, disabled or frail. The contract was titled *‘Research on carers based on the Australian Longitudinal Study on Women’s Health’* and was commissioned to provide *‘evidence to develop policy approaches that support women caregivers (Including employed and mid-age caregivers) who look after the frail living at home by examining caregiver transitions, caregiver needs and caregiver support interventions’*.

The first program was a survey of 296 women in the 1946-51 cohort who belong to the pilot study group of women who test the main ALSWH surveys. The second involved re-analysis of data from 280 caregivers from the 1921-26 cohort who had previously participated in a

substudy about health service use. The third involved analysis of data from ALSWH Surveys 2 to 5 of the 1921-26 cohort (conducted over the years 1999-2008). The objectives were to investigate the following questions:

- What is the broad impact of caring on women's lives?
- How do women manage caregiving transitions, particularly in relation to labour force participation?
- What services/interventions do women use?

The final report, [*Carrying the load: Transitions, needs and service use of Australian women carers*](#), was delivered in October 2009). A summary is below:

- While caregivers may have willingly entered a caregiving relationship, their lives were still impacted by their caregiver role and they had poorer mental health and less social support than non-caregivers. The research highlighted the importance of knowing if the caregiver 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. Transitioning into and out of caregiving for someone who lived with them was also linked with poorer health and use of community services.
- Caregivers in all three analyses reported minimal financial difficulties. However, the older women (born 1921-26) who did report financial difficulties were more likely to visit a general practitioner and use community services. In addition, older women who were caregivers were at risk of poorer outcomes if they needed care themselves, and reported sleep difficulties and memory decline.
- Caregivers' satisfaction with their social support may provide a buffer to their strain and burden. The good aspects of caregiving, such as companionship and an appreciation for what they do have, may also moderate the burden and strain of caregiving.
- Caregiving was transient in women born 1921-26, with the majority of the women who were caregivers at some point across the survey period (1999 to 2008) not providing care at all surveys.

Key policy implications from this commissioned research were:

- Due to the transient nature of caring, services should be provided in a timely manner.
- Policies should consider the particular needs of caregivers who live with the person for whom they care. As these caregivers may experience difficulty leaving their care recipient at home, adequate respite services to allow caregivers to visit health services, or in-home health visits, may be necessary to ensure adequate access to services.

- In particular, older women who are caregivers are at risk of poorer outcomes if they also have difficulties managing on their available income, need care themselves, and report sleep difficulties and memory decline. This finding emphasises the importance of adequate financial provision and health services for caregivers.
- 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 caregiver(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.
- Caregivers 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.

2.8 Structure of this report

This report contains four results chapters. Chapter three reports on caring for children by women in the 1973-78, 1946-51 and 1921-26 cohorts. It examines the provision of child care, and use and perceptions of formal and informal child care provided by others. The results are stratified by socio-demographic factors. The chapter includes an analysis of free-text comments by the women about returning to paid work after having a child. The focus is principally on women of the 1973-78 cohort as we considered these women most likely to have written about the experience of caregiving and returning to work, given their age (37-42 years in 2015).

Chapter four reports on caregiving by women in the 1973-78, 1946-51 and 1921-26 cohorts for someone who has a long-term illness, disability or frailty. It examines transitions in caregiving over time, whether the women cared for someone who lived with them or elsewhere, socio-demographic factors associated with caregiving, the intensity of the caregiving provided, the conditions of the person the women cared for, and the womens' relationship with that person. The chapter also includes a summary of previous ALSWH research on this type of caregiving. The focus is principally on women of the 1946-51 cohort as most of the caregiving questions were asked of this cohort.

Chapter five presents data from women in the 1973-78, 1946-51 and 1921-26 cohorts on the health, health behaviours and health service use outcomes of women who care for any other person because of their long-term illness, disability or frailty. The health data included in this chapter are self-rated health, body mass index, physical activity, alcohol consumption, smoking, diet, chronic conditions, perceived stress, depression, anxiety, self-reported visits to a general practitioner and specialist, MBS unreferred visits and PBS scripts filled and use of health screening services. The chapter includes a summary of previous ALSWH research on some of the health impacts from this type of caregiving. The focus is principally on women of the 1946-51 cohort as this group provided most of this type of care. The chapter also includes

an analysis of free-text comments written by women who reported both providing care to someone else and needing assistance with their own self-care.

Chapter six reports on caring for multiple generations (also called ‘sandwich’ or ‘dual’ caregiving). This refers to caregiving performed by women simultaneously for both younger and older generations. Associations between this type of caregiving and whether the women lived with the person they cared for or elsewhere and on selected measures of health, health behaviours and health service use are also presented. The chapter concludes with an analysis of free-text comments by women who reported providing care to multiple generations.

Throughout this report associations between socio-demographic factors and caregiving are presented. To enable interpretation of the associations between caregiving and socio-demographic status, the following tables (Table 2-1, Table 2-2, Table 2-3, Table 2-4) summarise the socio-demographic characteristics of women in the 1973-78, 1946-51 and 1921-26 ALSWH cohorts, regardless of caregiver status, at two survey time points.

Throughout this report the term ‘significant’ should be taken to mean ‘statistically significant at $p \leq 0.01$ ’.

Table 2-1 Area of residence classifications for participants across three cohorts (born 1973-78, 1946-51 and 1921-26)

| 1973-78 | | Survey 1 – 1996 | Survey 7 – 2015 |
|----------------|--------------------------|----------------------------------|---------------------------------|
| Cohort | Area of residence | 18-23 years, (N = 14,247) | 37-42 years, (N = 7,186) |
| | | % | % |
| | Major city | 69.2 | 69.0 |
| | Inner regional | 19.0 | 20.0 |
| | Outer regional | 9.5 | 9.0 |
| | Remote | 2.3 | 2.0 |
| 1946-51 | | Survey 1 – 1996 | Survey 8 – 2016 |
| Cohort | Area of residence | 45-50 years, (N = 13,714) | 65-70 years, (N = 8,622) |
| | | % | % |
| | Major city | 67.7 | 62.0 |
| | Inner regional | 20.1 | 26.8 |
| | Outer regional | 10.1 | 10.1 |
| | Remote | 2.0 | 1.1 |

| 1921-26 Cohort | Area of residence | Survey 1 – 1996 | Survey 6 – 2011 |
|-------------------|-------------------|---------------------------|--------------------------|
| | | 70-75 years, (N = 12,432) | 85-90 years, (N = 4,055) |
| | | % | % |
| | Major city | 68.0 | 68.0 |
| | Inner regional | 21.3 | 21.6 |
| | Outer regional | 9.3 | 9.0 |
| | Remote | 1.4 | 1.3 |

Table 2-2 Levels of education for participants across three cohorts (born 1973-78, 1946-51 and 1921-26)

| 1973-78 Cohort | Highest qualification | Survey 1 – 1996 | Survey 7 – 2015 |
|-------------------|--------------------------|-------------------------|------------------------|
| | | 18-23 years, (N=14,247) | 37-42 years, (N=7,186) |
| | | % | % |
| | Less than Year 12 | 14.7 | 4.6 |
| | Year 12 or equivalent | 55.4 | 8.9 |
| | Certificate/Diploma | 17.5 | 25.2 |
| | University degree | 12.4 | 61.2 |

| 1946-51 Cohort | Highest qualification | Survey 1 – 1996 | Survey 6 – 2010 |
|-------------------|--------------------------|-------------------------|-------------------------|
| | | 45-50 years, (N=13,715) | 59-64 years, (N=10,011) |
| | | % | % |
| | Less than Year 12 | 46.4 | 36.3 |
| | Year 12 or equivalent | 17.5 | 19.4 |
| | Certificate/Diploma | 19.7 | 21.0 |
| | University degree | 16.4 | 23.2 |

| 1921-26 Cohort* | Highest qualification | Survey 1 – 1996 |
|--------------------|--------------------------|-------------------------|
| | | 70-75 years, (N=12,432) |
| | | % |
| | Less than Year 12 | 70.7 |
| | Year 12 or equivalent | 13.3 |
| | Certificate/Diploma | 11.7 |
| | University degree | 4.2 |

* Asked at Survey 1 only.

Table 2-3 Difficulty managing on income across three cohorts (born 1973-78, 1946-51 and 1921-26)

| 1973-78 Cohort | Ability to manage on available income | Survey 1 – 1996 18-23 years, (N=14,247) % | Survey 7 – 2015 37-42 years, (N=7,186) % |
|-----------------------|--|--|---|
| | Very difficult/impossible | 18.7 | 13.8 |
| | Difficult sometimes | 32.6 | 26.8 |
| | Easy/not too bad | 49.3 | 59.3 |
| 1946-51 Cohort | Ability to manage on available income | Survey 1 – 1996 45-50 years, (N=13,714) % | Survey 8 – 2016 65-70 years, (N=8,622) % |
| | Very difficult/impossible | 14.4 | 8.9 |
| | Difficult sometimes | 27.6 | 19.2 |
| | Easy/not too bad | 58.0 | 71.9 |
| 1921-26 Cohort | Ability to manage on available income | Survey 1 – 1996 70-75 years, (N=12,432) % | Survey 6 – 2011 85-90 years, (N=4,055) % |
| | Very difficult/impossible | 6.9 | 3.6 |
| | Difficult sometimes | 19.5 | 10.5 |
| | Easy/not too bad | 73.6 | 85.9 |

Table 2-4 Labour force participation across two cohorts (born 1973-78 and 1946-51)

| | | Survey 3 – 2003 | Survey 7 – 2015 |
|-----------------------|-----------------------------------|--------------------------------|-------------------------------|
| 1973-78 Cohort | Labour force participation | 25-30 years, (N=9,081) | 37-42 years, (N=7,186) |
| | | % | % |
| | Not in LF/ unemployed | 16.5 | 13.2 |
| | Part time (<35 hrs) | 25.2 | 40.0 |
| | Full time (35+ hrs) | 58.3 | 46.7 |
| | | Survey 1 – 1996 | Survey 8 – 2016 |
| 1946-51 Cohort | Labour force participation | 45-50 years, (N=13,714) | 65-70 years, (N=8,622) |
| | | % | % |
| | Not in LF/ unemployed | 27.0 | 69.8 |
| | Part time (<35 hrs) | 34.0 | 22.4 |
| | Full time (35+ hrs) | 39.0 | 7.8 |

3. Child care

This chapter presents data from women in the 1973-78, 1946-51 and 1921-26 cohorts on child care. Findings for women in the 1973-78 cohort are presented first as child care is most relevant to this cohort. In successive surveys these women have been asked questions about the number of children they have, their use of formal and informal child care (including its convenience, availability and affordability), their satisfaction with child care arrangements, if they were happy with their share of child care activities, and, if applicable, how long a period of leave they took before returning to work. These questions are detailed in [Appendix A](#).

Women in the 1946-51 cohort were asked questions about whether they provided care for a grandchild or other person's child and if they were happy with their share of child care activities. Women in the 1921-26 cohort were only asked about whether they provided care for a grandchild or other person's child.

Responses to questions about providing child care and use of formal and informal care have been analysed by relevant socio-demographic status and health factors.

3.1 Overview of women in 1973-78 cohort who have children

In 1996 when the women in the 1973-78 cohort were aged 18-23 years, less than 10% had children, with very few having more than one child (see Figure 3-1). The greatest increase in the number of children was between Survey 3 (when the women were aged 25-30 years) and Survey 5 (31-36 years). At Survey 7 in 2015, 14%, 39%, and 26% had 1, 2, or 3 or more children respectively while 21% had never reported having a child.

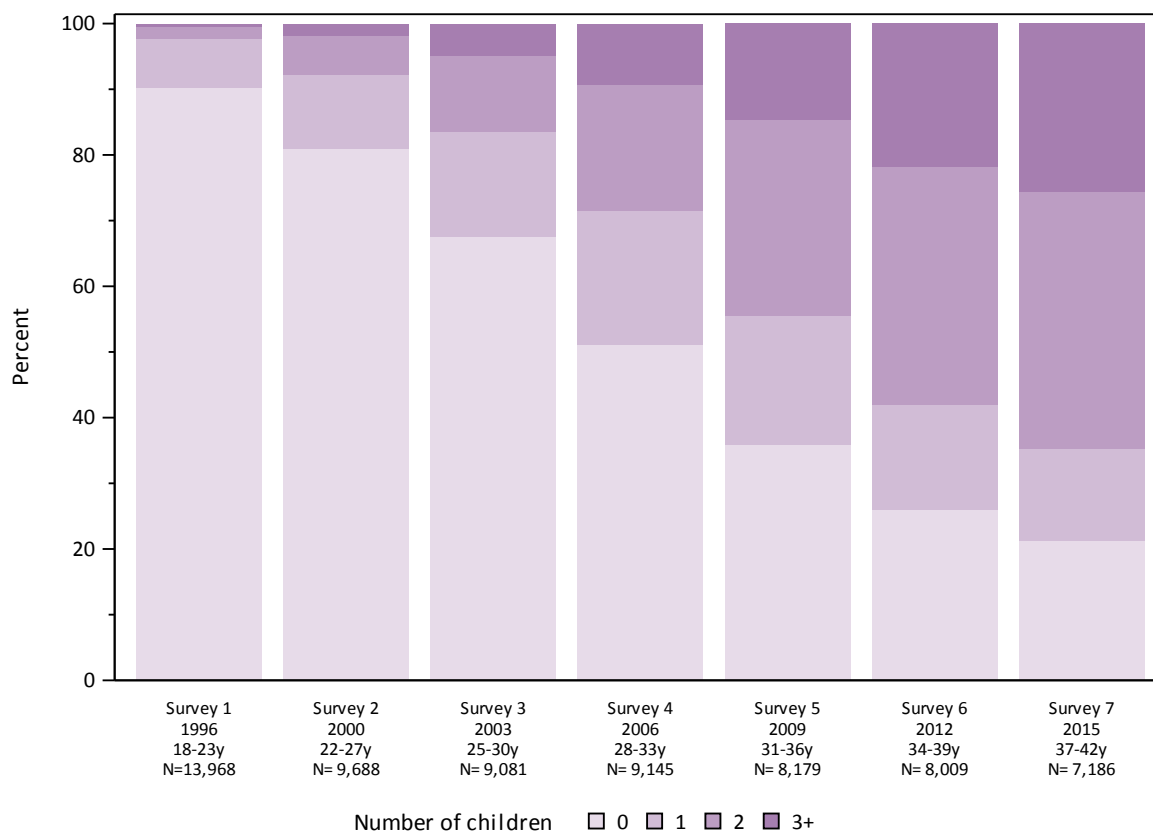


Figure 3-1 Percentage of women in the 1973-78 cohort at Surveys 1 to 7, by the number of children reported at each survey.

3.2 Child care use by women in the 1973-78 cohort

Table 3-1 shows the numbers and percentages of women with children who reported using formal and informal child care from Survey 4 when they were 28-33 years of age to Survey 7 when aged 37-42. Formal child care was defined as ‘before and/or after school care, long day care, family day care, occasional care and preschool’. Informal child care was defined as ‘care by family, friends (paid or unpaid) and a baby sitter’. Over this period from 2006 to 2015, formal and/or informal child care use decreased from around 75% of women to 60%. At all

surveys slightly more women only used informal care than only using formal care. Use of both types of care was the most prevalent when the women were aged between 31 and 39 years.

Table 3-1 Percentages of women in the 1973-78 cohort with children reporting use of formal and informal child care from Survey 4 to Survey 7.

| Survey | Age | N | Used child care % | | | Did not use child care % |
|----------|-------|------|-------------------|---------------|------------------------|--------------------------|
| | | | Only formal | Only Informal | Both formal + informal | |
| Survey 4 | 28-33 | 4342 | 20.8% | 28.2% | 25.9% | 25.0% |
| Survey 5 | 31-36 | 4920 | 17.7% | 26.6% | 28.6% | 27.1% |
| Survey 6 | 34-39 | 5801 | 21.2% | 22.0% | 24.6% | 32.1% |
| Survey 7 | 37-42 | 5079 | 15.6% | 22.6% | 21.3% | 40.4% |

3.2.1. Hours of formal and informal child care use by women in the 1973-78 cohort by socio-demographic status

This section presents the association between socio-demographic status (labour force participation, years of education, managing on income, area of residence) of women in the 1973-78 cohort by whether they use formal and informal child care (measured as number of hours ‘in a normal week’). Socio-demographic and child care data at the most recent survey (Survey 7, when the women were aged 37-42 years) are presented here. Graphs or text descriptions of the associations at earlier surveys are not presented because the nature of the associations were similar at all surveys. [Appendix A](#) presents information about how the socio-demographic indicators were characterised.

3.2.2. Child care use and labour force participation

Figure 3-2 and Figure 3-3 show comparisons of labour force participation by women in the 1973-78 cohort by their hours of use of formal and informal child care at Survey 7. Women who were not in the labour force had significantly less use of either types of care, while use was highest in employed women, with full-time women using the most hours. Among employed women (working part-time and full-time) use of informal child care was higher than use of formal child care.

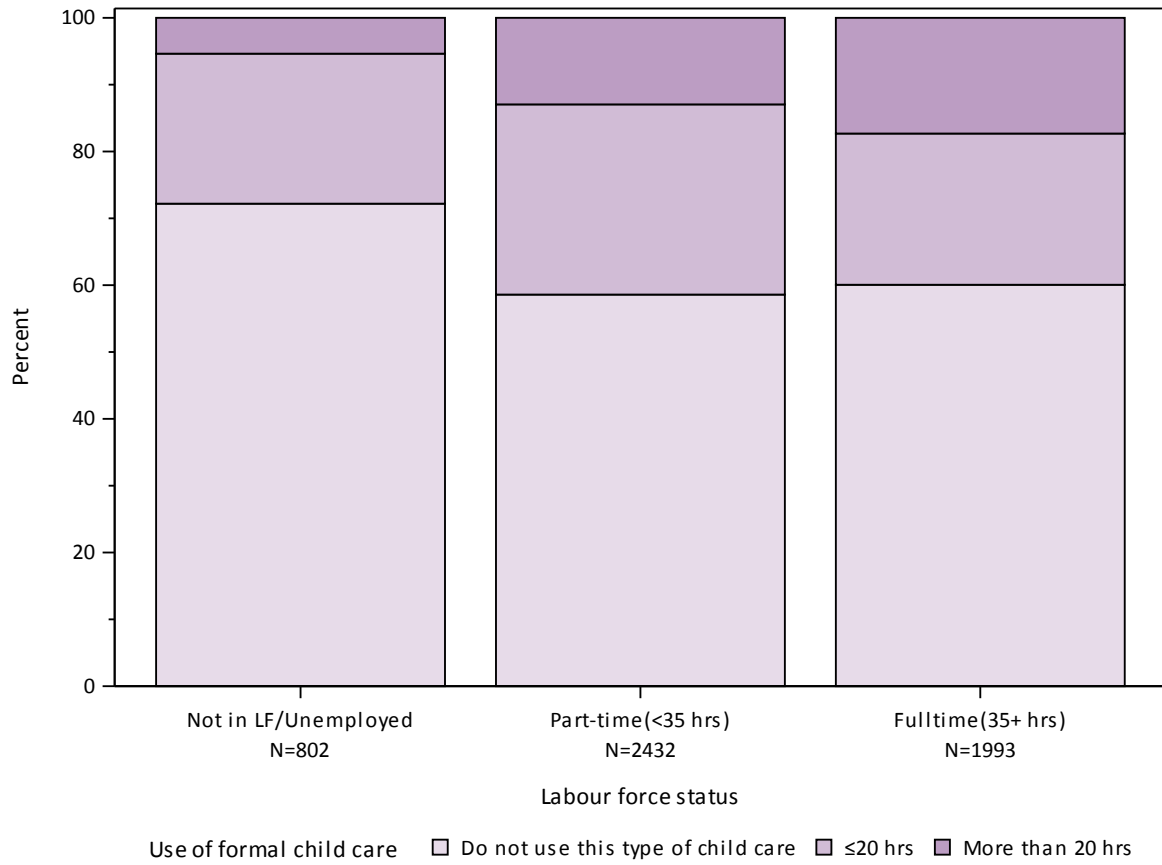


Figure 3-2 Percentage of women in the 1973-78 cohort at Survey 7 using formal child care, by labour force (LF) participation.

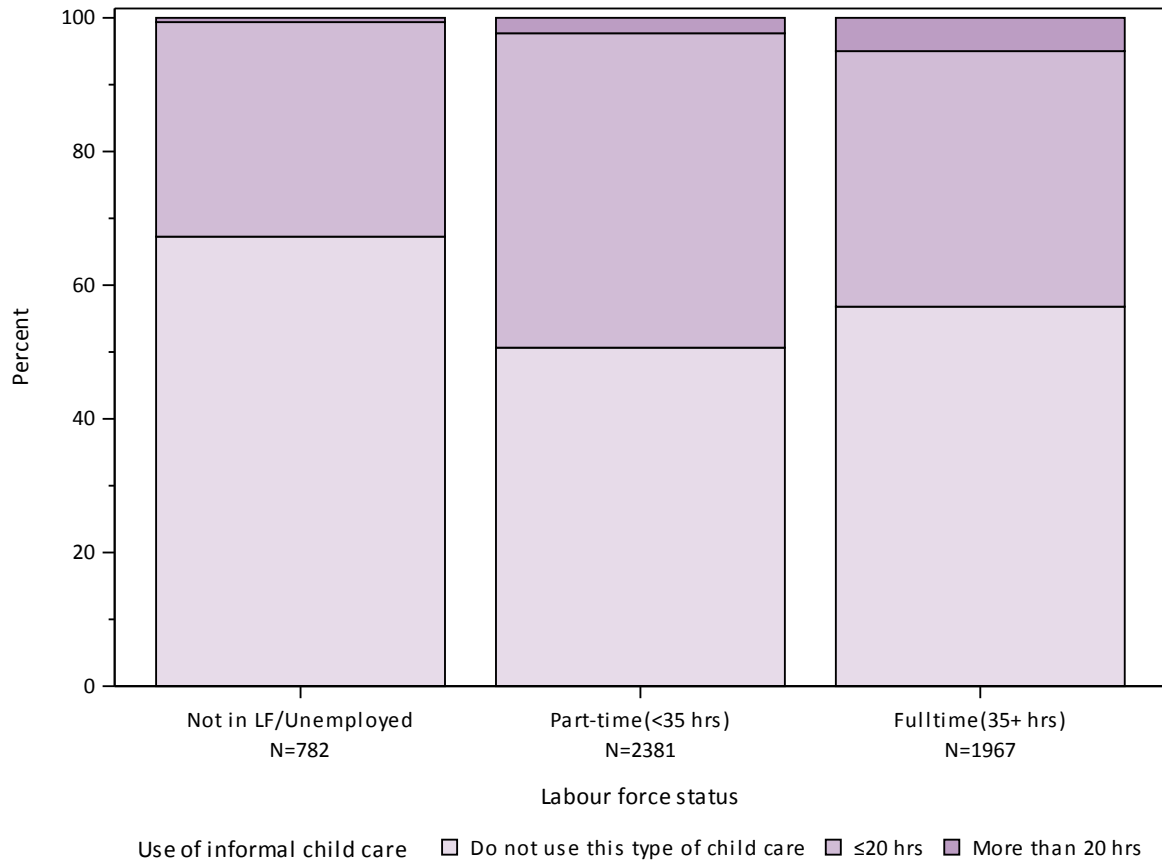


Figure 3-3 Percentage of women in the 1973-78 cohort at Survey 7 using informal child care, by labour force (LF) participation.

3.2.3. Child care use and years of education

Figure 3-4 and Figure 3-5 show comparisons of the highest level of education attained by women in the 1973-78 cohort by their reported use of formal and informal child care at Survey 7. The graphs show the higher a women’s level of education the more she used both types of child care. Significantly more hours of formal child care use, in particular, was observed for women with post-school and university level education.

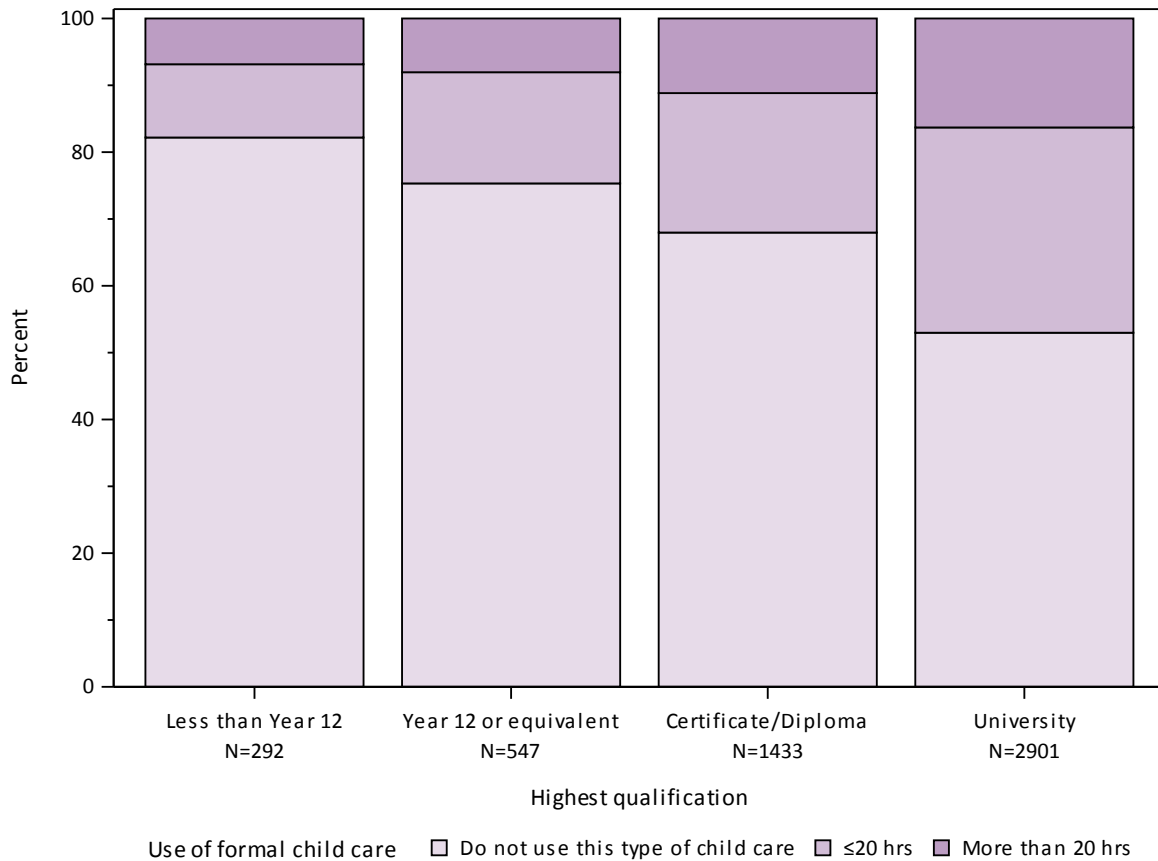


Figure 3-4 Percentage of women in the 1973-78 cohort at Survey 7 using formal child care, by years of education.

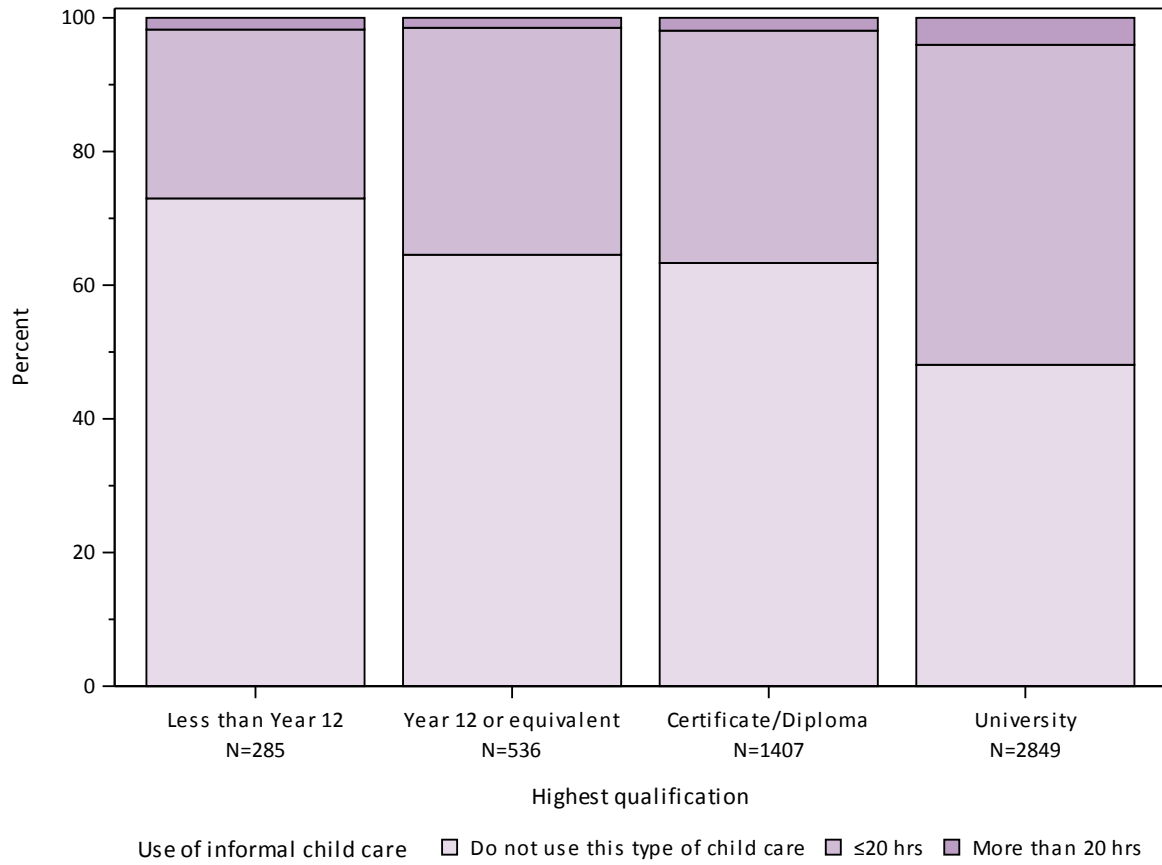


Figure 3-5 Percentage of women in the 1973-78 cohort at Survey 7 using informal child care, by years of education.

3.2.4. Child care use and managing on income

How well women in the 1973-78 cohort reported managing on their income, by their formal and informal child care use at Survey 7, are respectively presented in Figure 3-6 and Figure 3-7. Of note, use of 20 or more hours per week of formal (12-14%), and informal child care (around 3%) was reported by a similar percentage of women regardless of how well they reported managing on their income. Compared to women who reported it was impossible to manage on their income, a higher percentage of women who reported that it was easy/not too bad used up to 20 hours of formal or informal child care per week.

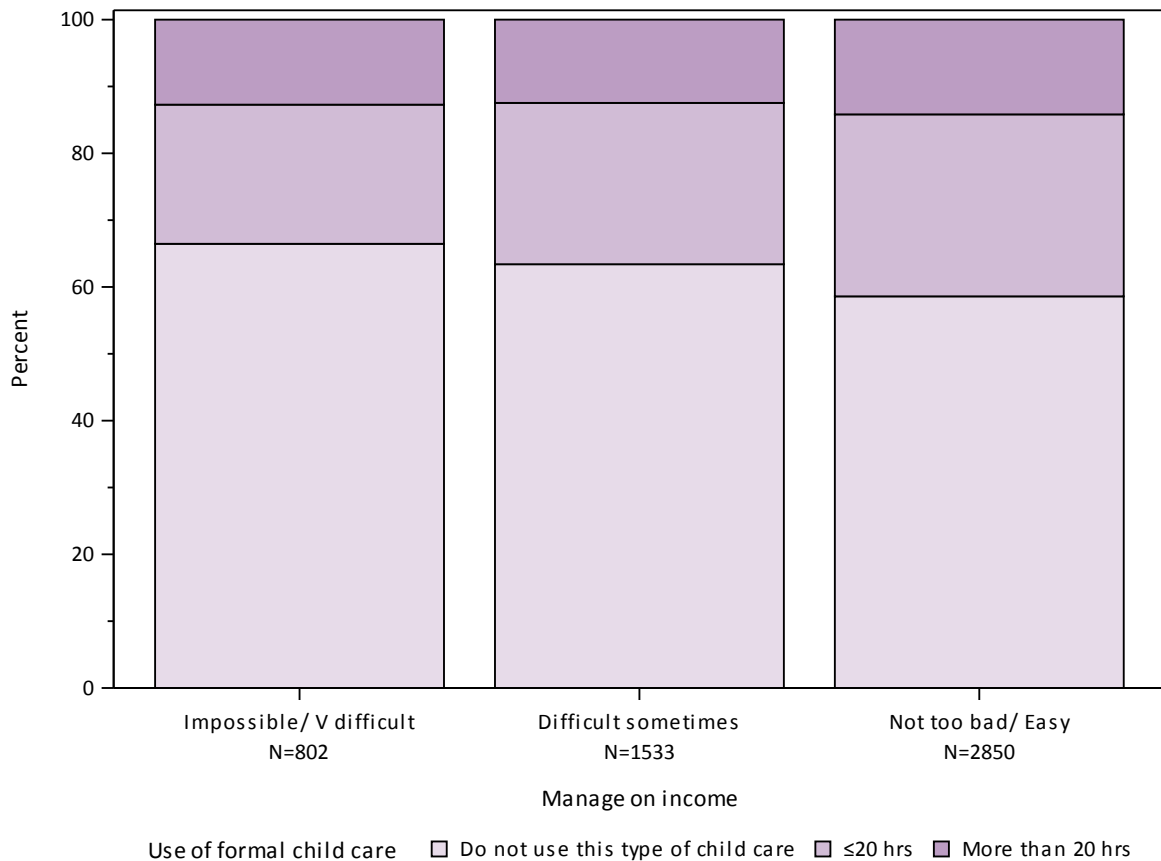


Figure 3-6 Percentage of women in the 1973-78 cohort at Survey 7 using formal child care, by managing on income.

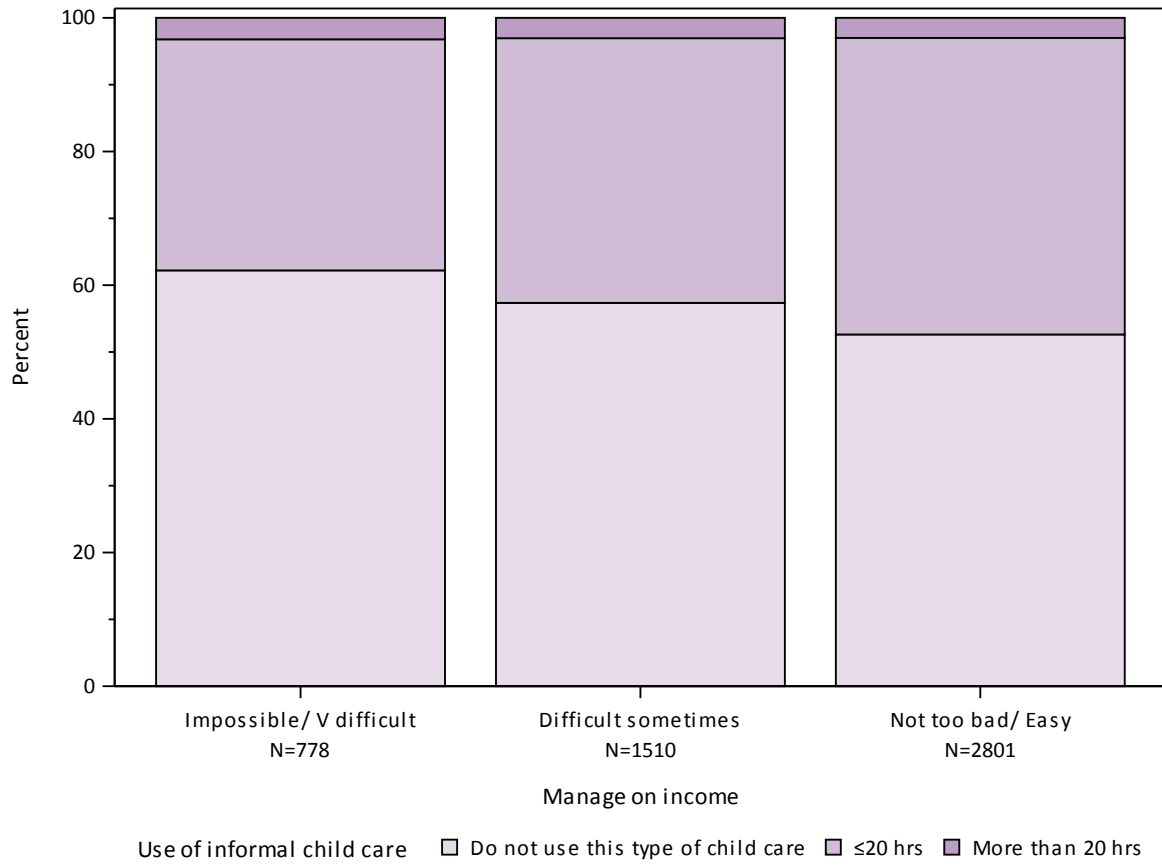


Figure 3-7 Percentage of women in the 1973-78 cohort at Survey 7 using informal child care, by managing on income.

3.2.5. Child care use and area of residence

There was a clear significant association between where women lived and their use of formal and informal child care (Figure 3-8 and Figure 3-9). Almost double the percentage of women living in a major city used 20 or more hours of formal child care compared with women living outside these cities. There was no difference in the percentages of women reporting 20 or more hours of formal child care use for inner regional, outer regional or remote areas (around 8%), possibly reflecting the lack of availability of these services or difficulty accessing services due to distance in more remote areas. Informal child care use was lowest in remote areas (26%) compared to 42 to 48% for women living closer to or in major cities.

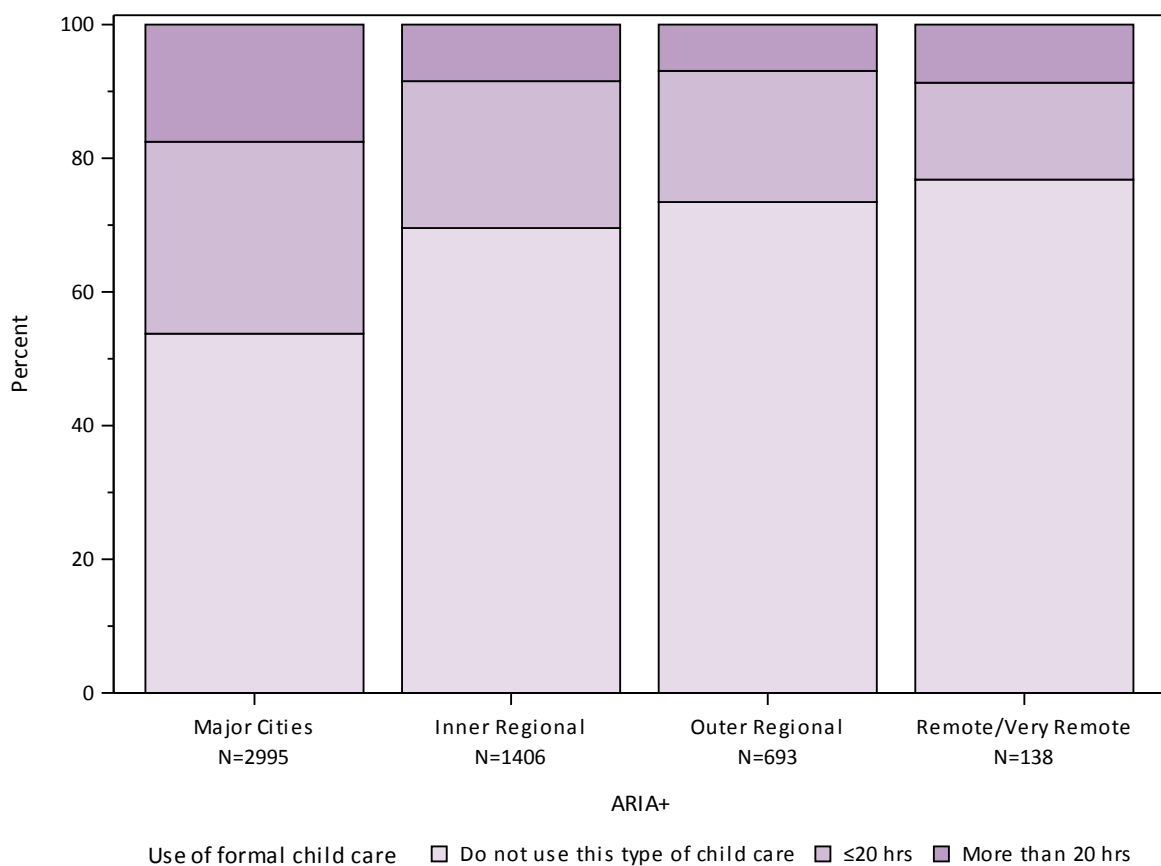


Figure 3-8 Percentage of women in the 1973-78 cohort at Survey 7 using formal child care, by area of residence.

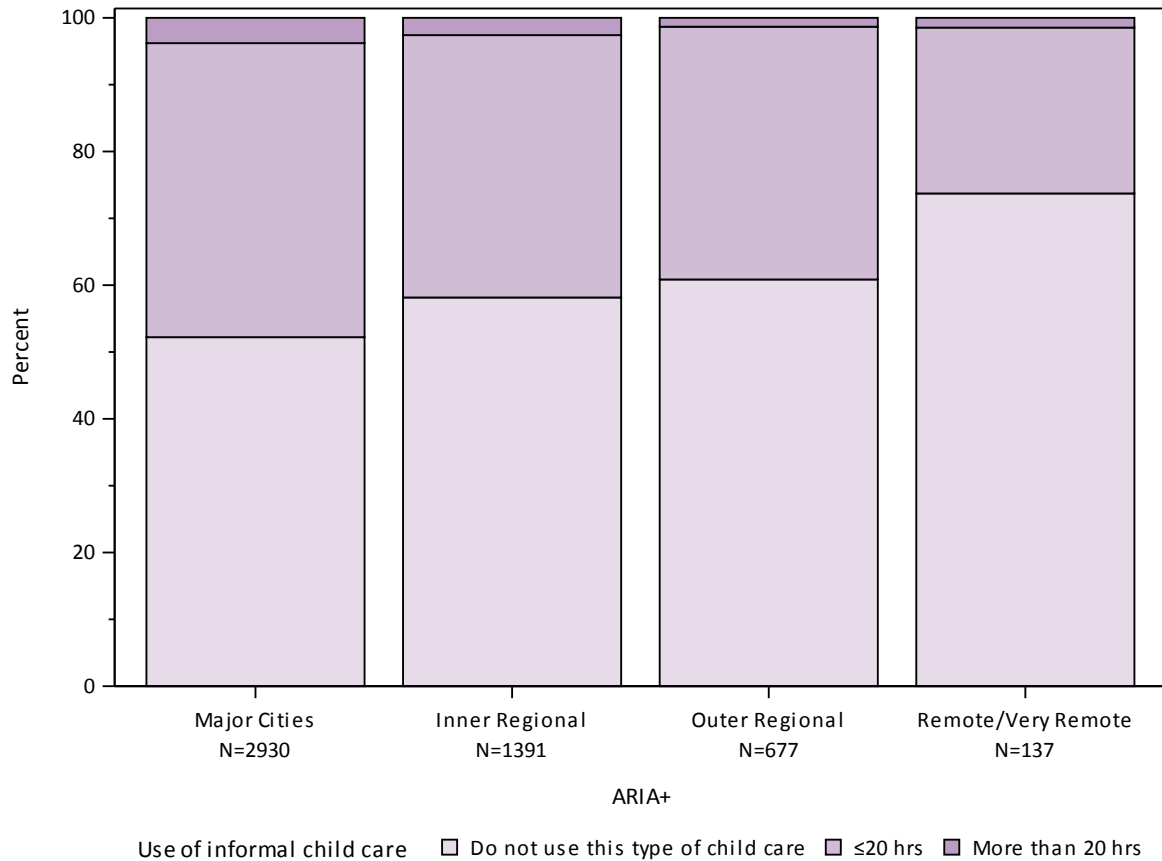


Figure 3-9 Percentage of women in the 1973-78 cohort at Survey 7 using informal child care, by area of residence.

Key Points

- In the 1973-78 cohort, less than 10% of women aged 18-23 (in 1996) had at least one child; by the time they were 31-36 years, 79% had at least one child.
- 75% of women used informal and/or formal child care when they were 28-33 years of age; this percentage dropped to 60% when the women were aged 37-42.
- Women who were not in the labour force had the least child care use and working women (either part-time or full-time) had the most use.
- The higher a woman's education level, the more informal and formal child care she used.
- Use of formal and informal care was similar, regardless of how well women reported managing on their income.
- Women who lived in a major city used more formal child care services than those who did not live in a major city.
- The percentages of women who used informal child care were similar amongst those who lived in major cities, and inner and outer regional areas with those in remote areas being the least likely to use this type of care.

3.3 Perceptions of the convenience, availability and costs of formal child care by women in the 1973-78 cohort

From Survey 4 to Survey 7 women were asked about the convenience, availability of places and costs of formal child care, and about the availability of informal child care (see Appendix A for questions). Figure 3-10 shows the responses to these questions by women who used formal child care (N=2099) at Survey 7, when they were aged 37-42 years. Similar results were also found at Surveys 4 to 6.

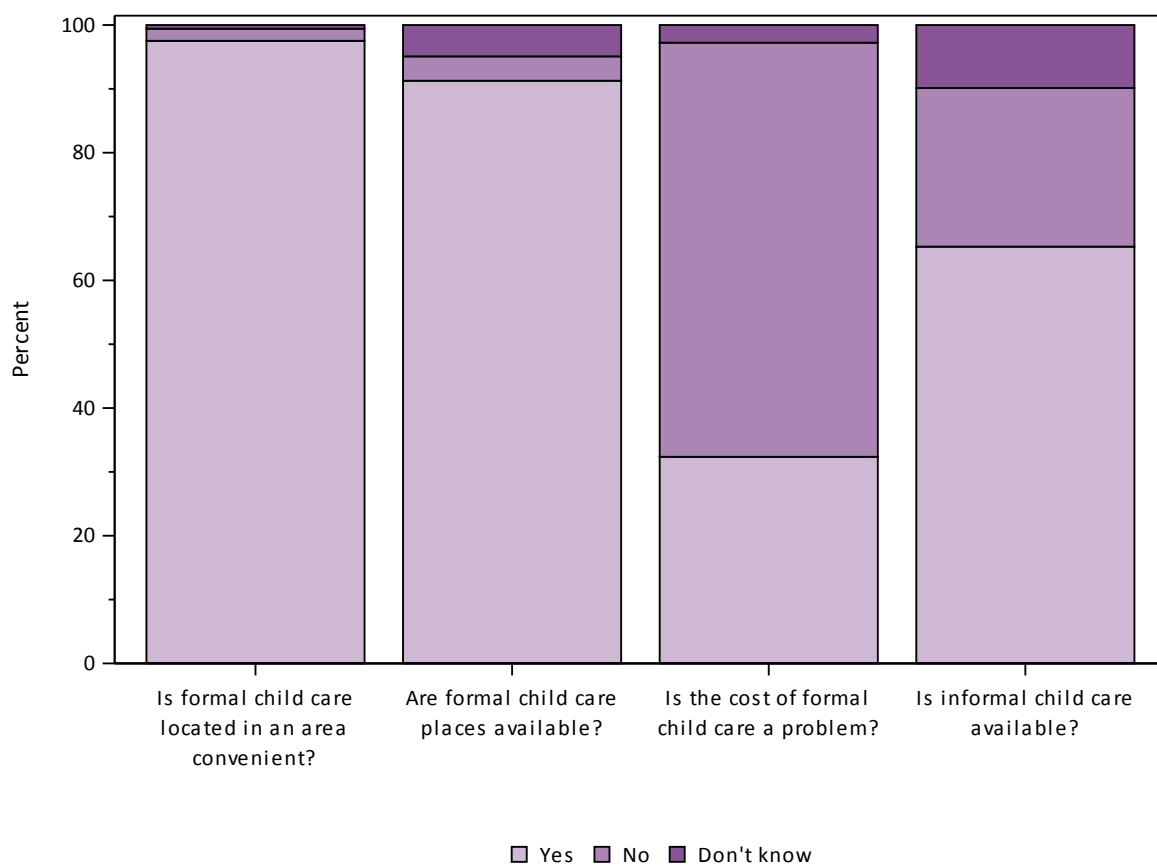


Figure 3-10 Percentages of women in the 1973-78 cohort at Survey 7 who use formal child care, by the convenience, availability and cost of formal child care and availability of informal child care (N=2099).

The figure shows that overwhelmingly women considered formal child care to be convenient and available, with very few (less than 10%) reporting otherwise. About 30% of women using formal child care reported that the cost was a problem for them. Of women using formal child care, around 65% said that informal child care was available to them.

The responses to the same questions about convenience, availability and costs of formal child care were also analysed for women who did not use formal child care to gauge these issues

from their perspective. Not surprisingly, there were higher percentages of ‘don’t know’ responses, around 13% for convenience, 46% for availability and 36% for costs.

3.3.1. Perceptions of convenience, availability and costs of formal child care by women in the 1973-78 cohort at Survey 7 by socio-demographic status

Table 3-2 presents a summary of the analysis of the convenience, availability and costs of formal and informal child care by women in the 1973-78 cohort by socio-demographic status. The analysis revealed general trends by which women with labour force participation, more years of education, greater ease in managing on their income, and living in or closer to major cities found formal child care more conveniently located and affordable. There were fewer significant associations between socio-demographic status and women’s perceptions of the availability of child care places.

Table 3-2 Summary of significant associations found in the analysis of the convenience, availability and costs of formal and informal child care at Survey 7 by women in the 1973-78 cohort, by socio-demographic status (labour force participation, years of education, managing on income and area of residence) (N for formal child care=2099; N for informal child care=3203).

| | Convenient location | | Availability* | | Affordable cost | |
|--|---------------------|---------------------|--------------------------|---------------------|-------------------|---------------------|
| | Formal child care | Informal child care | Formal child care places | Informal child care | Formal child care | Informal child care |
| Higher labour force participation | | ↑ ¹ | | ↑ ¹ | ↑ ¹ | ↑ |
| Higher education | | ↑ | | | ↑ | ↑ |
| Easier to manage on income | ↑ | ↑ | | | ↑ | ↑ |
| More urban residence | ↑ | ↑ | ↑ ² | | | ↓ ³ |

Arrows represent significant associations at $p \leq 0.01$; upward arrows represent positive associations between higher socio-demographic status and positive perception of convenience, availability or affordability, and downward arrows represent negative associations.

¹Significant for part-time labour force participation only;

²Places perceived as more available by women in inner regional areas compared with major cities;

³Significant association represents that fewer women in remote areas found the cost a problem.

3.3.2. Satisfaction and happiness with share of child care activities by women in the 1973-78 cohort

At various surveys the women in the 1973-78 cohort were asked about their satisfaction with their child care arrangements and how happy they were with their share of performing child care (see [Appendix A](#) for questions). Satisfaction with their child care arrangements was asked at Surveys 1 to 4, with 87 to 95% of women at these surveys indicating they were satisfied or very satisfied. Few reported being very dissatisfied, with this percentage highest at Survey 1 (at 4.7%) when women were aged 18 to 23. Women were asked if they were happy with their share of child care activities at Surveys 1, 3 and 4. At the three surveys about 70% of women were 'happy the way it is', 24 to 27% wanted 'other family members to do more' and 4 to 8% 'would prefer another arrangement'.

Key points

- The majority of women using formal child care considered it to be convenient and available when aged 37 to 42 years.
- Approximately one-third of women using formal child care reported that cost of this service was a problem.
- Convenience and availability of formal child care was perceived to be more of a problem by women who did not use formal child care than by women who did.
- Higher socio-demographic status was associated with the perception that formal child care was more conveniently located and affordable.
- Overall, the majority of women experienced high levels of satisfaction with their child care arrangements and were happy with their share of child care activities.

3.4 Caring for children and paid work participation: A qualitative examination of free-text comments from ALSWH participants

“The village no longer exists!!”

*Comment by an ALSWH participant from the
1973-78 cohort at Survey 7 in 2015*

The quantitative data suggests that overall, women are satisfied with their childcare arrangements, however the qualitative analysis revealed a far more complex experience of women returning to work and providing care for their children. This section includes an analysis of ALSWH qualitative data conducted to determine the nature of child care use and needs among women of employment age and to identify the factors that might facilitate or deter a return to paid work after having children.

There were 58,910 free-text comments from ALSWH participants across all four cohorts of women (see [Appendix A](#)). Therefore, reducing the sample for analysis according to responses in the quantitative section of the survey was necessary.

We defined active participation in paid work as occurring where women indicated that they were undertaking any amount of paid work. Women were included in the sampling frame regardless of their paid work status. Women were considered to have responsibility for children where they reported having and providing care for their children or their partner’s children. Only women who had responsibility for children were included in the sampling frame, which included data collected from the most recent surveys of the 1973-78 and 1989-95 cohorts. To capture difficulties in returning to paid work after having children or becoming responsible for children, data from two separate groups of women formed the sampling frame:

- a. Women who responded ‘yes’ to the question about regularly caring for children **and** who reported engaging in some form of paid work on the most recent survey **and** who provided a free-text comment at the end of the survey
- b. Women who responded ‘yes’ to a question about regularly caring for children **and** who reported not engaging in some form of paid work on the most recent survey **and** who provided a free-text comment at the end of the survey

For the 1989-95 cohort, Survey 3 was used to identify women who had given birth as data on births was not collected at Survey 4. Survey 4 was used to identify women based on their employment status. Free-text comments were reviewed and those relevant to the research question were identified. Comments were included if they mentioned being a mother, caring for children, participating in paid work, or reported some form of leave from paid employment to care for children. Of the 979 total comments across both cohorts, 136 were deemed relevant.

The longitudinal data (that is, free-text comments from all surveys for each included participant) were collated. There were 457 longitudinal comments from 137 women. Data from two participants were excluded during analysis as they did not meet inclusion criteria, bringing the total to 135 women with 449 comments. Comments were coded using thematic analysis (see [Appendix A](#) for details).

3.4.1. Results

In this analysis, the comments reviewed pertained to women who were or who referred to themselves as a 'mother.' Therefore, the term 'mother' is used to describe the women who had responsibility for children. The major themes arising from this analysis included *how she feels* (e.g., stressed, tired, busy), *managing multiple roles* (e.g., career compromise, health, housework, motherhood), *return to paid work* (e.g., deterrents and facilitators to returning to work), *type of paid work* (e.g., casual, full time), *type of leave taken* (e.g., annual leave, maternity leave, unpaid leave), *type of child care used* (if any; e.g., formal child care, share care with partner). Women expressed that being a mother is often difficult and challenging, requiring them to juggle multiple roles at the same time. Some women spoke about the impossibility of being 'super mum' and being able to 'have it all' (a successful career and being a mother), while others reported feeling challenged and tired, but happy and lucky with their family and life.

Overwhelmingly, the women in this analysis reported that being a mother involved fulfilling multiple roles (e.g., mother, wife, paid employee), often concurrently. Although each woman described her own individual circumstances, the exhaustion of managing the demands of motherhood, the daily work of maintaining a household, and balancing this with being a wife or partner, and, for some, an employee, was a common experience:

"I have found motherhood and paid work so difficult; of course this involves 100% of housework as well and helping on our farm..."

"...Having 3 children I feel constantly exhausted and overwhelmed on a daily basis, juggling work, family, friends, relationships with husband and house duties but I still love my life. Most women my age that I speak to say they feel the same..."

"Full time mother with zero spare time for exercise (sic), reading etc. Extremely limited family support and no external child care (by choice) = hard! But very satisfied with motherhood."

“Currently studying at TAFE which has its ups and downs. Being a wife and mother at times can become a bit too much. Stay at home mother as husband works odd hours and shift work.”

Returning to paid work was often difficult and required compromise in the type of job, the hours worked, the money earned, or by not returning to paid work at all.

“I live in a remote part of Australia. We have great services (sports, government facilities etc) for a town so small but the work and lifestyle opportunities are reduced. I long for the career I had before I had children but employment opportunities here are reduced for my field. This at times causes me to feel disappointed with my career and work. I have chosen to support my husband (with a great career) and support our choice of having children (not leaving them in child care). I have accepted part time work below my level while they are young.”

“There are questions about work and work life balance. My situation is that I have recently stopped paid work as I found it impossible for both my husband and myself to maintain careers and have the level of involvement in our children's lives that we wanted. The lack of flexibility in mid-level corporate jobs mean that for many people it is a choice of all (full-time) or nothing. The inability for me to maintain my career has led to dissatisfaction and worry about our financial future, especially as I am no longer financially independent.”

The lack of flexibility offered in some workplaces meant a return to paid work was difficult for some women.

“I've experienced extreme discrimination after child birth relating to my career/job. I am a highly educated, competent individual who lost their position after having children. I now find options for part time work extremely limiting and hence I am not currently able to work. This should be explored in this survey as this cohort is one that would have valuable information on how many women/parents have faced similar hardship.”

Some women reported frustration at the circumstances leading to having to make career compromises, suggesting that it is not possible to be a successful mother and a successful professional at the same time.

“...I had to give up my senior management role to put my family first & now I can't get a look in for anything because I can't work full time. It seems I can be a mum or a professional but not both. Why are women still cornered into this type of decision?”

Many women chose to stay at home with their children.

“Generally I'm happy with all areas of my life. I love being a SAHM [sic- stay at home mum]. And enjoy watching and helping them grow into beautiful individuals...”

"To clarify, I am currently at home looking after my two small children, the youngest being 5 months. My paid maternity leave ran out after 18 weeks. I do not have a position of employment to return to however I am content to remain at home with my children for the next couple of years."

Some women reported concern for their future job prospects, or difficulty adjusting to not engaging in paid employment outside the home.

"I have given up a career to raise my son who is 2. Trying to find confidence without the satisfaction of work is difficult..."

"I feel that a lot of my health and well being issues are affected by being a mother of two young children. Most of my time and energy is taken up bringing them up and looking after the house. I miss my full time/part time work but feel i have little choices in returning to work due to child care options. I feel even though my eldest child is 3 years old i am still adjusting to my role as a mother and housewife."

For those who returned to paid work, juggling child care with working commitments, house duties and motherhood, regardless of the amount of support was difficult.

"Life is hectic raising 4 children and working part time. It is hard to find time for yourself, let alone your partner! I wouldn't be able to do what I do without the help, love and support of my partner and my mum!"

"Very stressful time at the moment so this has influenced my current mood, coping behaviours (i.e. poor choices) and as such; my survey answers. We have just sold our home, moved to my parents (housesitting for 2 months), looking for rental, have bought a house, getting plans done, planning a build, struggling with my masters study workload, working shiftwork, very demanding job and trying to be super mum and fulfil all family obligations!! But I'm sure it's transient...life changes quickly and I'm normally upbeat."

Many women reported feeling busy and tired from juggling their responsibilities.

"Since entering my thirties I have stopped paid employment and have become a stay-at-home mother. It is by far the most exhausting job I have ever done..."

"I am very healthy, work part time in the hours I choose, have 3 healthy kids, a loving husband but life is very very busy no matter how hard I try for it not to be. This inevitably results in me feeling a bit stressed, a bit irritable a bit worn out. 3 young children and part time work is hard work, but I don't want to have 3 older children and no work. It is hard, but I see no other way."

Child care upon return to paid work was individual and depended on personal circumstances. The women reported using formal and informal child care, including friends and family, au pairs, or home schooling their children themselves.

"The questions about child care arrangements were difficult to answer accurately. Since returning to work I have had informal assistance from a friend who was living in our home (total of about 16 occasions) and my mother and sister. My son has commenced formal child care (three days per week) this week."

"I like to add that I currently use an overseas "au pair" as my informal child care arrangement....I find formal child care very inflexible for my work hours and now that I am separated and cannot rely on my husband for child care after-hours, I find that having a live-in au pair is the best solution for our family..."

"I am a homeschooling mother at home with no paid work."

Flexible working conditions, including being able to work part-time, were important to facilitate women returning to paid work.

"As an overall comment on where life is at the moment - I feel quite upbeat. Both of my children are at school now and are happy there. I work 24 hours a week and am fortunate to be to do two 4 hour days from home during school hours, with the other two days in the office. This has given me more time at home, particularly without the kids being there and I found I am able to be more organised. Life runs more smoothly as a result. Also, I am doing more exercise than I have ever done. Thanks for the opportunity to participate."

"Left my previous job during my second pregnancy and returned to work when my youngest child was 18 months old. When I returned to work I took a job that was more family friendly with part time hours and is a flexible workplace."

Several women spoke about having their own business, allowing them to work from home. This was considered both a benefit, granting greater child care flexibility, but also as a disadvantage with long hours and an inability to 'switch off.'

"I am generally a very happy person and very optimistic. I feel like there is not enough time in the day as I run a family business with my partner and we raise our 2 kids. I am lucky that he and I 'job share' and haven't had formal child care up until now - preschool and school age kids. Whilst I would like to do less work, I am not unhappy about it. I have trouble sleeping because I have so much on my mind and really wish I knew how to switch off."

"I'm in unusual circumstances in that my husband left a very stressful full time job nearly 18 months ago and now we both work from home, sharing parenting and housework roughly 50/50, which has radically changed our household dynamics. In my case, my business grew from a hobby and now consumes all my available time. I would estimate 70 plus hours, but it is part hobby too, so I am willing to sacrifice some sleep for it. It is great and I love it, however I am constantly pulled between demands of parenting and wanting to work."

The cost and availability of child care was a concern for many, and for some, was prohibitive to returning to employment outside the home.

“Having had a child in the last year and needing Child care I have found it be quite expensive. Although the government is subsidising it, I've found that the money I get for working doesn't actually cover it. And actually working means I get less subsidy which means it covers even less. I understand that child care centres in [capital city] are among the most expensive but we needed to put our daughter in child care close to where we both work so if needed we will be close by as we commute over an hour to get to the area. The system seems designed to keep mothers in the home.”

“The questions in relation to work do not reflect my experience and seem to make various assumptions. I feel I have a choice between unsatisfying work (that barely covers the cost) and chronic depression. Economically, it makes no sense. Eg. No, I chose not to return to work - well only in the broadest sense. Eg. In general, I give up work for family, rather than giving up family for work. I take unpaid leave. Well frankly, who else is going to do it, paying anyone to help costs more than I earn plus you have to find someone available. The village no longer exists!!!”

Some women reported sharing child care with their partner.

“Still at home with 4 month old baby. I went back to work when my first child was 6 months and my husband took over as full time carer. I plan to go back to work when this baby (second child) is 9 months. My husband and I are both planning to work part time and share care for our baby.”

However, sharing child care did not necessarily reduce the women's caring load.

“Sorry for sending this in so late. I think my biggest problem is lack of time. I work full time and have 4 small children (age 1-9). My husband is currently a stay at home Dad, and whilst he helps with a lot of things (like cooking and taking the children to after school activities) there are a lot of roles that he doesn't help with (or there is minimal help with) like homework, organising things for the children (sport, play dates, school related tasks, clothes, children's needs), washing and cleaning. I need to spread my time between work, caring for the children and home related tasks. There is not much time left over for me (although i have started to exercise regularly which i enjoy).”

Overall, while many report the difficulties inherent in juggling their multiple roles, they also reflected positively upon their life circumstances.

“I am very happy with my life - although I would like to slow it down a little and have more time to spend with my family and to exercise and relax. I am currently working 2 jobs and my husband is FIFO so there are times when I feel absolutely knackered. I, and many others, still face inequalities in the workplace - particularly when it comes to having career interruptions. I feel like I am mainly responsible for the day to day household running and

the kids extracurricular and school activities. This is mostly because my husband works away, but it does still impact on my health and well being as it does get quite stressful. This being said, in general I feel I am very lucky to have three healthy kids, a loving partner, a house to live in and the opportunity to still participate in my career.”

3.4.2. Changing roles over time: Examples from the longitudinal data

Returning to paid work after having children is complex, requiring women to juggle multiple roles. Below are the comments from one woman who regularly provided a comment in her surveys. These comments span 19 years (from Survey 1 in 1996 to Survey 7 in 2015) and provide a unique insight into the changes women face over time as they become mothers. These comments are reflective of experiences shared by the broader cohort included in this analysis.

Survey 1 (1996) *Four years ago I contracted glandular fever from university. Since this time, although I engage in vigorous activity, I feel I have to be very careful as I become sick quite easily. In the years preceding my glandular fever, I did not visit a doctor once. Afterwards, and especially the following year, I suffered from Bronchitis, Tonsillitis (sic), even Pneumonia. I am also suffering mild depression as a result of my fiancé accepting a position overseas for an indefinite period of time.*

Survey 2 (2000) *Regarding Q50. I don't actually use rigorous exercise to control my weight per se. I do a lot of vigorous exercise which of course does control my weight, however, the reason I exercise is because it makes me feel good. My body's shape is merely a bi (sic) product. If I felt this good without doing exercise I probably wouldn't do it. I guess I'm an endorphin junky!*

Survey 3 (2003) *Please refer to my change of address card! My father died within the last month resulting in my answers reflecting emotional pressure at times and conflict with family members. If this event had not occurred, I can't envisage having any other emotional issues.*

Prior to having children, women described their lives in terms of their own experiences and priorities. Once women had children, the focus of comments shifted to the experiences of birth and motherhood, including the emotional and health impact of being a mother. The longitudinal results also clearly demonstrated the uptake of multiple roles. Women described their working and leisure activities prior to children. However, subsequent to motherhood, the number of roles they wrote about dramatically increased. Women dealt with this in different ways. Most women wrote about the overlap and intersections between these roles, or the impossibility of being able to do it all, while some described compartmentalising their roles.

Survey 4 (2006) *A lot of your questions relate to the last week or month. I feel fantastic now - my baby is 5 months old and a real gem. But the first 3 months were absolute hell and I often wondered if I was doing anything right. Support from my family was excellent but didn't seem to lessen my feelings of panic, anxiety and my constant fatigue. I don't think I was ever depressed but i was often concerned i might be heading that way. I'm not sure if your survey should include questions on motherhood - especially for the first few months. Maybe it would be useful?*

Survey 5 (2009) *Over the last month the whole family has been sick with flu and the kids (and hence myself) are up a lot at night. For this reason I feel tired and worn out but generally I'm pretty happy although always busy. I am still positive and hopeful about the future etc but just feel like I need a break night now and definitely some sleep. I really wish that I had help (informal) closer to home. My mum lives 2 1/2 hrs away. I would love to have a network of friends or family for help when I need it but all my friends seem to be in the same boat so while we support each other emotionally, we are unable to actually relieve each other or mind each other's kids. I wish I had someone to help out when I'm sick but we have our own business and we just can't have sick days.*

The support available to women raising children varied widely. A strong network involved having child care available, as well as support for emotional and practical needs. However, not all women perceived that support was accessible and, for some women, the support available did not necessarily alleviate the demands of motherhood.

Survey 6 (2012) *I am generally a very happy person and very optimistic. I feel like there is not enough time in the day as I run a family business with my partner and we raise our 2 kids. I am lucky that he and I 'job share' and haven't had formal child care up until now - preschool and school age kids. Whilst I would like to do less work, I am not unhappy about it. I have trouble sleeping because I have so much on my mind and really wish I knew how to switch off. I exercise to try and take my mind off work. This used to work for me but now I can't even score a simple squash game because I'm always thinking about work. Life is good, I wouldn't change much and I am grateful that I have the access to cash that I have as it enables me to channel it into many social welfare programs. I support 7 charities on a direct debit arrangement and sponsor 6 children in 4 different countries. I couldn't do this if I didn't work so I am happy about this.*

As children became older, some women appeared to reflect on their roles with more pragmatism and perhaps with less stress. Women recognised that, while their lives were hectic, the choices they made left them largely 'happy'. However, other women continued to struggle with juggling their multiple roles.

Survey 7 (2015) *My husband and I are self-employed and work very hard. My husband and I juggle work and child care, we have the luxury of always being there for our kids and not using any form of child care. When we are with the kids, we are truly connected to them. We surf together, play board games, watch movies, I coach my daughter's netball team and manage my son's soccer. We do museums and bake cakes. The flip side is that we often work into the night and weekends. Any holidays we take still require remote work. We haven't had a true break from the business (ie one where we weren't checking emails and making calls or discussing plans late at night) for over 10 years. Consequently we are exhausted and are currently in the middle of selling the business. Despite the challenges, I am very happy. We recognise that we have far more than others. I have an excellent relationship with my husband, my children and my exceptional friends. Exhausted, yes. Blessed, absolutely.*

3.4.3. Conclusions from the qualitative analysis

This analysis suggests that being a mother is often difficult and challenging, requiring women to juggle multiple roles. While each woman shared her own individual experiences, the exhaustion from managing the demands of motherhood was a common experience. Returning to paid work after having children often required compromise, either in the type of job, hours worked, money earned, or for some, by deciding not to return to paid work. Some women who decided to stay at home to care for their children reported concern for their job prospects in the future. Others had difficulty adjusting to not participating in paid employment.

The lack of flexibility offered by some workplaces meant returning to paid work was difficult for some, while others reported frustration at having to make career compromises, suggesting the impossibility of having a successful career and being a 'good mother.' Flexible working conditions facilitated a return to paid work.

Various combinations of child care were used to facilitate returning to paid work, including formal and informal care. The cost and availability of child care was a concern for some, while for others, the cost was prohibitive, preventing women from returning to paid employment. While many women reported the inherent difficulties in juggling their multiple roles, many also reflected positively on their life circumstances.

Key points and Recommendations

- Flexible employment conditions are important to facilitate returning to paid work for women after having children. However, a better understanding of the types of flexibility that are most useful would be helpful.
- Some women felt the cost of formal child care negated their potential earnings. An investigation into the costs to families and the economy of this lost productivity would be useful, in order to more fully understand the benefits of high quality affordable child care.
- Alternatives to formal child care include care by family members and social support networks. However, these are not available to all women. Further investigation of social support, child care and paid employment could illuminate the value of social networks to women with children. Furthermore, support for building networks to assist with child care could provide an affordable alternative to parents who wish to undertake paid work.
- The current research did not assess the needs of women raising children without a partner. The child care needs of women in this position are likely to exceed those of women with a partner and should be more fully investigated.

3.5 Care for their grandchildren or other people’s children by women in the 1946-51 cohort

At Surveys 3 to 8 women in the 1946-51 cohort were asked if they regularly provide unpaid care for their grandchildren or other people’s children. Figure 3-11 shows the percentage of women at these surveys by the frequency of care they provided. The figure shows a clear and steady increase in the percentage of women providing care up to when they were aged 62 to 67 years (Survey 7). Occasional care was the most prevalent amount of care provided (ranging from 30-40% over the surveys). By Survey 8 when the women were aged 65 to 70 years, 60% were still providing care with 20% doing so on a daily or weekly basis.

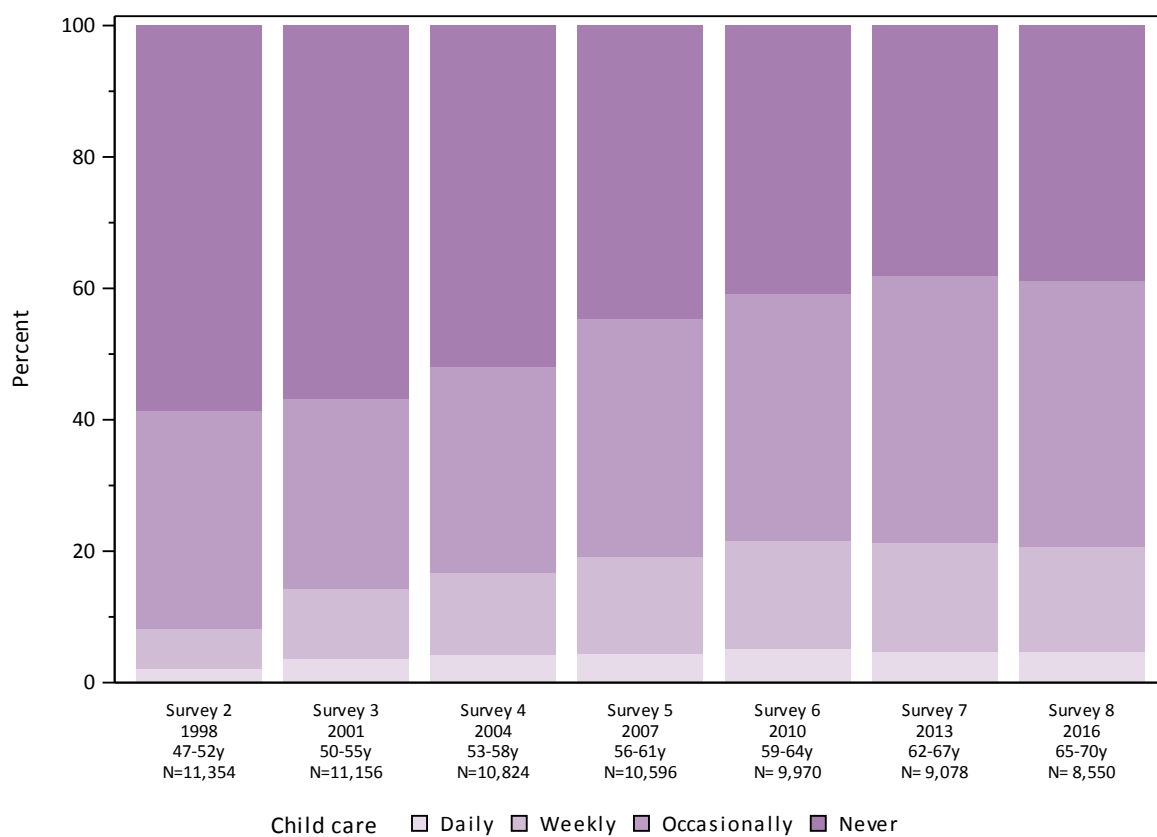


Figure 3-11 Percentages of women in the 1946-51 cohort at Surveys 3 to 8 who provide unpaid care for their grandchildren or other people’s children.

3.5.1. Care for grandchildren or other people's children by women in the 1946-51 cohort by socio-demographic status

This section presents the association between socio-demographic status (labour force participation, years of education, managing on income, area of residence) of women in the 1946-51 cohort by whether they care for their grandchildren or other people's children. Socio-demographic and caregiving data at Survey 5 (conducted in 2007 when the women were aged 56-61) were used as these data reflect the time when many of these women were still in the labour force and thus provides a better understanding of the associations between socio-economic factors and provision of care for grandchildren or other people's children. Where the nature of these associations changed in more recent surveys, these are discussed in text.

3.5.2. Care for grandchildren or other people's children and labour force participation

Figure 3-12 shows the percentage of women providing unpaid care for children by their own participation in the labour force. The figure shows that at Survey 5 significantly more women who worked full-time did not provide care (50%), compared with women who worked part-time (44%), who in turn were significantly more likely to not provide care than women not in the labour force (40%). At Survey 5 however, women who worked part-time were just as likely as women not in the labour force to provide weekly care to their grandchildren or other person's children (16-17%) than women working full-time (11%). By Survey 8 (when the women were aged 65-70), a slight difference had emerged whereby significantly more women who worked part-time provided care for children on a weekly basis (19%) than women not in the labour force (15%) or those working full-time (12%).

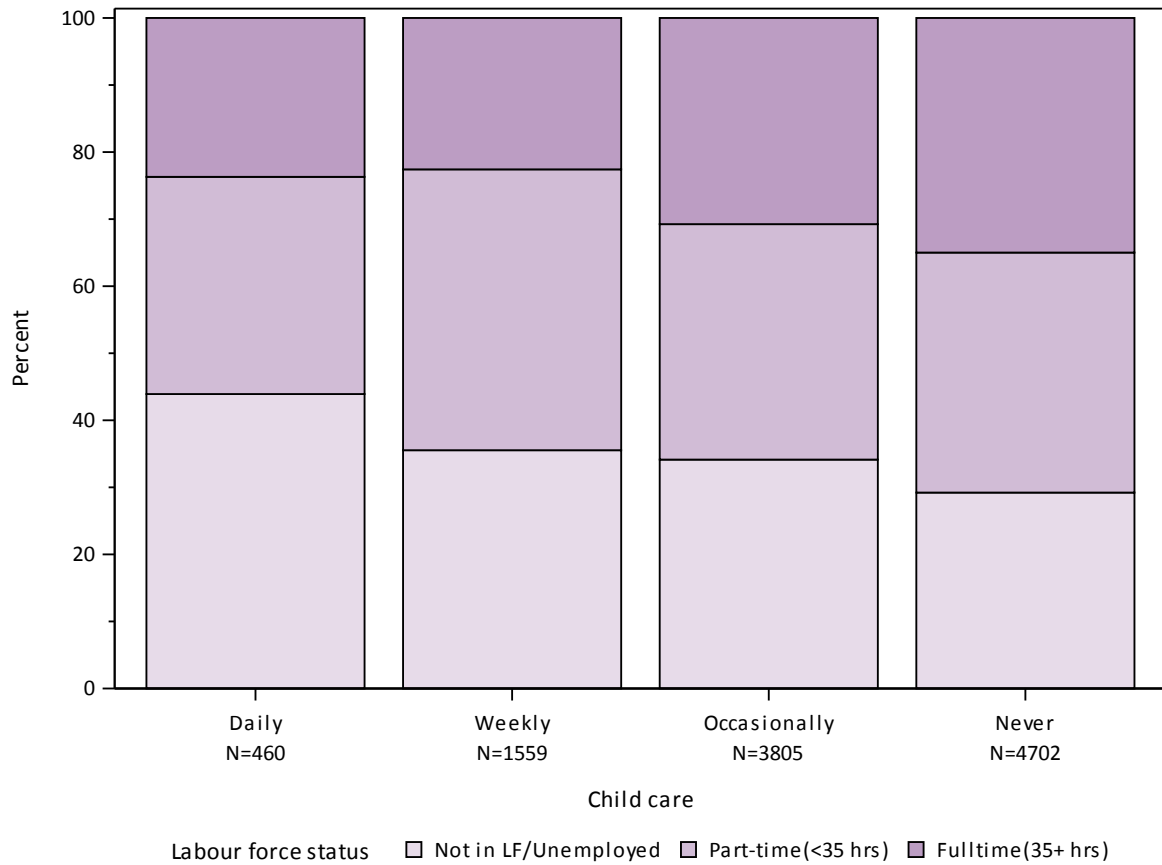


Figure 3-12 Percentage of women in the 1946-51 cohort providing unpaid care for their grandchildren or other people's children at Survey 5, by their labour force (LF) participation.

3.5.3. Care for grandchildren or other people’s children and years of education

Figure 3-13 shows a clear highly significant difference between level of education and provision of child care at Survey 5. University-educated women were much less likely to provide daily, weekly, or occasional care compared with women with lower levels of educational attainment. This most probably reflects that these more educated women were working. By Survey 8 when the women were 65-70 years, this significant difference remained but was not as strong.

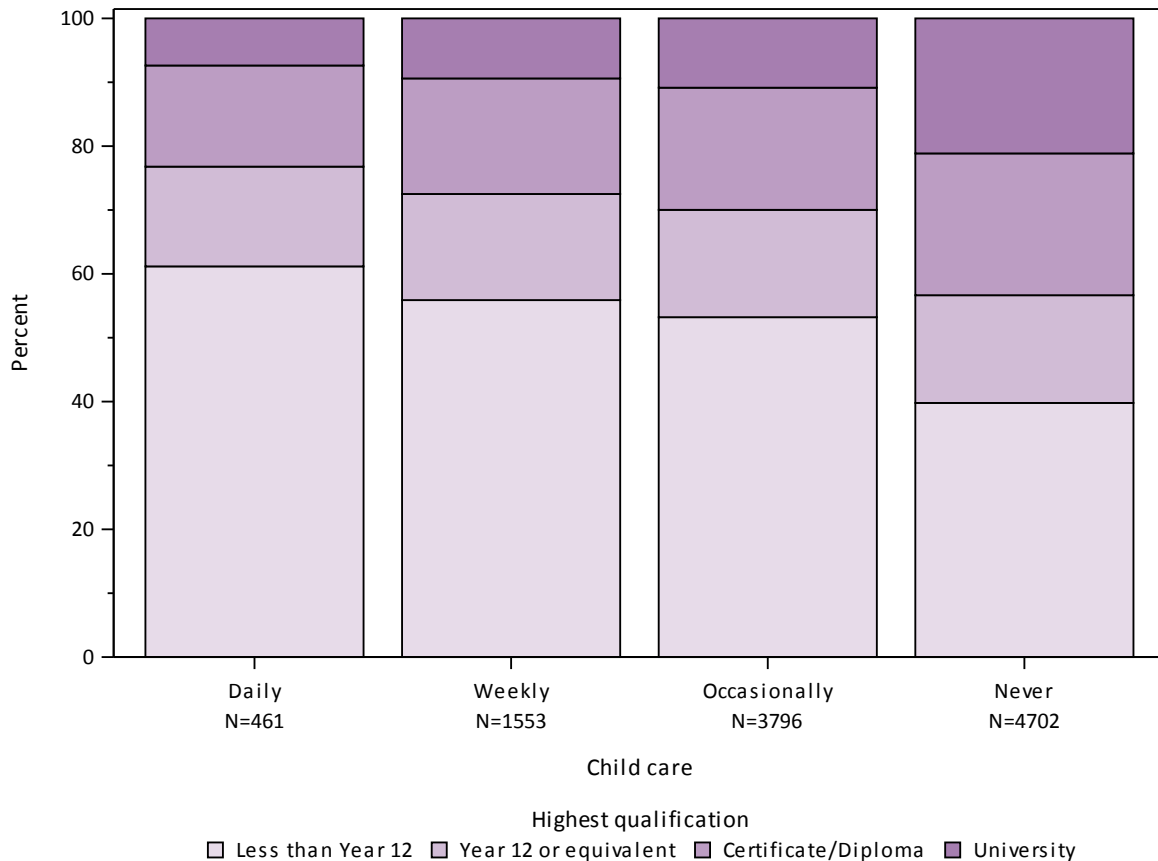


Figure 3-13 Percentage of women in the 1946-51 cohort providing unpaid care for their grandchildren or other people’s children at Survey 5, by their level of educational attainment.

3.5.4. Care for grandchildren or other people’s children and managing on income

Figure 3-14 shows the percentage of women providing unpaid care for grandchildren or other people’s children by how they reported managing on their income. The figure shows that at Survey 5 women who found it easiest to manage on their income were less likely to provide care on a daily basis (3%) compared with women who found it impossible/very difficult to manage on their income (8%) or those who found it difficult sometimes (6%). Of note, women who found it impossible/very difficult to manage on their income and those who found it easiest were about equally likely to not provide care (43-46%, respectively) than women who found it difficult sometimes (41%). Over successive surveys, women who found it impossible/very difficult to manage on their income continued to provide the most daily care but women who found it easier to manage their income (difficult sometimes, easy/not too bad) began providing more care on a weekly basis (by Survey 8, 15-16% of women in the two easiest income management groups provided weekly care compared with 12% of women who found it the most difficult).

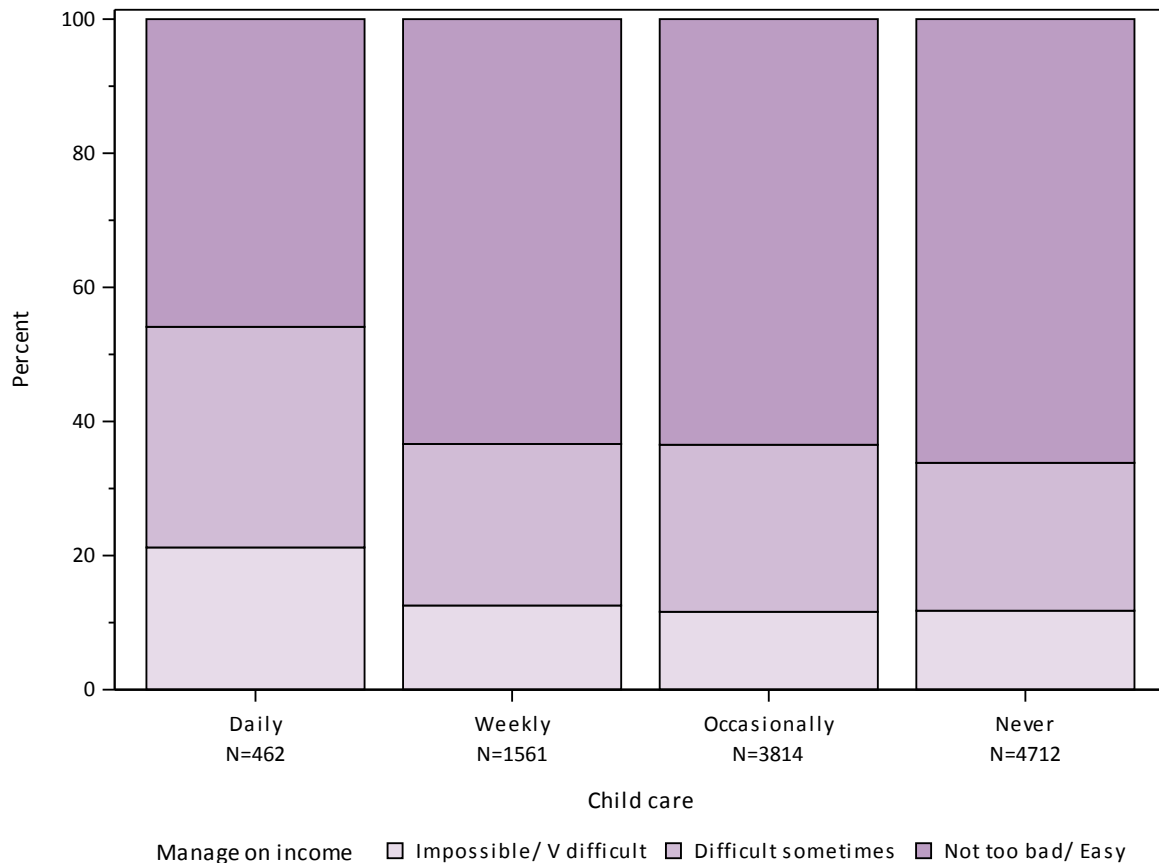


Figure 3-14 Percentage of women in the 1946-51 cohort providing unpaid care for grandchildren or other people’s children at Survey 5, by how well they reported managing on income.

3.5.5. Care for grandchildren or other people’s children and area of residence

Figure 3-15 shows the percentage of women providing unpaid care for grandchildren or other people’s children by where they lived. At Survey 5, women living in major cities and those in remote areas were equally likely to not provide care for their grandchildren or other people’s children (around 46%) compared to women living in outer or inner regional areas (40-43%, respectively). Women living in major cities were also less likely to provide occasional care compared with women living in the other areas (32% versus 38-39%, respectively). By Survey 8 however, these differences between the groups had changed with more women aged 65-70 years who lived in remote/very remote areas never providing care (47%) compared with women living in major cities (37%), and more women in major cities providing care on a weekly basis (20%) compared with women living in regional and remote areas (10-14%).

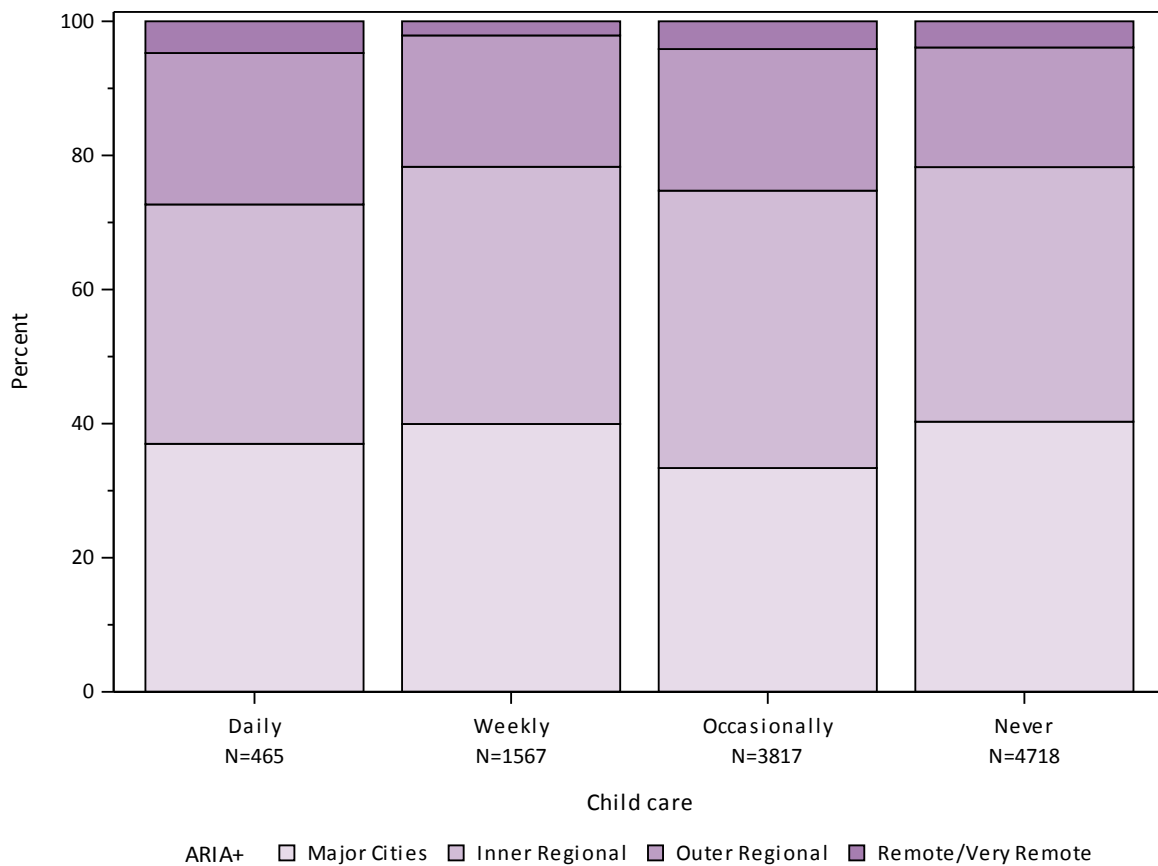


Figure 3-15 Percentage of women in the 1946-51 cohort providing unpaid care for their grandchildren or other people’s children at Survey 5, by area of residence.

3.5.6. Happiness with share of performing child care activities by women in the 1946-51 cohort

At Surveys 1, 4, 5, and 6 the women in the 1946-51 cohort were asked whether they were happy with their share of child care activities. The response options to this question were ‘happy the way it is’, ‘would like other household members to do more’ and ‘would prefer another arrangement’. Overwhelmingly the women responded that they were ‘happy the way it is’ with around 90% of women at each survey reporting this.

3.5.7. Care for grandchildren or other people’s children by women in the 1921-26 cohort

At Surveys 2 to 6 women in the 1921-26 cohort were asked if they regularly provide unpaid care for grandchildren or other people’s children (Figure 3-16). The figure shows a clear and steady decrease in the percentage of women providing this care as they aged. In Survey 2 when aged 73 to 78 years, about 45% were providing care (mostly occasionally). By age 85-90 years, about 12% were still providing care, with 59 women doing so regularly.

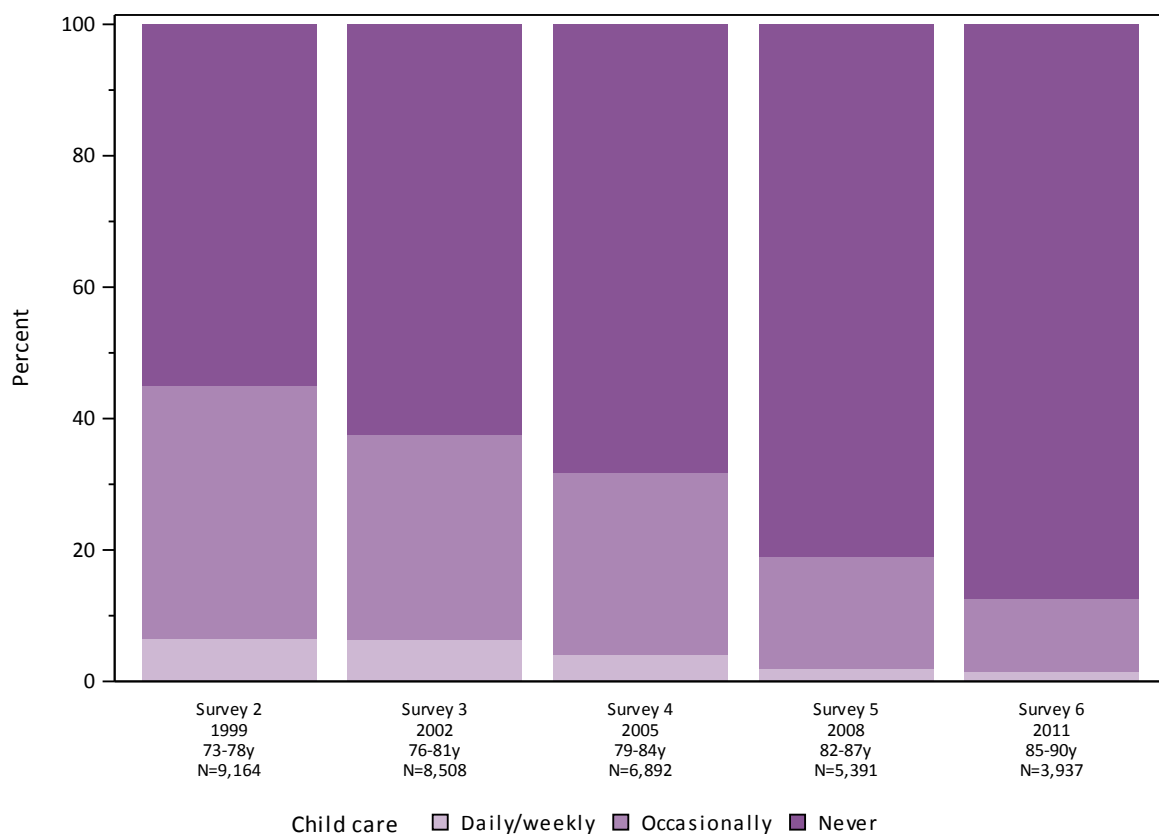


Figure 3-16 Percentages of women in the 1921-26 cohort at Surveys 2 to 6 who provide unpaid care for their grandchildren or other people’s children.

3.5.8. Care for their grandchildren or other people's children by women in the 1921-26 cohort by socio-demographic status and self-rated health

Associations between providing care for their grandchildren or other people's children and socio-demographic characteristics of women in the 1921-26 cohort were also examined. Associations were found between providing care for grandchildren or other people's children and self-rated health. Across Surveys 2 to 6, a higher percentage of women who reported their health as fair or poor reported never providing care for grandchildren or other people's children (with the percentage difference ranging from 11-25%).

Key points

- The percentage of women in the 1946-51 cohort who provided care for their grandchildren or other people's children steadily increased up to 60% by the time they were 62-67 years.
- Those in the 1946-51 cohort who worked full-time or had a university degree were less likely to provide care than women not in the labour force or with lower educational attainment.
- The percentage of women in the 1946-51 cohort who provided occasional, weekly, or no child care did not differ by their ability to manage on income, however women who found it impossible or very difficult were more likely to provide daily child care compared with women who found it easiest to manage on income.
- Around 90% of women in the 1946-51 cohort were happy with their share of child care activities.
- The percentage of women in the 1921-26 cohort who provided child care steadily decreased from 45% when they were aged 73-78 to 12% when they were aged 85-90.
- In the 1921-26 cohort, women who had better self-reported health were more likely to provide child care than women who reported their health as fair or poor.

3.6 Women, children and employment: Previous research from the ALSWH.

In 2017, Majeed published a PhD thesis containing an analysis of workforce participation patterns for women in the 1973-78 cohort without children and those who had one or more child/ren (Majeed, 2017). Majeed examined employment patterns between Survey 2 (when the women were aged 22-27) and Survey 6 (34-39 years) and used latent class analysis to identify 'classes' or 'trajectories' of women who have similar employment patterns over time. She found different 'trajectories' of employment for women with and without children. For women with children, 44% worked part time, 21% showed an increasing pattern of full time paid work as they entered their 30's, and 34% transitioned in and out of paid work. For women without children, 75% worked full time, 17% transitioned between full time and part time work, and 8% shifted in and out of paid work over time. The presence of chronic conditions (for example, asthma, depression) was associated with reduced employment patterns in women without children but not women with children. Residence in rural/remote areas, caring responsibilities (for somebody who was old, frail or disabled), less education and having underweight or overweight body mass index was found to be negatively associated with full-time work in women without children. For women with children drinking alcohol (low or high risk consumption), residence in rural areas, less education and being obese was found to be negatively associated with employment. Majeed concluded that different strategies are needed to cater to the needs of women experiencing varied life roles. While, mothers need accessible and flexible work options, women without children, with chronic diseases need supportive work environments.

4. Caring for any other person because of their long-term illness, disability or frailty

This chapter presents data from women in the 1973-78, 1946-51 and 1921-26 cohorts on caregiving other than child care. Data for the women in the 1946-51 cohort are presented first as they had the highest prevalence of caregiving and were asked more questions about caregiving. Women in all three cohorts were asked at all surveys whether they provided care for any other person because of their long-term illness, disability or frailty. More detailed questions were also asked at specific surveys. These included whether they lived with the person they cared for or elsewhere, the intensity of the caregiving, the conditions of the person they cared for and their relationship with the person (see [Appendix A](#)).

4.1 Caregiving by women in the 1946-51 cohort for any other person because of their long-term illness, disability or frailty

For the 1946-51 cohort, only data from Surveys 3 to 8, when the women were aged between 50 and 72 years, are used. This is because the response option at Survey 1 differed from the response options at later surveys, and a scanning error of Survey 2 data rendered the data potentially unreliable.

At each Survey from 3 to 8, 25%, 30%, 30%, 29%, 27% and 24% of women respectively reported that they cared for another person because of long-term illness, disability or frailty. The line graph in Figure 4-1 illustrates how the proportions changed over time for whether the women lived with the person they cared for, or lived elsewhere. While the percentage of women caring for someone who lived elsewhere peaked when the women were aged between 53 and 64 and then started to decline, the percentage of women caring for a person they lived with increased. This likely reflects change in the person they cared for. When the women were younger they cared mainly for their parents, whereas caring for a spouse/partner increased as these women progressed through their 60s and early 70s.

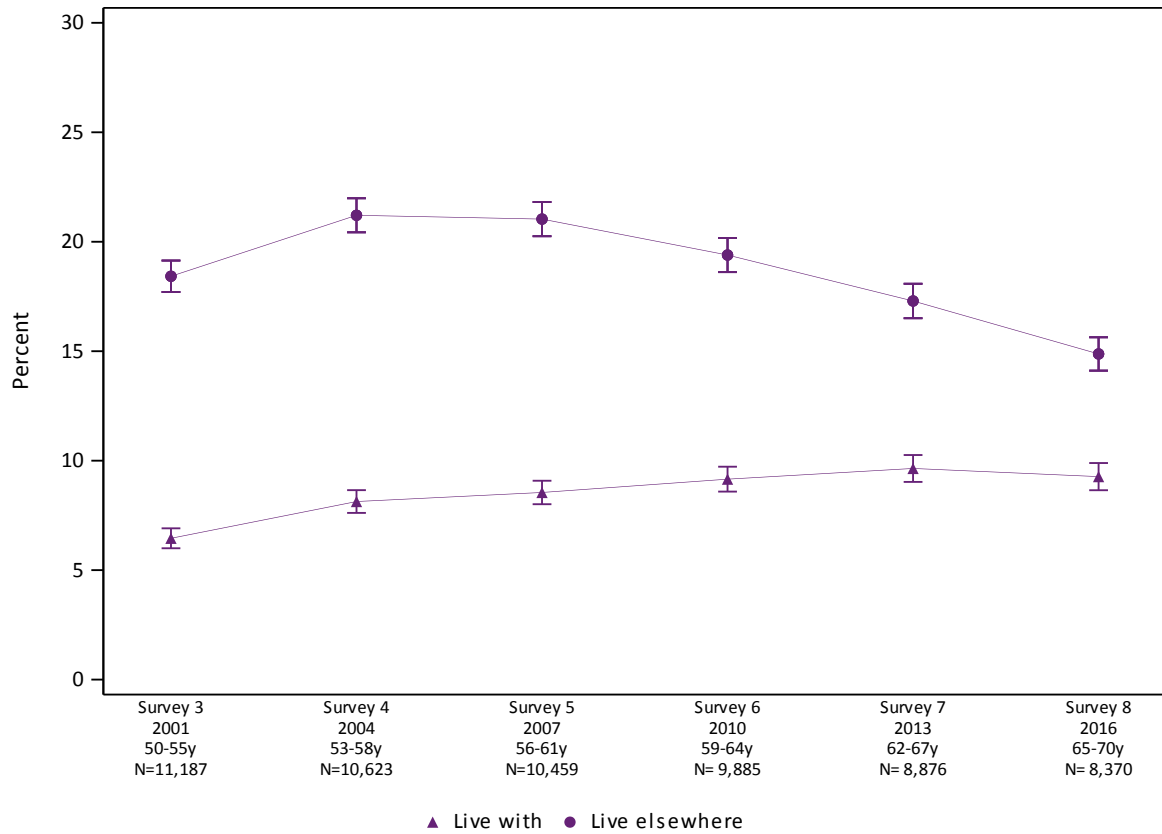


Figure 4-1 Percentage of women in the 1946-51 cohort at Surveys 3 to 8, by whether they live with or live elsewhere from the person they care for.

Transitions (or movements) in and out of caregiving by women across the surveys are presented in Figure 4-2. The figure includes only women who answered every survey (N=6598). At each survey, women who provided care (for people living with them or elsewhere) are depicted in the dark purple band, while those not providing care are in the light purple band. The figure shows a high degree of movement into and out of caregiving across the surveys. For example, 1654 women (25% of total) were providing care for any other person at Survey 3 and at Survey 4 1053 (16% of total) were still providing care, 601 (9% of total) had stopped and 935 (14% of total) who were not providing care at Survey 3 had started doing so. The graph also shows that only a small percentage of women (4%) provided care at every survey while 36% did not provide care at any survey.

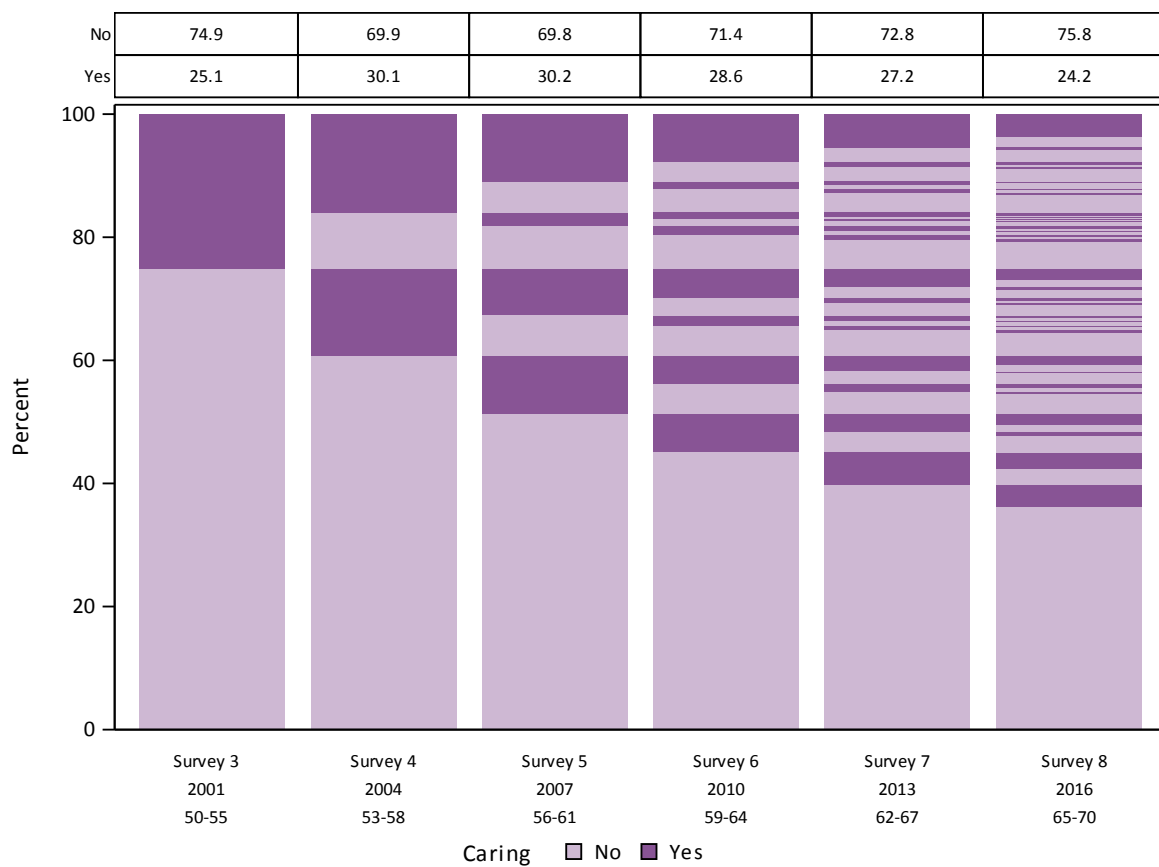


Figure 4-2 Percentage of women in the 1946-51 cohort at Surveys 3 to 8, by whether they provided care for any other person (dark purple) across Surveys 3 (aged 50-55) to Survey 8 (aged 65-72) (N=6598).

Transitions in caregiving by whether the women lived with or elsewhere from the care recipient between Survey 3 and 8 are shown in Figure 4-3.

The figure shows the highly transitional nature of caring by whether women live with the person they care for or elsewhere. At every survey a small percentage of women begin live-in caring and while this percentage drops over time a small core of women continue to provide this care.

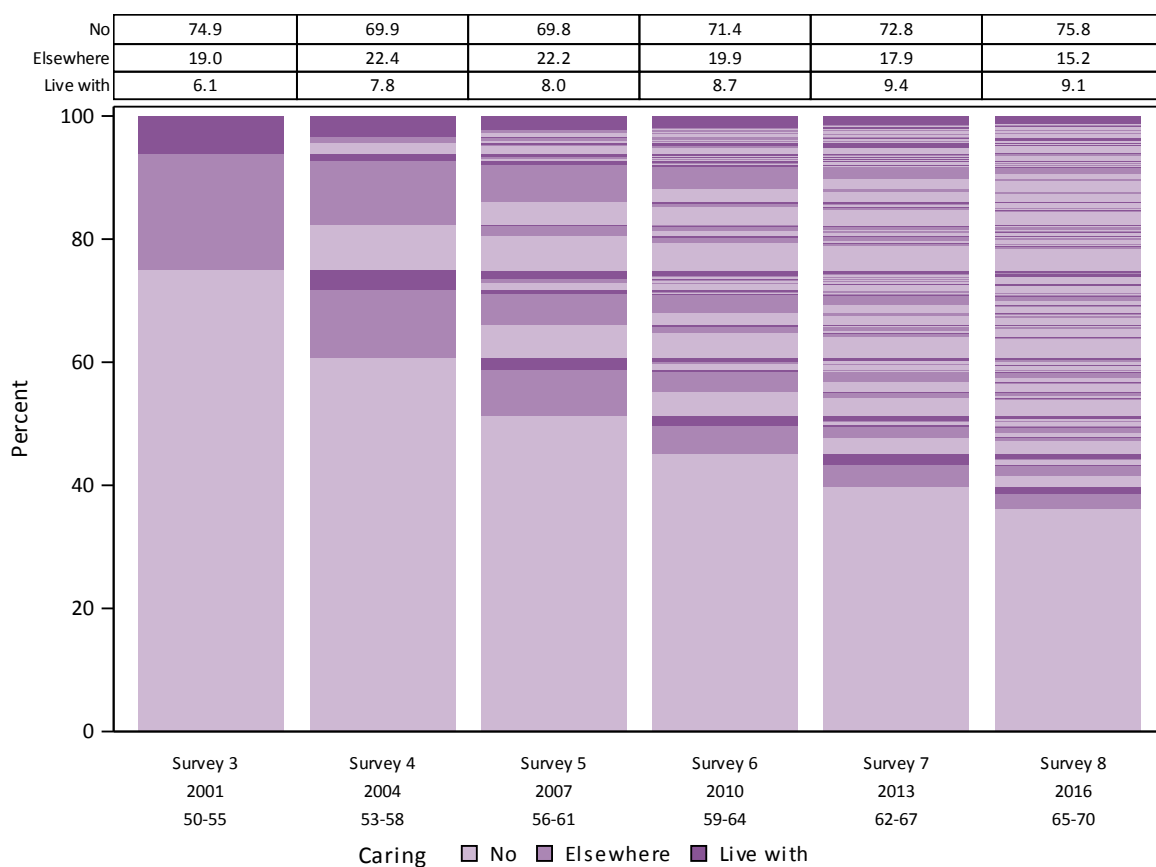


Figure 4-3 Percentage of women in the 1946-51 cohort at Surveys 3 to 8, by whether they provided care for any other person who lived with them (darkest purple) or elsewhere (mid-purple) across Surveys 3 (aged 50-55) to Survey 8 (aged 65-72). Women who did not provide care are in the lightest purple bands (N=6598).

4.2 Caregiving by socio-demographic status and living situation

This section presents the association between socio-demographic status of women in the 1946-51 cohort by whether they were caregivers, and where they lived in relation to the person they cared for. Socio-demographic and caregiving data at the most recent survey (Survey 8, when the women were aged 65-70 years) are presented here. Data from earlier surveys are not presented because the associations were similar at all surveys.

4.2.1. Caregiving and Labour Force participation

Figure 4-4 shows that a higher percentage (about 10% higher) of caregivers living with the person they cared for were not in the labour force, and fewer worked part-time (by 5-9%), compared with either women caring for someone living elsewhere or non-caregivers. Significantly fewer caregivers (either living with or elsewhere) were working full-time (about 6%) at Survey 8 compared with non-caregivers (9%).

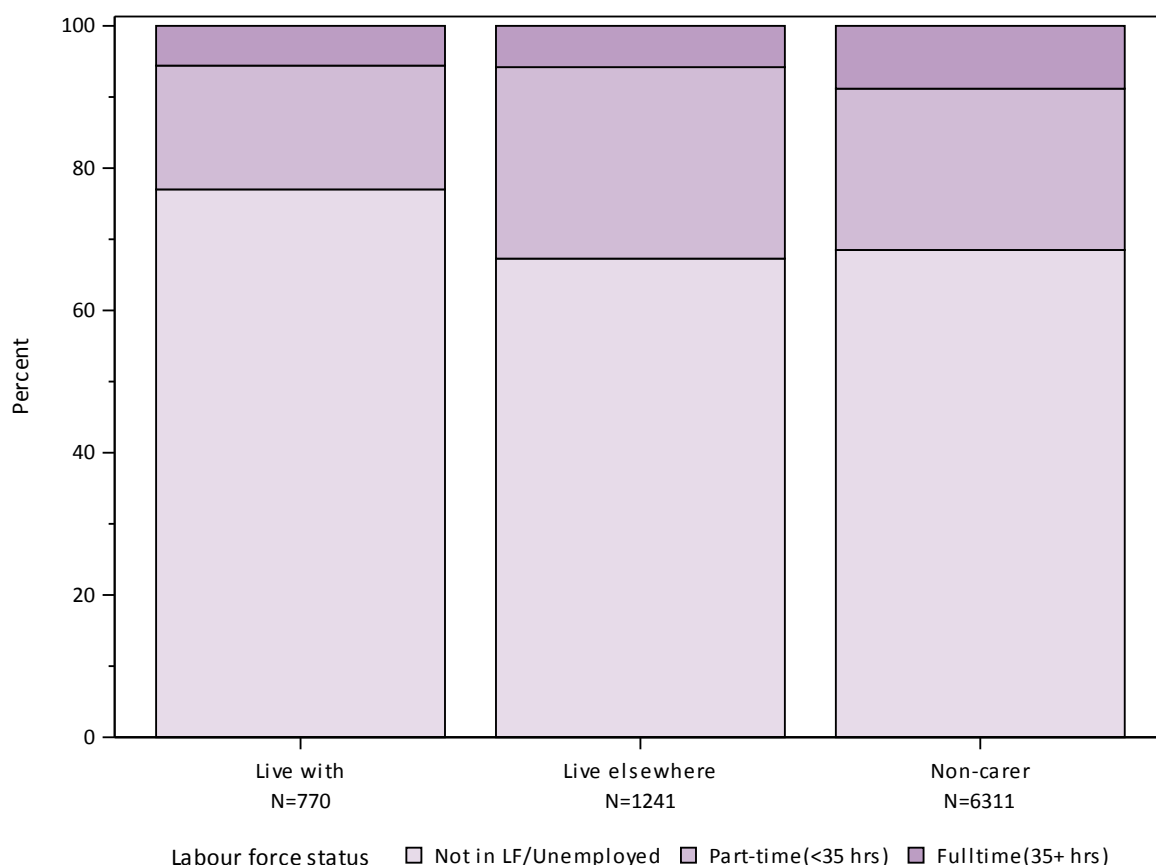


Figure 4-4 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and labour force (LF) participation.

4.2.2. Caregiving and years of education

Figure 4-5 shows that caregivers living with the person they cared for had significantly less education (by 10-13%) compared with either caregivers living elsewhere or non-caregivers.

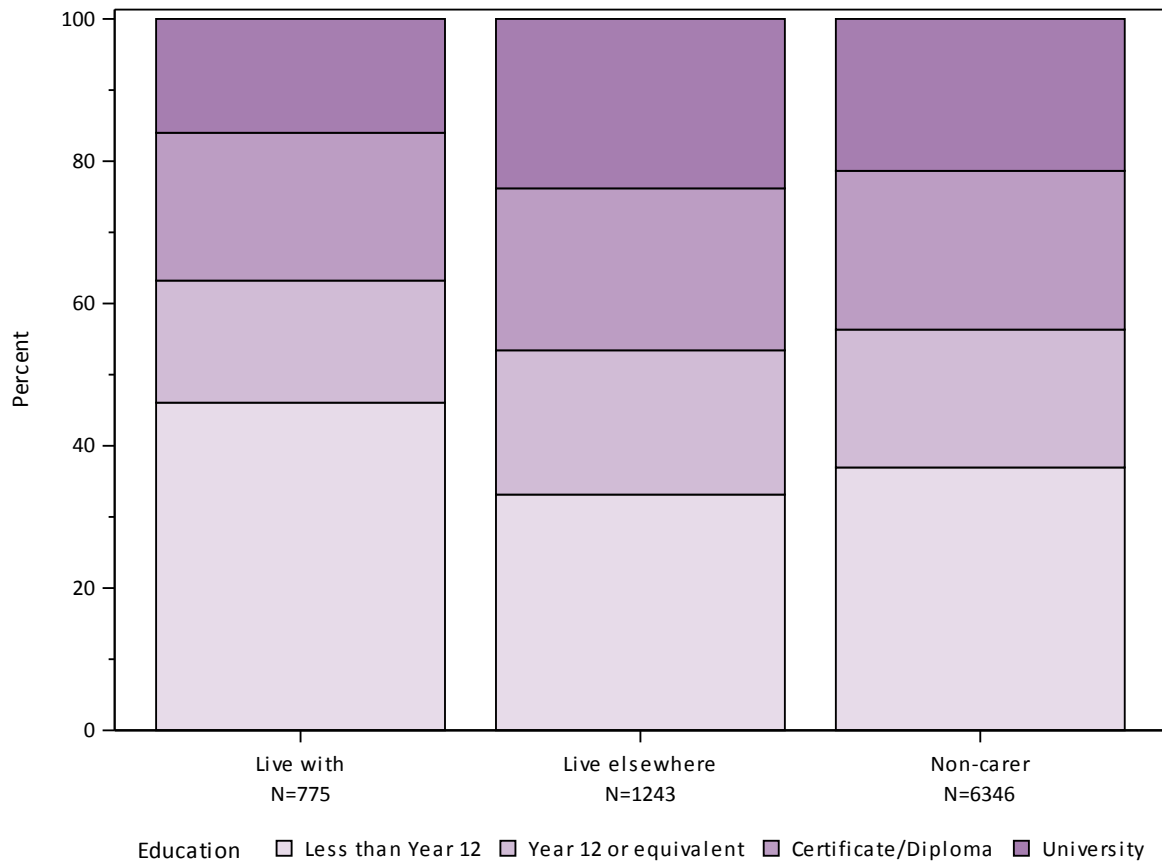


Figure 4-5 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and years of education.

4.2.3. Caregiving and managing on income

Unsurprisingly, given the associations between labour force participation and years of education and caregiving, caregivers (particularly those living with the person they care for) reported more difficulty managing on their income than non-caregivers. Figure 4-6 shows about 16% of caregivers living with the person they cared for said it was impossible/very difficult to manage on their income compared to just under 10% and 8% of caregivers living elsewhere or non-caregivers, respectively.

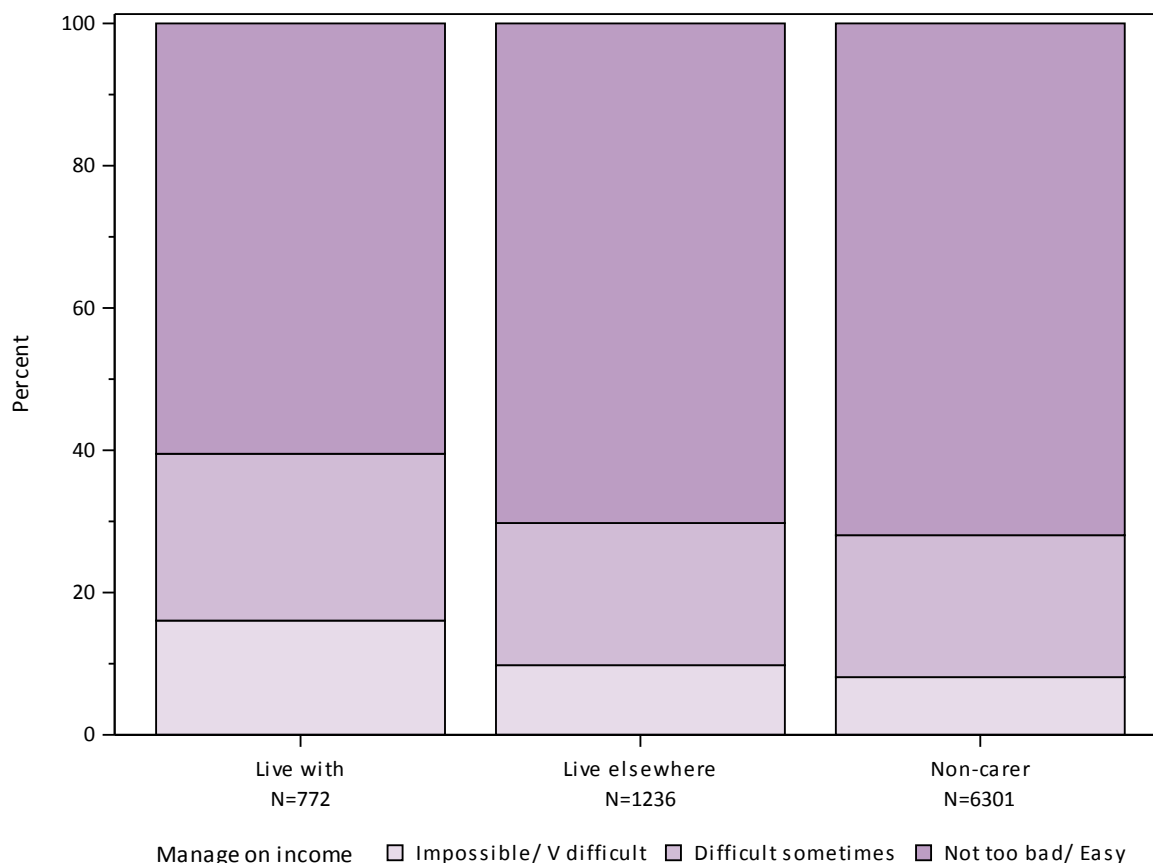


Figure 4-6 Percentage of women in the 1946-51 cohort at survey 8, by caregiving status and managing on income.

4.2.4. Caregiving and area of residence

The percentage of caregivers living with the person they cared for or elsewhere was similar among women living in major cities, inner regional, outer regional or remote/very remote areas.

Key points

- 24-30% of women in the 1946-51 cohort reported caring for another person across eight successive surveys.
- As these women aged, the percentage who cared for someone they lived with increased while the percentage who cared for someone they did not live with decreased after 2004 when they were aged 53-58 years.
- There was a high degree of movement into and out of caregiving over time.
- Of the caregivers living with the person they cared for, the greatest percentage were not in the labour force and had less education.
- Caregivers living with the person they cared for also reported more difficulty managing on their income than non-caregivers.
- There was no difference in the percentage of caregivers among women living in major cities, regional, or remote areas.

4.3 Intensity of caregiving by women in the 1946-51 cohort for any other person because of their long-term illness, disability or frailty

The intensity of caregiving duties was summarised in a caregiving index. The caregiving index was created by combining answers to questions about frequency of caregiving (ranging from daily to every few weeks) and duration of caregiving (ranging from all day/night to caring for about an hour at a time, see [Appendix A](#) for the questions used). Whether the caregiver lived with the person they cared for or elsewhere was not considered in the calculation of the caregiving index. Caregiving frequency and duration scores were multiplied and the resulting score was grouped into three categories as shown in Table 4-1.

Table 4-1 Overview of the caregiving intensity index

| Intensity categories | Description |
|----------------------|--|
| Low | Caregiving once per week for one hour at a time; or caregiving every few weeks for several hours at a time |
| Medium | Caregiving several times per week for several hours at a time; or caregiving every day for about an hour |
| High | Caregiving all day, several times a week, or caregiving every day for several hours at a time |

At Survey 3, when the women were 50 to 55 years, 8.5%, 11.5% and 6% of caregivers reported a low, medium and high intensity caregiving. Between Surveys 4 and 6, when the total prevalence of caregiving was at its highest, medium intensity caregiving continued to be the most frequently reported (around 12-13%). By Survey 8, when the women were aged 65 to 70, 8%, 9% and 8% of caregivers reported a low, medium and high intensity caregiving, respectively. Throughout the 15 years captured by these surveys, 6 to 9% of women in this cohort were providing high intensity caregiving.

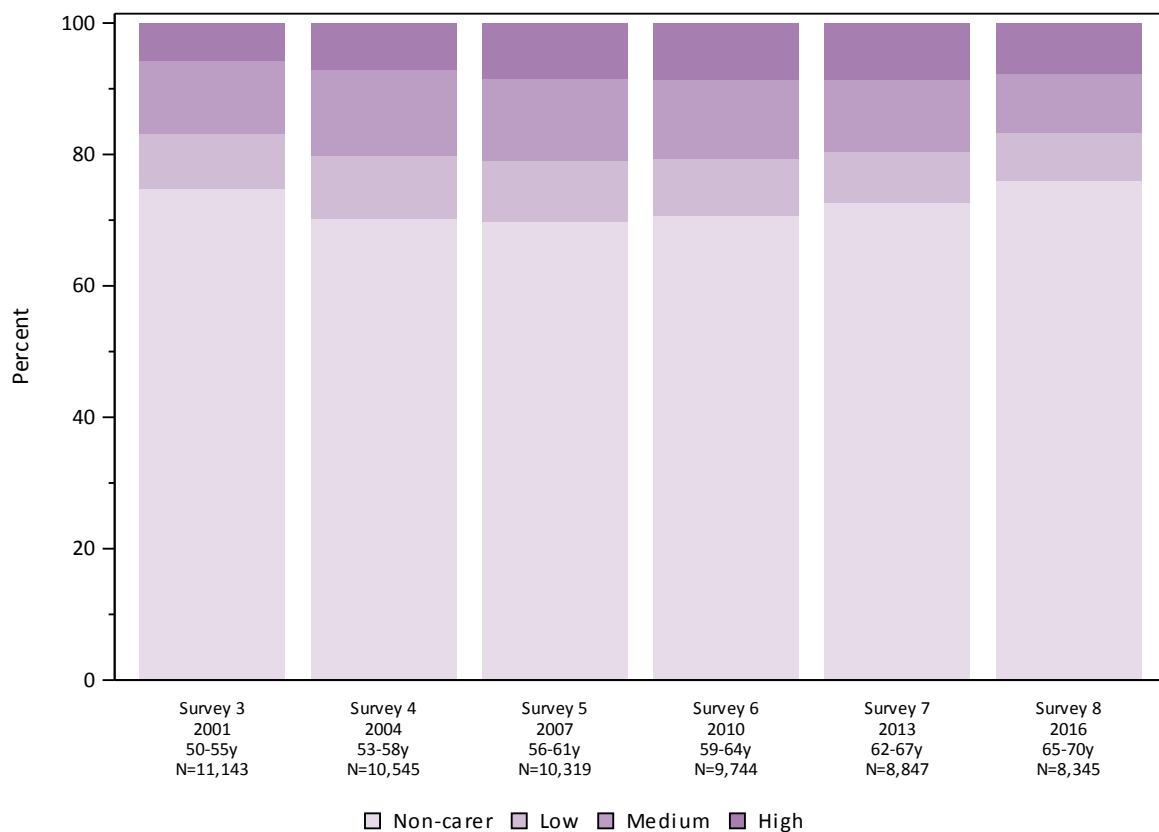


Figure 4-7 Percentage of women in the 1946-51 cohort at Surveys 3 to 8, by intensity of caregiving (high, medium, low, none).

4.4 Relationships with people cared for because of their long-term illness, disability or frailty by women in the 1946-51 cohort

At Survey 8 in 2016 when the women were aged 65 to 70, the women were asked to identify their relationship with the person they provided care for (or the person they provided care for the most, if there was more than one). Figure 4-8 shows the majority of women were caring for their parents/parents-in-law or spouse/partner (accounting for almost 58%). About 10% of women were caring for a child.

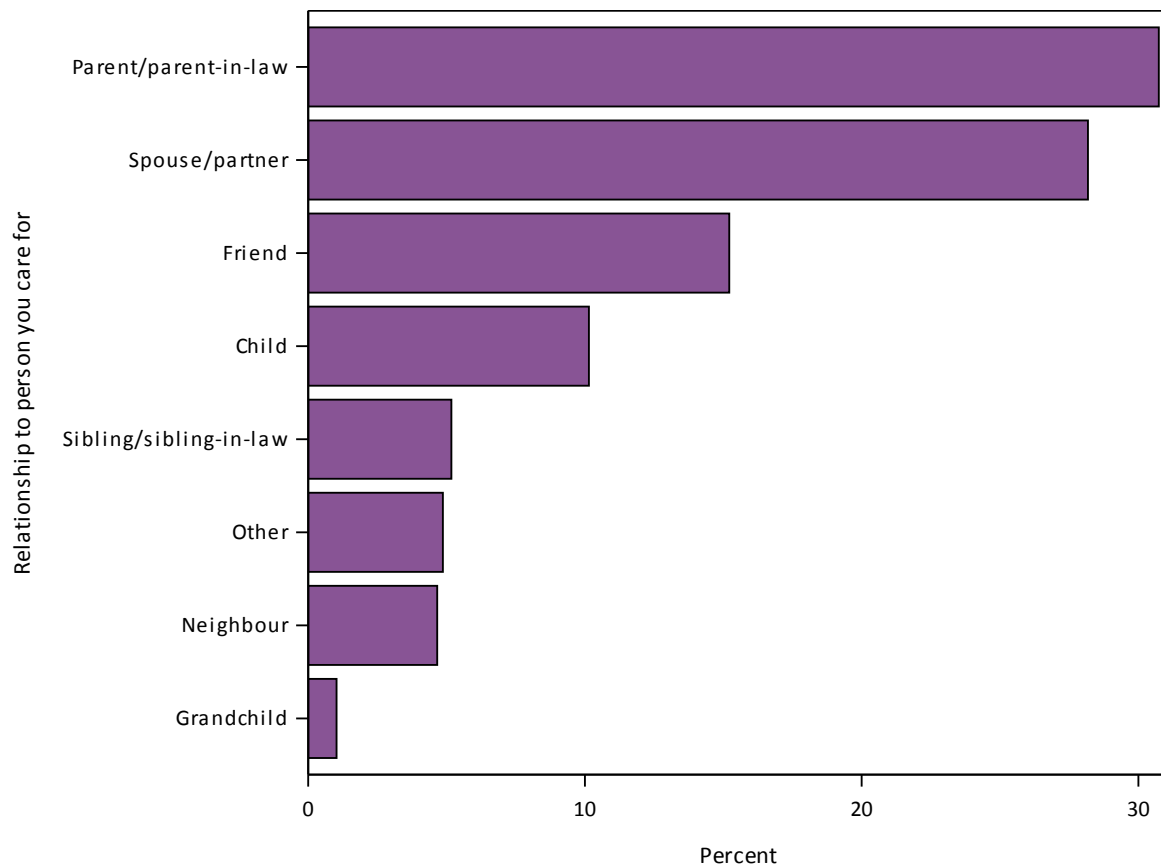


Figure 4-8 Percentages showing the nature of the relationship between the caregiver and the person they cared for at Survey 8 (2016) in women aged between 65 and 70 years (N=1952).

Figure 4-9 shows the nature of the relationship between the caregiver and the person they cared for at Survey 8 (2016) by whether they lived with the person they cared for or elsewhere. Of the caregivers who lived with the person they cared for, the majority (almost 70%) cared for their spouse/partner, followed by around 12% who cared for either a child or parent/parent-in-law. Of the caregivers who did not live with the person they cared for, the majority (41%) cared for a parent/parent-in-law, followed by a friend (22%) or child (9%).

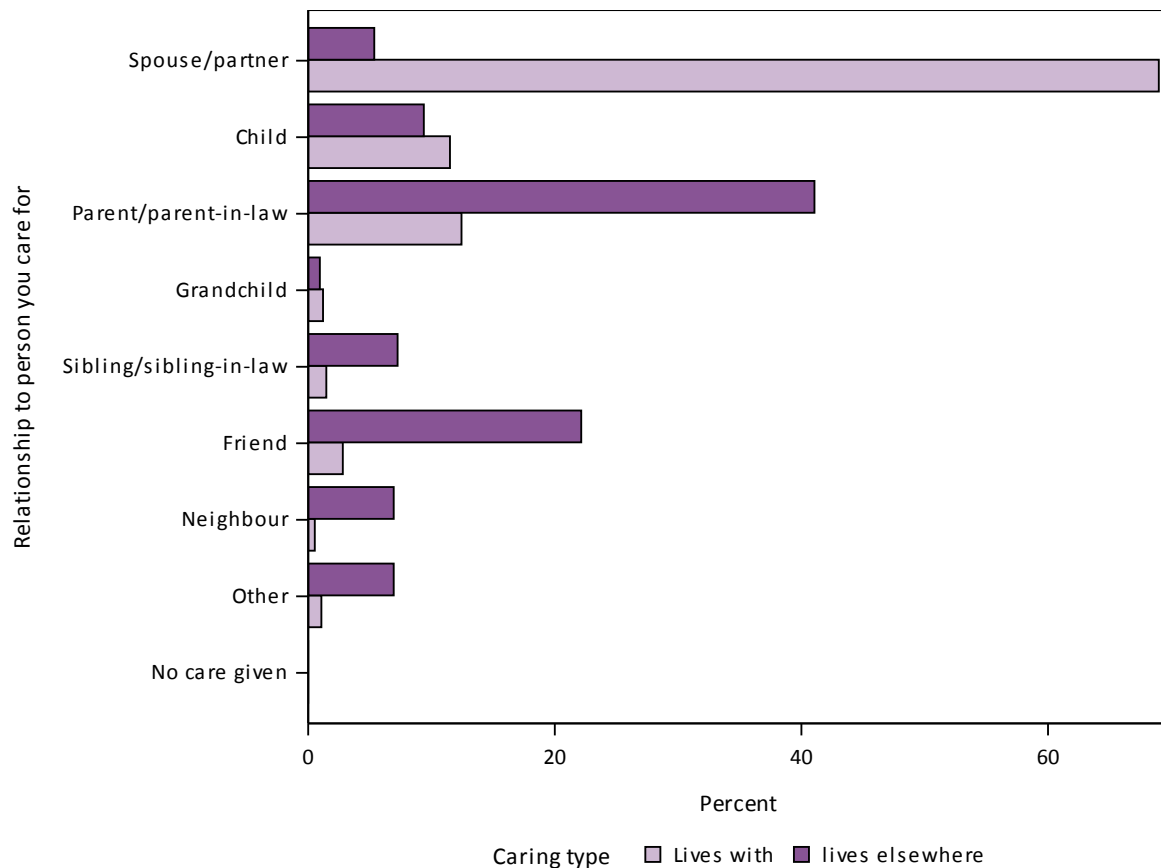


Figure 4-9 Percentages showing the nature of the relationship, and living situation, between the caregiver and the person they cared for at Survey 8 (2016) in women aged between 67 and 72 years (N=1952).

The nature of the relationship between the caregiver and the person they cared for and caregiving intensity is shown in Figure 4-10. Of caregivers providing high intensity caregiving, most were caring for a spouse/partner (around 60%), followed by parents/parents-in-law (20%), and children (11%). This reflects the relationships with the care recipients they were most likely to live with. Of caregivers providing low intensity caregiving, most of them were caring for a parent/parent-in-law (30%) or friend (28%). Medium intensity caregiving was provided mostly to parents/parents-in-law (40%) or friends (15%). The provision of lower intensity caregiving was more prevalent in caregivers who did not live with the person they cared for.

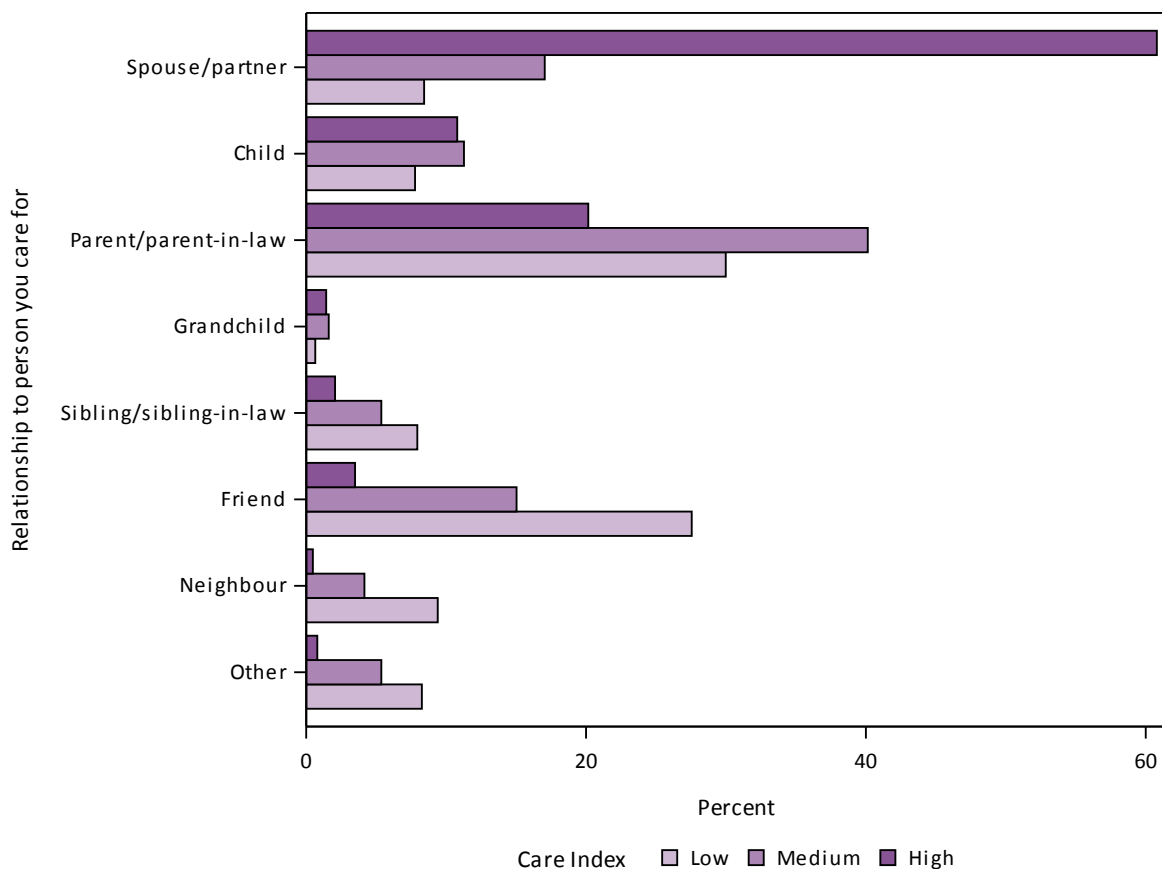


Figure 4-10 Percentages showing the nature of the relationship between the caregiver and the person they cared for and caregiving intensity at Survey 8 (2016) in women aged between 67 and 72 years (N=1996).

4.4.1. Nature of the condition of the person being cared for by women in the 1946-51 cohort

In Surveys 7 (2013) and 8 (2016), when the women were aged 62 to 67 and 65 to 70 respectively, they were asked to indicate the major medical conditions or disabilities of the person they cared for. Figure 4-11 shows the most prevalent condition at both surveys was frailty (between 45-55%). Heart disease and mental health problems were present in about 20% of the care recipients, followed by Alzheimer's disease/dementia and visual impairment (about 15%). Women could tick more than one option in this question. At Survey 8, approximately 180 women selected 'other' for this question and provided additional details. Around 15% were caring for someone with musculoskeletal conditions (for example, osteoarthritis or arthritis, or recovery from knee/hip/back surgery), 10% reported caring for someone with a disability from birth (for example, Down syndrome) or early childhood (autism), 7% noted they were caring for people with Parkinson's disease or multiple sclerosis, and just over 5 % were caring for a person with a hearing impairment.

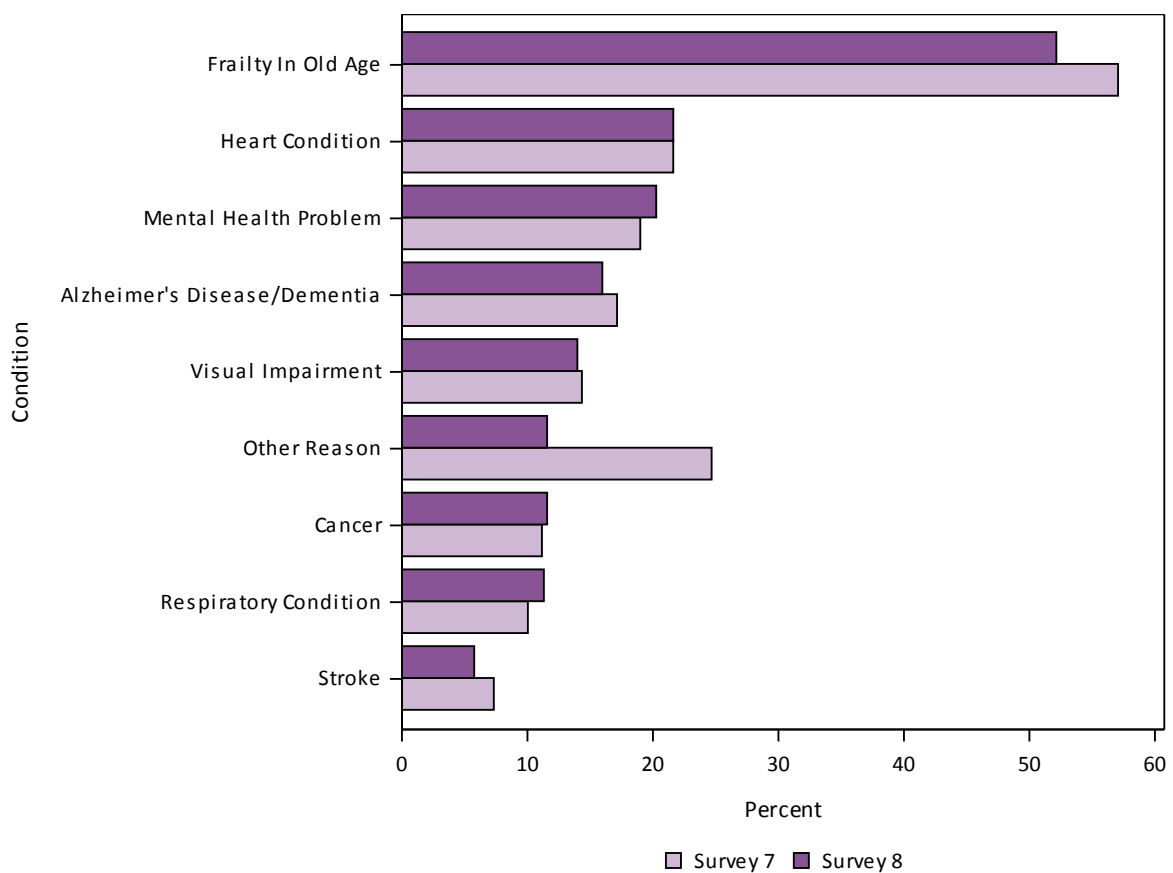


Figure 4-11 Percentages showing the nature of the condition of the person being cared for at Survey 7 (when caregivers were 62-67 years, N=2391) and Survey 8 (65-70 years, N=2021).

Figure 4-12 and Figure 4-13 present the nature of the conditions of the care recipient at Survey 8 by living situation and caregiving intensity. Together these figures show that 20 to 30% of women were caring for people they lived with who had heart disease, mental health problems and 'other' conditions and that the highest intensity caregiving was provided to recipients with these conditions. Caregivers also provided high intensity care for people with less prevalent ($\leq 10\%$) conditions such as cancer, respiratory conditions and stroke. Medium and low intensity caregiving was more prevalent than high intensity caring for conditions such as Alzheimer's disease/ dementia, frailty and visual impairment.

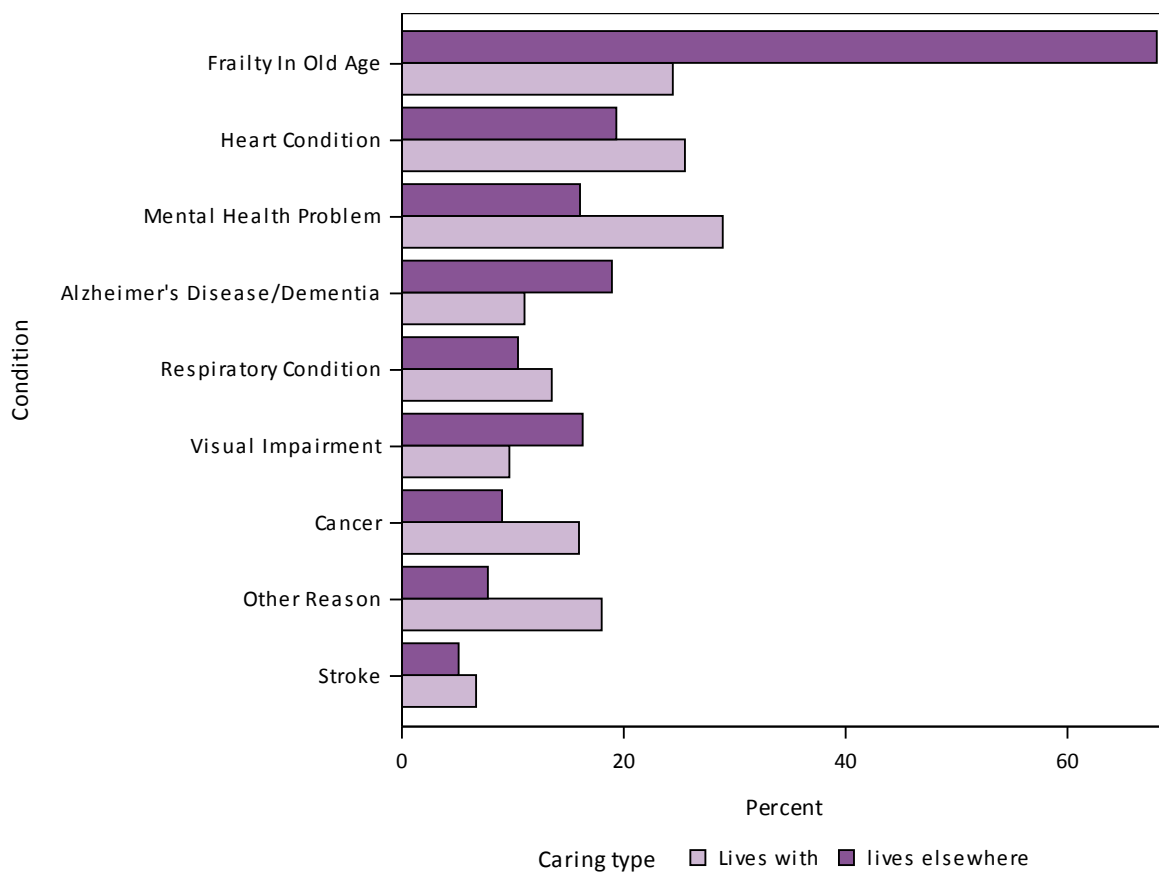


Figure 4-12 Percentages showing the nature of the condition of the person being cared for at Survey 8 (65-72 years), by living situation (N=2021).

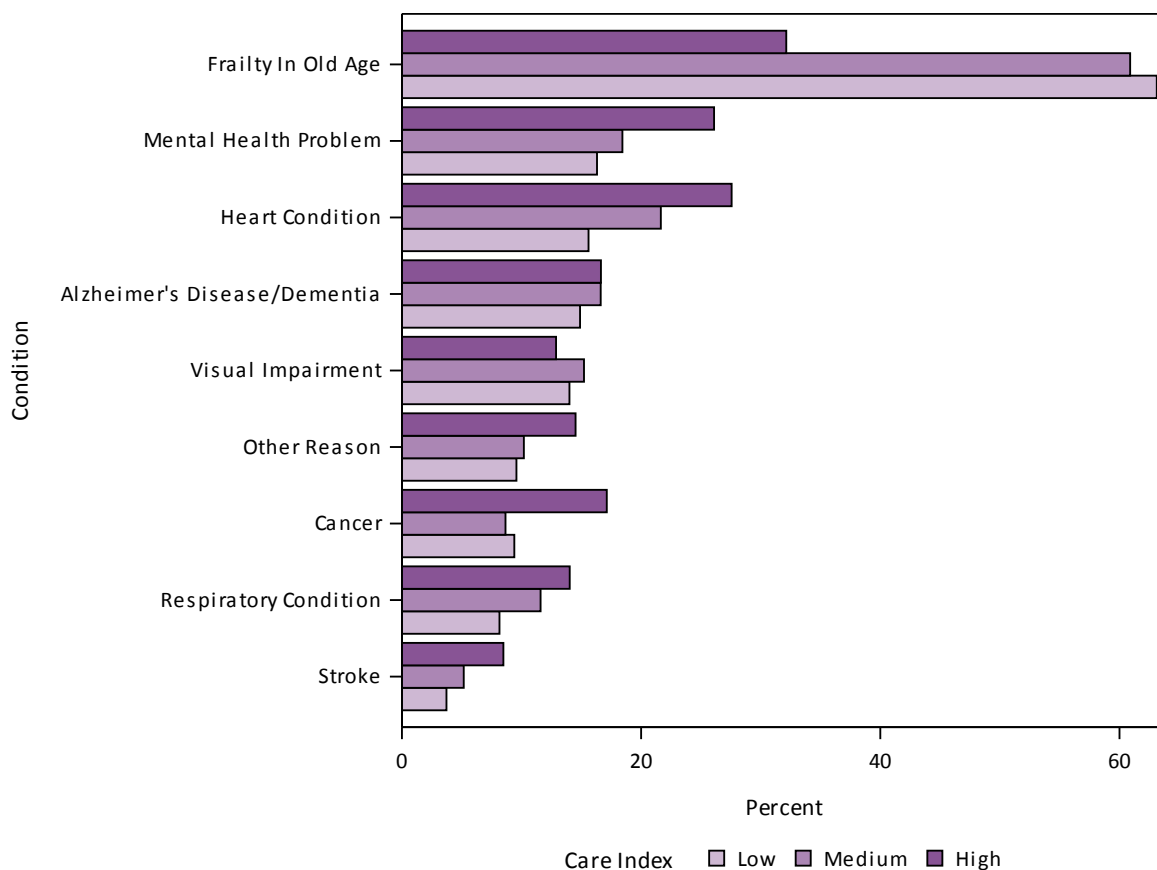


Figure 4-13 Percentages showing the nature of the condition of the person being cared for at Survey 8 (65-72 years), by caregiving intensity (N=2021).

4.4.2. Happiness with share of caring for another adult by women in the 1946-51 cohort

At Surveys 1, 4, 5, and 6 the women in the 1946-51 cohort were asked whether they were happy with their share of caregiving activities for another adult who is elderly, disabled or sick. The response options to this question were 'happy the way it is', 'would like other household members to do more' and 'would prefer another arrangement'. The percentages of women who reported that they were 'happy the way it is' were 66% at Survey 1 (when they were aged 45-50), 81% at Survey 2 (47-52 years) and around 75% at Surveys 4 and 5 (56-61 years). A steady 8-10% reported that they 'would prefer another arrangement' at each of the surveys. The percentage reporting that they 'would like other household members to do more' was highest at Survey 1 (26%) and lowest at Survey 2 (10%).

Key points

- Medium intensity caregiving was most frequently reported when the total prevalence of caregiving was at its highest. This was when the women were aged in their mid-to-late 50s.
- 6-9% of women in the 1946-51 cohort provided high intensity caregiving from Survey 3 to 8.
- The majority of caregivers were caring for their parents or parents-in-law, or spouse/partner.
- Where caregivers lived with the person they cared for, it was principally their spouse or partner who received the care.
- Where caregivers lived elsewhere from the person they cared for, they primarily provided care for their parents or parents-in-law.
- Of the caregivers providing high intensity caregiving, most were caring for their spouse/partner, followed by their parents/parents-in-law.
- Of the caregivers providing low intensity caregiving, most were caring for their parents/parents-in-law, followed by a friend.
- The most prevalent condition in the people who required care was frailty in old age.
- Where caregivers lived with the people they cared for, the person receiving their care were more likely to have heart disease, mental health problems, or other conditions; all of which required high intensity care.
- Medium and low intensity care was more prevalent for people who were frail.
- Overall, the majority of women in the 1946-51 cohort who provided care (66-81%) were happy with their share of caregiving activities and approximately 10% reported at each survey that they would prefer another arrangement.

4.5 Caregiving by women in the 1973-78 cohort for any other person because of their long-term illness, disability or frailty

Only a very small percentage of women born in 1973-78 and aged between 18 and 36 years (Surveys 1 to 5) reported providing care for other people (average of 6% across the surveys, Figure 4-14). For the first 5 surveys the women were only asked if they provided care for someone. From Survey 6 onwards, the 1973-78 cohort were asked to report their caregiving status by where the care recipient lived. This may have accounted for the almost doubling in prevalence in the latter two surveys. However we know from the patterns in the 1946-51 cohort that at age 45 to 50 around 30% of women were caregivers so we may expect the prevalence in the 1973-78 cohort to rise as they enter their 40s.

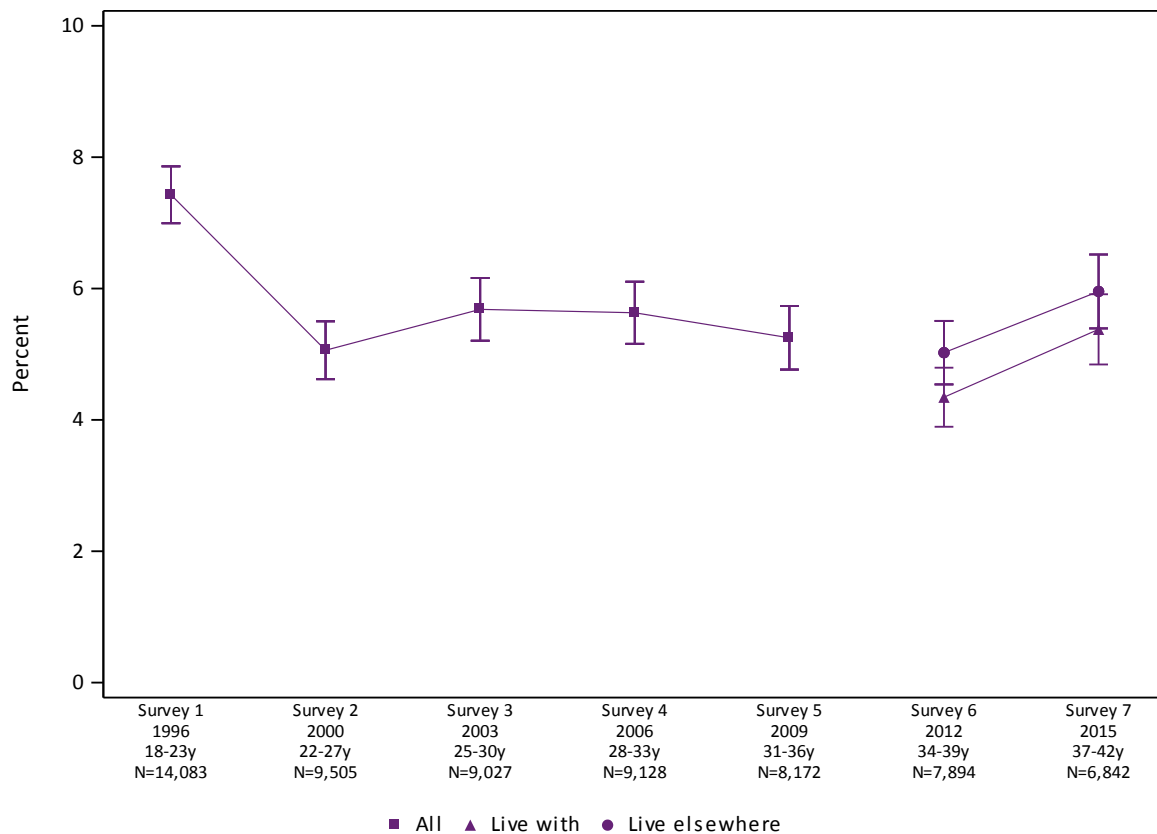


Figure 4-14 Percentage of women in the 1973-78 cohort at Surveys 1 to 5 by whether they care for any other person (Yes/No) and for Surveys 5 and 6, by whether they live with or live elsewhere from the person they care for.

4.5.1. Caregiving by women in the 1973-78 cohort by socio-demographic status

This section presents an overview of the associations between caregiving by women in this cohort and socio-demographic status (labour force participation, years of education, managing on income, area of residence) at Survey 7 when the women were aged 37 to 42. For women born 1973-78 the associations were broadly similar to those found for women born in 1946-51, that is, those caring for someone who lived with them had poorer socio-demographic indicators than non-caregivers and those caring for someone living elsewhere. A lower percentage of live-in caregivers (compared with caregivers who lived elsewhere to the person they care for or non-caregivers) had university level education (46% compared with 52-58%) and were in the labour force (77% compared with 87-91%, respectively). A higher percentage of live-in caregivers also reported finding it impossible or very difficult to manage on their income compared with non-caregivers or those not living with the person they cared for (26% compared with 13-20%, respectively). There were no significant differences between caregivers and non-caregivers on their area of residence.

4.5.2. Intensity of caregiving by women in the 1973-78 cohort for another person because of their long-term illness, disability or frailty

The questions used to calculate caregiving intensity were asked at Surveys 6 and 7 in the 1973-78 cohort. As we showed previously in Figure 4-14, few women in this cohort, 9% and 11%, reported being a caregiver at Survey 6 and 7, respectively. At Survey 6, the distribution of caregiving intensity was evenly split with about a third of women each reporting being a low, medium or high intensity caregiver. At Survey 7 about 4% of the women reported providing either medium or high intensity caregiving, with 2% low intensity caregiving. The very low numbers precluded further analysis by whether the women lived with the care recipient.

Key points

- When aged in their 20s and 30s about 6% of women in the 1973-78 cohort provided care for other people, with this prevalence increasing as the women entered their 40s.
- Similarly to women in the 1946-51 cohort, those caring for other people had poorer socio-demographic status than non-caregivers and those caring for someone who lived elsewhere.
- No particular trend for caregiving intensity was found for women born in 1973-78 when they were in their mid-30s to early 40s.

4.6 Caregiving by women in the 1921-26 cohort for any other person because of their long-term illness, disability or frailty

For the 1921-26 cohort, data are presented separately for Surveys 2 to 6, and then for the subsequent 6-month follow-up surveys (see Figure 4-15). The 6-month follow-up data are presented separately because the surveys were closer together in time. While the 6-month follow-up surveys included the same caregiving question, the surveys were briefer, were processed differently and fewer women completed them. In examining the first section of Figure 4-15, the prevalence of caregiving was highest when the women were aged 76 to 84 years, with caring for someone living elsewhere peaking at around 15%. From the ages of 82 to 90 years, the prevalence of women caring for someone living with them or elsewhere was approximately equal, dropping from 8% at Survey 5 to 6% at Survey 6. At Survey 5, when the women were aged 82 to 87, there also appeared to be crossover in prevalence, with caring for someone living elsewhere becoming slightly more prevalent than caring for someone they lived with. This may reflect the death of their spouse or partner. The trajectory of the percentage caregiving shown in data from the 6-monthly surveys was similar to that shown in the original ALSWH surveys for this cohort but at a higher level reflecting the different methodology, and possibly cohort attrition.

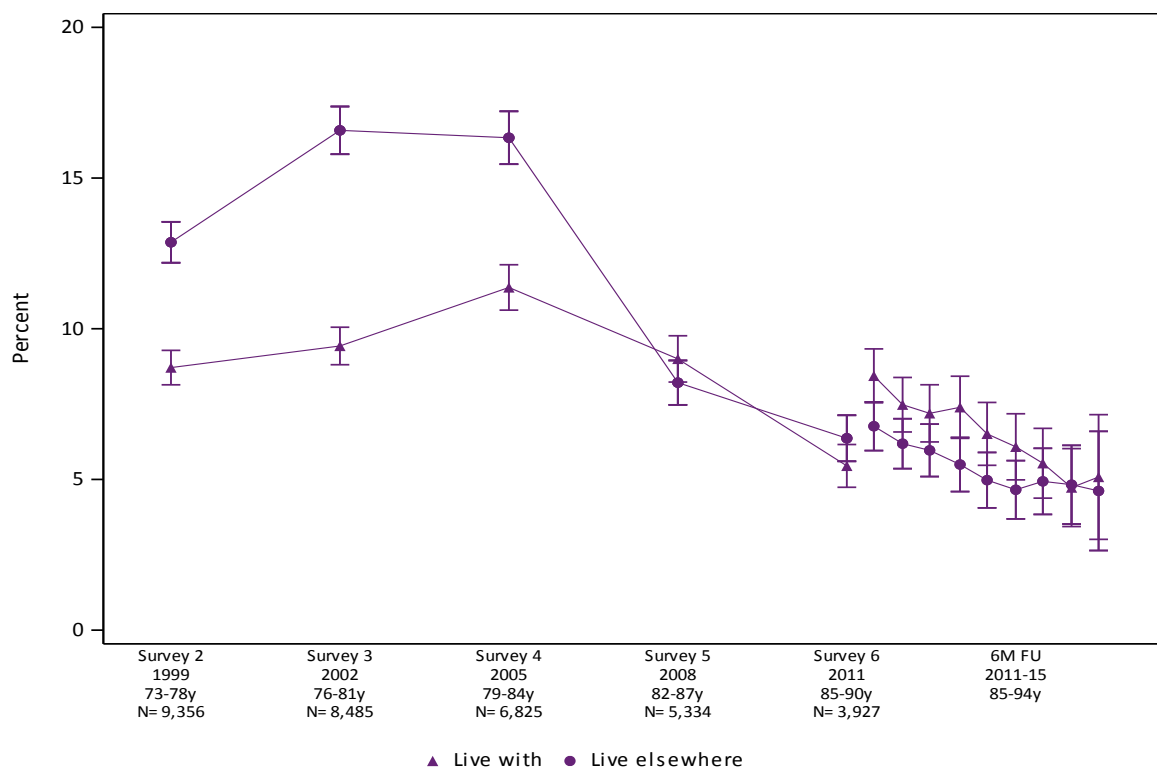


Figure 4-15 Percentage of women in the 1921-26 cohort at Surveys 2 to 6, and then at each of the 6-month follow-up surveys, by whether they live with or live elsewhere from the person they care for. Note: the sample sizes for each of the 6-month follow-up surveys are not included due to the number of surveys, however the sample size at the 9th follow-up was 433.

4.6.1. Caregiving by women in the 1921-26 cohort by socio-demographic status

Data from Survey 4, conducted in 2005 when the women were aged 79 to 84, were used as this was when the prevalence of caregiving was highest in women of the 1921-26 cohort. There were no significant differences between caregivers and non-caregivers for any of these socio-demographic status indicators.

4.6.2. Intensity of caregiving by women in the 1921-26 cohort for any other person because of their long-term illness, disability or frailty

Women of the 1921-26 cohort were asked to describe how long and how often they provided care for another person only at Survey 2 (1999). Of the 1596 women who reported being a caregiver, 38% reported they provided low intensity caregiving, 28% reported medium intensity and 34% high intensity caregiving. Low and medium intensity care was most frequently provided by caregivers who did not live with the person they care for (56% and 36% compared with 8% and 15% of live-in caregivers, respectively). High intensity care was overwhelmingly provided by live-in caregivers (77% compared with 8% of caregivers living elsewhere).

Key points

- In the 1921-26 cohort, the percentage of women who were caregivers peaked when they were aged 76 to 84 years before sharply decreasing.
- In contrast to the 1973-78 and 1946-51 cohorts, there were no differences in socio-demographic status indicators between caregivers and non-caregivers.
- Low and medium intensity care was provided by caregivers in the 1921-26 cohort who did not live with the person they cared for. High intensity care was provided by caregivers who lived with the person they cared for.

4.7 Transitions in caregiving by women in the 1973-78 and 1946-51 cohorts: Previous research from the ALSWH.

Several authors have examined changes in caregiving over time for ALSWH participants, and the associations of such transitions with various socio-demographic status, health status and health behaviour factors. A brief summary of the key findings is presented here (abstracts from these papers are included in the [appendix](#)).

Lee and Gramotnev (2007) described transitions into and out of caregiving by 9555 women in the 1946-51 cohort between Survey 2 and Survey 3 (when the women were aged 47-55). Women were classified as continuing to give care (3%), stopped (5%), started (3%), or never caregivers (89%). At both surveys, women in the three caregiver groups showed poorer physical and emotional health, greater use of health services, poorer health behaviours and lower engagement in the paid workforce compared with never caregivers. The authors concluded that mid-aged women in poor health tended to be selected into caregiving, possibly because they were less engaged with the paid workforce and that poor health and disengagement from the paid workforce continued even when caregiving stopped.

In 2008, Berecki et al., studied the order of events leading to informal caregiving (defined as providing care for an ill, frail or disabled person at least 7 hours per week) and changes in labour force participation in women in the 1946-51 cohort, taking into account their health and socioeconomic status. This analysis included 9857 women who responded to Survey 3 and Survey 4 (when they were aged 50-58). Between the surveys, the percentage of women providing care increased from 12 to 14% while paid employment participation decreased from 67 to 62%. Transitions into caregiving at Survey 4 were not associated with how many hours the women had spent in paid employment at Survey 3. But once the women began caregiving they subsequently reduced their hours of employment. The authors concluded that policies to support continuing labour force participation during caregiving could include creating flexible working arrangements and that re-employment programs could support women who quit work after a period of caregiving.

Tooth and Mishra (2014) investigated longer term transitions in caregiving in women in the 1973-78 cohort (over 13 years, from Surveys 1-5) and the 1946-51 cohort (over 9 years, from Surveys 3 to 6) and associations between these transitions and the women's baseline demographic, socioeconomic status, health status and health behaviour characteristics. The authors postulated that the early identification of women who may be likely to take on caregiving roles may enable policy makers to design policies and programs pre-emptively to counter some of the negative effects, particularly from continued caregiving. The study included 14,202 women in the 1973-78 cohort and 12,282 women in the 1946-51 cohort, and latent class analysis was used to identify 'classes' or 'trajectories' of women who have similar patterns of caregiving over time.

For the 1973-78 cohort, five distinct trajectories of caregiving were found to represent distinct groups of caregivers. However, most women (94%) were in a single class which had the lowest probability of being a caregiver over the time frame, and most women had 'never' provided care. The other four classes were: 'ongoing' with the highest probability of caregiving across the 5 surveys (1%), 'starting' with an initial low probability of caregiving which increased over time (2%), 'short-term' with an initial low probability of caregiving which spiked and then dropped to low (3%), and 'early high then fluctuating' (1%). Indicators of poorer socioeconomic factors at baseline (difficulties with income management, reduced labour force participation) were associated with the latent classes representing 'ongoing' and 'starting' caregiving. However, the socioeconomic factors associated with the latent class representing 'short-term' caregiving were more mixed: while they represented financial hardship at baseline, they also reflected varying levels of labour force participation (from no work or study up to full-time work and study) and both low and high educational qualifications (≤ 10 years and also trade/certificate/diploma). In a further contrast, no socioeconomic factors were associated with the latent class representing 'fluctuating' caregiving. The authors suggested this may indicate that self-selection into more transitory caregiving behaviours by young women may be less influenced by socioeconomic factors, or that young women who participate in transitory caregiving may comprise distinct groups. There were mixed and inconsistent findings on the associations between health and health behaviours on caregiving (the abstract of this study is in [Appendix A](#)).

For the 1946-51 cohort, three distinct trajectories of caregiving were identified representing 'ongoing' (21% of women with the highest probability of being a caregiver across the 4 surveys), 'starting' (9% of women, who showed an initial low probability of caregiving which increased over time) and 'never' caregiving (70% of women with the lowest probability of being a caregiver across all surveys). The latent class trajectories also revealed potential turning points in caregiving. At Survey 4, when the women were aged 53–58 years, women in the 'ongoing' class began to decrease caregiving and the 'starting' class showed an upwards spike in caregiving. After Survey 5, the 'starting' class began to show a small decline. The authors postulated that these turning points possibly indicated a new wave of caregiving behaviour or new type of caregiving. Poorer socioeconomic status (no occupation, part-time employment, difficulties with income management) were associated with 'ongoing' caregiving, but not 'starting' caregiving. The authors suggested that by mid-age self-selection into new caregiving roles may not be as strongly influenced by opportunity cost related to socioeconomic factors (that is, if a woman assesses she has less to lose by becoming a caregiver she may be more likely to self-select into caregiving compared to a woman who assesses she has more to lose). No associations between health factors and trajectories of caregiving were found.

Key points

- In the 1946-51 cohort, women who provided care when aged 47-55 had lower engagement in the labour force compared with non-caregivers, which is possibly due to their poorer health status and greater use of health services.
- As women aged from their early to late 50s, the percentage of women who provided care increased and, simultaneously, participation in paid employment decreased.
- Transition into caregiving was not influenced by the number of hours of paid employment undertaken prior to caregiving, however once caregiving commenced, women in the 1946-51 cohort subsequently reduced their hours of employment.
- In the 1973-78 and 1946-51 cohorts, women who provided continuous caregiving over time had poorer socioeconomic indicators at baseline; no other socioeconomic or health-related associations were apparent for other types of caregivers or non-caregivers.
- Turning points in the percentage of different types of caregiving over time by women in the 1946-51 cohort suggest that the women were engaging in a new type of caregiving behaviour, or that factors that influence the decision to be a caregiver had changed.

5. Caregiving and health, health behaviours and health service use

This chapter presents data from women in the 1973-78, 1946-51 and 1921-26 cohorts on the health, health behaviours and health service use outcomes of women who care for any other person because of their long-term illness, disability or frailty compared to women who do not provide this type of caregiving. Data for the women in the 1946-51 cohort are presented first, as they had the highest prevalence of this type of caregiving. Where appropriate, data are also analysed by whether they lived with the person they cared for or elsewhere. The health data included in this chapter are self-rated health, body mass index, physical activity, alcohol consumption, smoking, diet, chronic conditions, perceived stress, depression, anxiety, visits to a general practitioner and specialist, Medical Benefit Scheme (MBS) unreferred visits and Pharmaceutical Benefit Scheme (PBS) scripts filled and use of health screening services (see [Appendix A](#) for how these are characterised).

The chapter includes an analysis of free-text comments from women who reported both providing care to someone else, and requiring help and assistance with their own self-care. Where appropriate, other pre-existing research on caregiver's health using data from the ALSWH is also summarised.

5.1 Caregiving by women in the 1946-51 cohort and associations with health, health behaviours and health service use

This section presents the association between health, health behaviours and health service use of women in the 1946-51 cohort by whether they were caregivers, and where they lived in relation to the person they cared for. Health, health service use and caregiving data at the most recent survey (survey 8, when the women were aged 65-70 years) are presented here. Where the nature of the associations at earlier surveys was different this is discussed in text.

5.1.1. Caregiving and self-rated health

Figure 5-1 shows poorer self-rated health among caregivers living with the person they cared for compared with other caregivers or non-caregivers. At Survey 8, the discrepancies were significantly different for very good health (32% of live in caregivers as compared with 38% for the other groups) and good (44.4% of live in caregivers as compared with 39% of non-caregivers). However, stronger associations were found among the groups at earlier surveys.

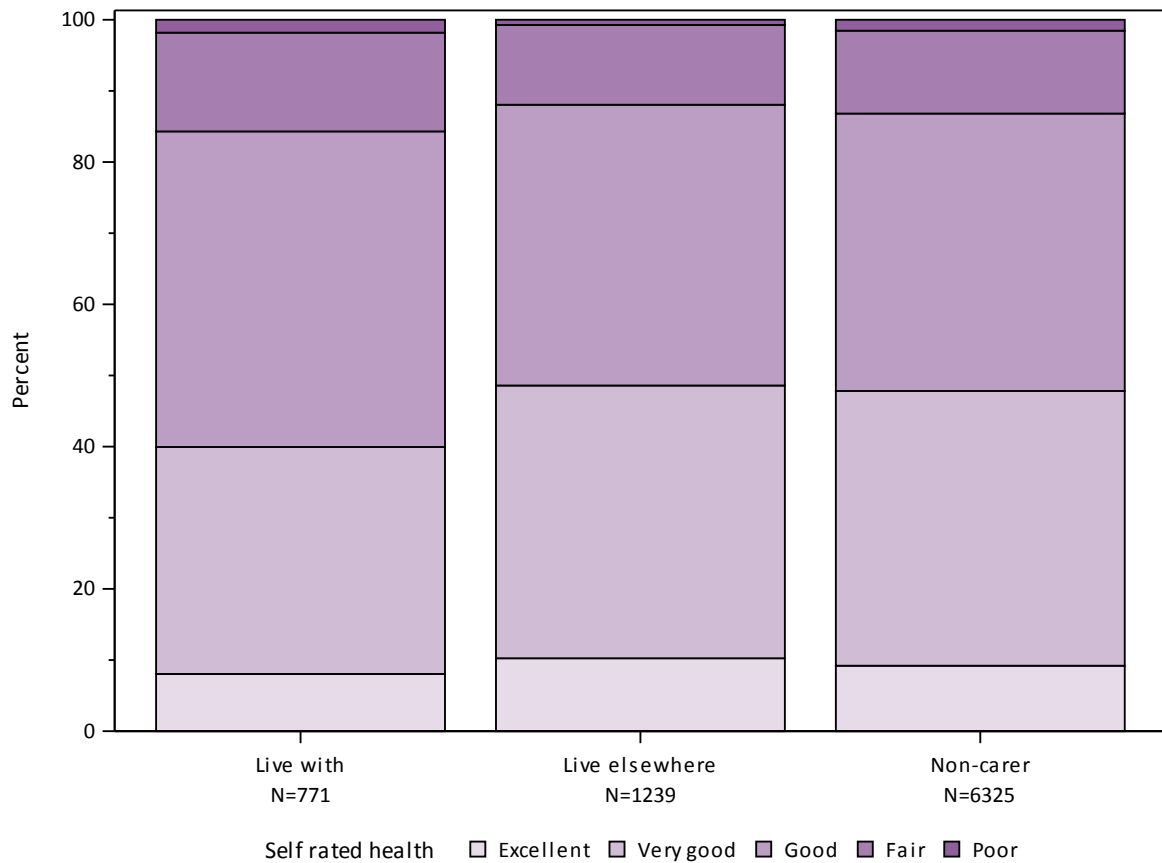


Figure 5-1 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and self-rated health.

5.1.2. Caregiving and Body Mass Index

Figure 5-2 shows that at Survey 8 a significantly higher percentage of caregivers living with the person they cared for were obese (about 5% more) compared with either caregivers living elsewhere or non-caregivers. Consistently stronger and more significant associations were reported at earlier surveys.

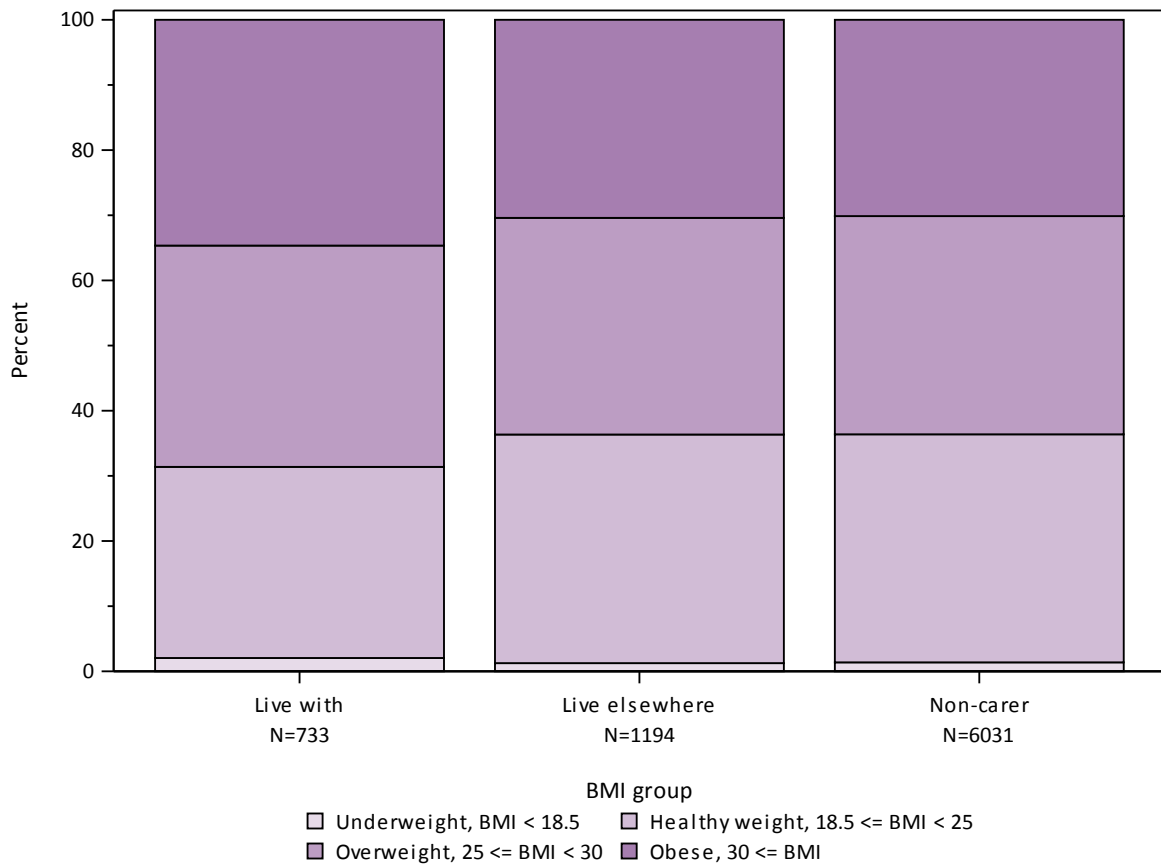


Figure 5-2 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and body mass index.

5.1.3. Caregiving and Physical Activity

Caregivers living with the person they cared for at Survey 8 reported less high level physical activity (by around 7%) and more physical inactivity (by 3-5%) compared with either caregivers living elsewhere or non-caregivers (Figure 5-3). This pattern was not consistent however over all surveys, only beginning to emerge from survey 4 onwards (when the women were aged 53-58).

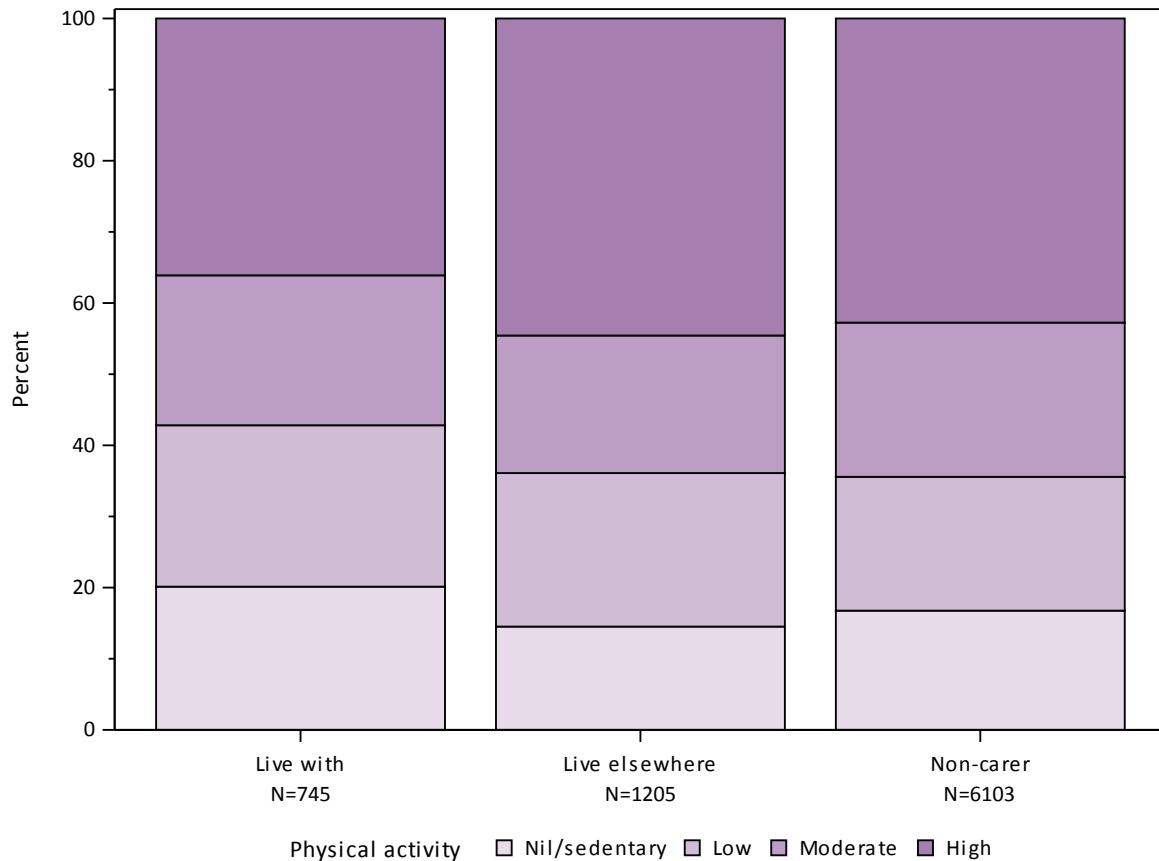


Figure 5-3 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and physical activity.

5.1.4. Caregiving and alcohol consumption

A significantly higher percentage of caregivers living with the person they cared for reported not consuming alcohol compared with either caregivers living elsewhere or non-caregivers (24% compared with 14-17%, respectively). They also had a significantly lower percentage of low risk drinkers than the other groups (70% compared with 76-82%). Of note, caregivers living with the person they cared for had a similar percentage (around 6%) of those who were risky drinkers (>14 drinks/week) to non-caregivers.

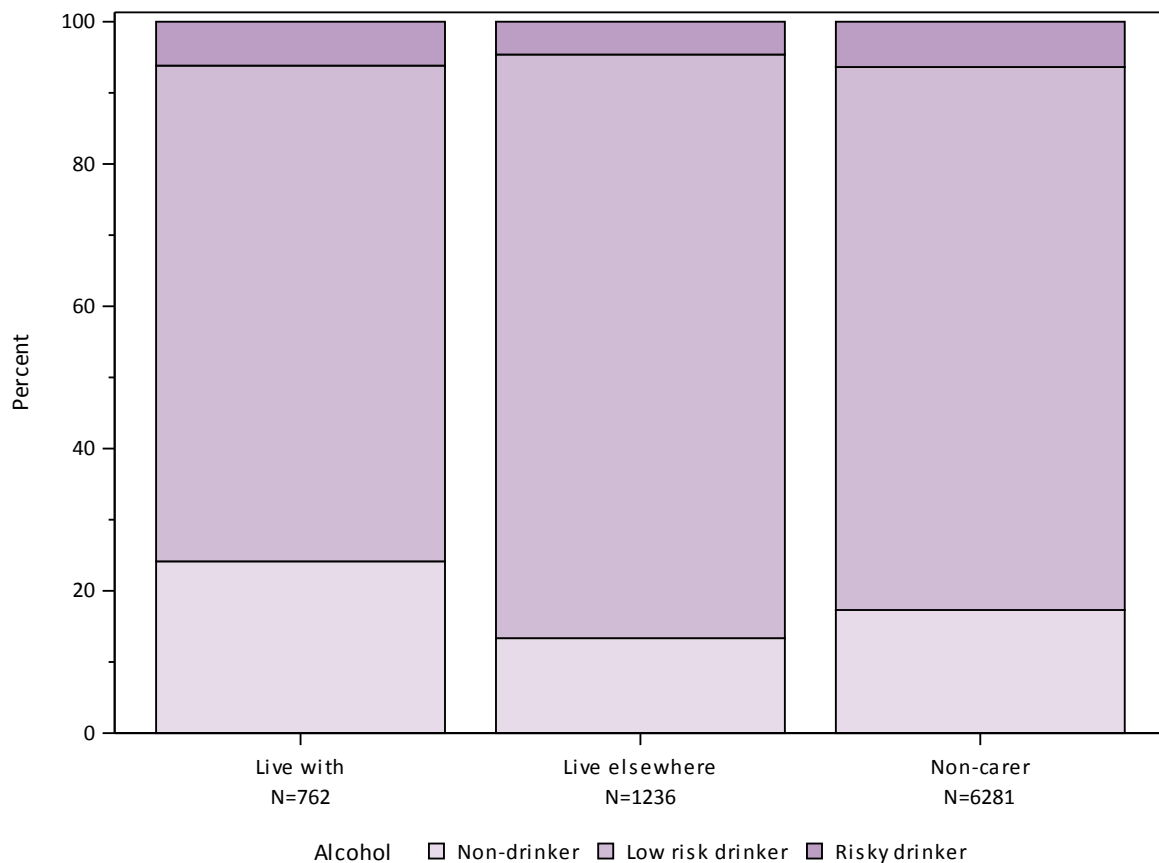


Figure 5-4 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and alcohol consumption.

5.1.5. Caregiving and smoking

At Survey 8 there was no significant difference in smoking patterns between caregivers and non-caregivers. At some earlier surveys (Surveys 4 to 7, when the women were aged from 53-67), a significantly higher percentage of caregivers who lived with the person they cared for reported smoking compared to women caring for someone who lived elsewhere (difference of around 3-4%), but this was not found at Surveys 2 and 3 (when aged 45-52).

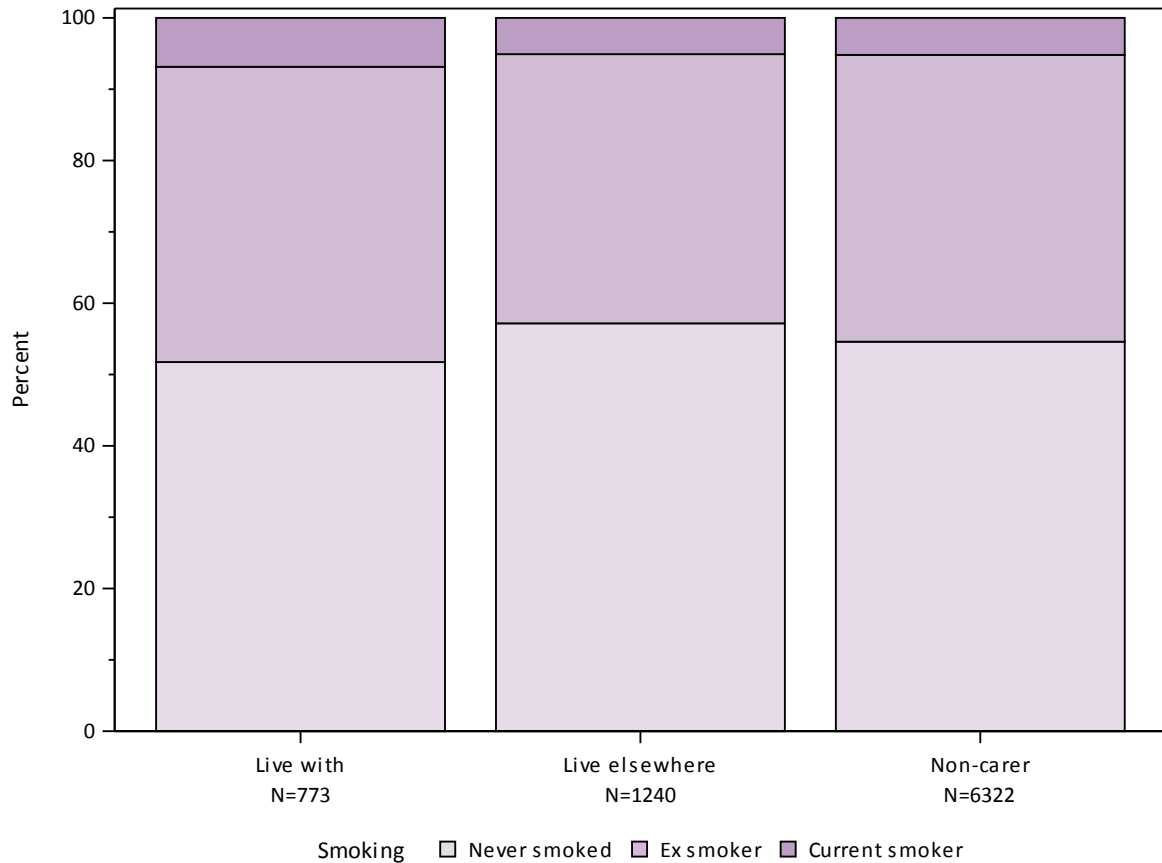


Figure 5-5 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and smoking.

5.1.6. Caregiving and diet

The indicator of adherence to a healthy diet used in this report is consumption of fruit and vegetables, and whether consumption matched national dietary guidelines of five serves of vegetables and two serves of fruit per day (National Health and Medical Research Council of Australia, 2013). The women were asked a similar question about their fruit and vegetable consumption at Surveys 3, 7 and 8. Overall, at Survey 8 (when the women were aged 65-70) adherence to guidelines for fruit and vegetables was mixed. In all women, adherence to two or more pieces of fruit was reported by 63% of women. When analysed by caregiver status, adherence was significantly lower for caregivers living with the person they cared for (58%) compared with women caring for people who lived elsewhere (66%) and non-caregivers (65%). Overall, adherence to guidelines for vegetable consumption was low, at just 16%. There was no significant difference in adherence to vegetable consumption guidelines between caregivers and non-caregivers. Similar associations were found also at Surveys 3 and Survey 7.

5.1.7. Caregiving and chronic conditions

The number of chronic conditions the women in the 1946-51 cohort reported (scored as 0, 1, 2 or 3 or more) was calculated out of a possible maximum of the six main chronic conditions for women of this age. These were breast cancer, diabetes, asthma, heart disease, stroke and arthritis. At Survey 8 (when the women were aged 65-70), a higher percentage of caregivers living with the person they cared for reported three or more chronic conditions (14%) compared with non-caregivers (10%), while a lower percentage, 22%, reported no conditions compared with 26%, respectively. This pattern was consistently found at Surveys 2 to 7. The prevalence of chronic conditions increased generally over time in all of the women, regardless of caregiver status. However, the percentage difference in having no chronic conditions between live in caregivers and non-caregivers was highest (around 10%) at Surveys 3 to 5 (when the women were aged 50-61).

5.1.8. Caregiving and perceived stress

Figure 5-6 shows that caregivers (living with the person they cared for or elsewhere) had higher mean scores for perceived stress than non-caregivers. The highest stress was reported by caregivers living with the person they cared for. This finding was significant at all of Surveys 2 to 8.

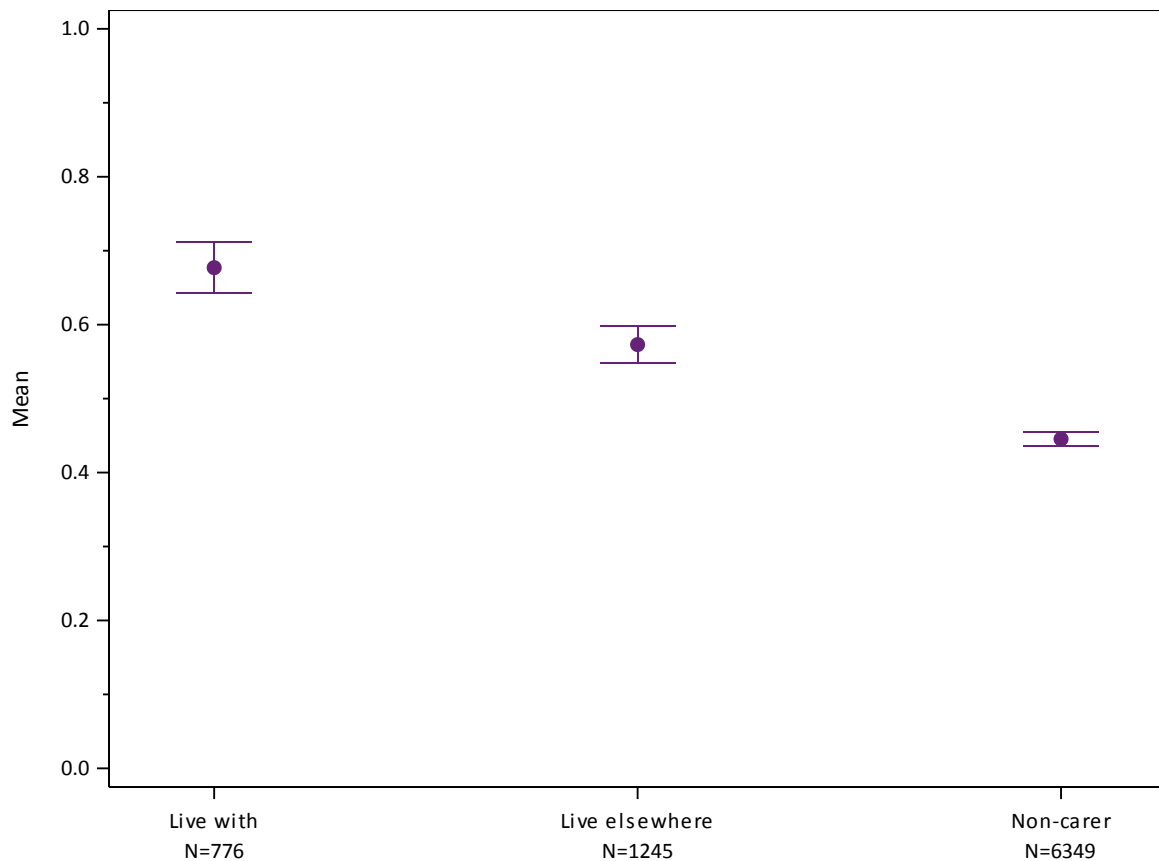


Figure 5-6 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and perceived stress (mean scores and 95% confidence interval).

5.1.9. Caregiving and anxiety

Figure 5-7 shows that at Survey 8 a higher percentage of caregivers (living with or elsewhere to the person they cared for) reported anxiety than non-caregivers. The same significant association was also found at Survey 7. At the earlier surveys however, only caregivers living with the person they cared for reported a higher percentage of anxiety compared with non-caregivers (by a percentage difference of 3-5%).

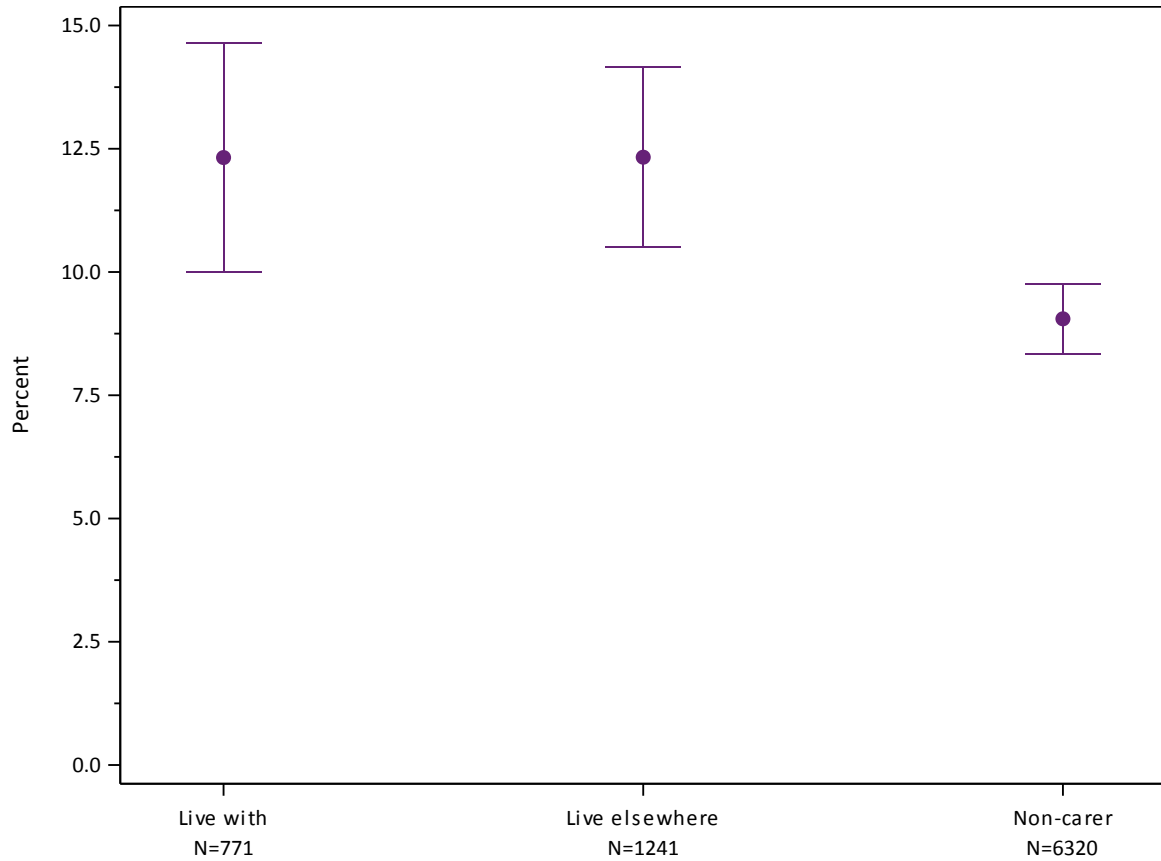


Figure 5-7 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and anxiety (percentage and 95% confidence interval).

5.1.10. Caregiving and depression

Figure 5-8 shows that at Survey 8 a higher percentage of caregivers living with the person they cared for reported depression compared with non-caregivers (with the percentage difference 4%). This result was also found at Survey 2 (when aged 47-52), Survey 5 (aged 56-61) and Survey 6 (aged 59-64), with similar percentage differences. At Survey 4 (aged 53-58) and Survey 7 (aged 62-67), a higher percentage of caregivers living with the person they cared for reported depression than both caregivers who lived elsewhere to the person they cared for and non-caregivers (with the percentage difference ranging from 4-5%).

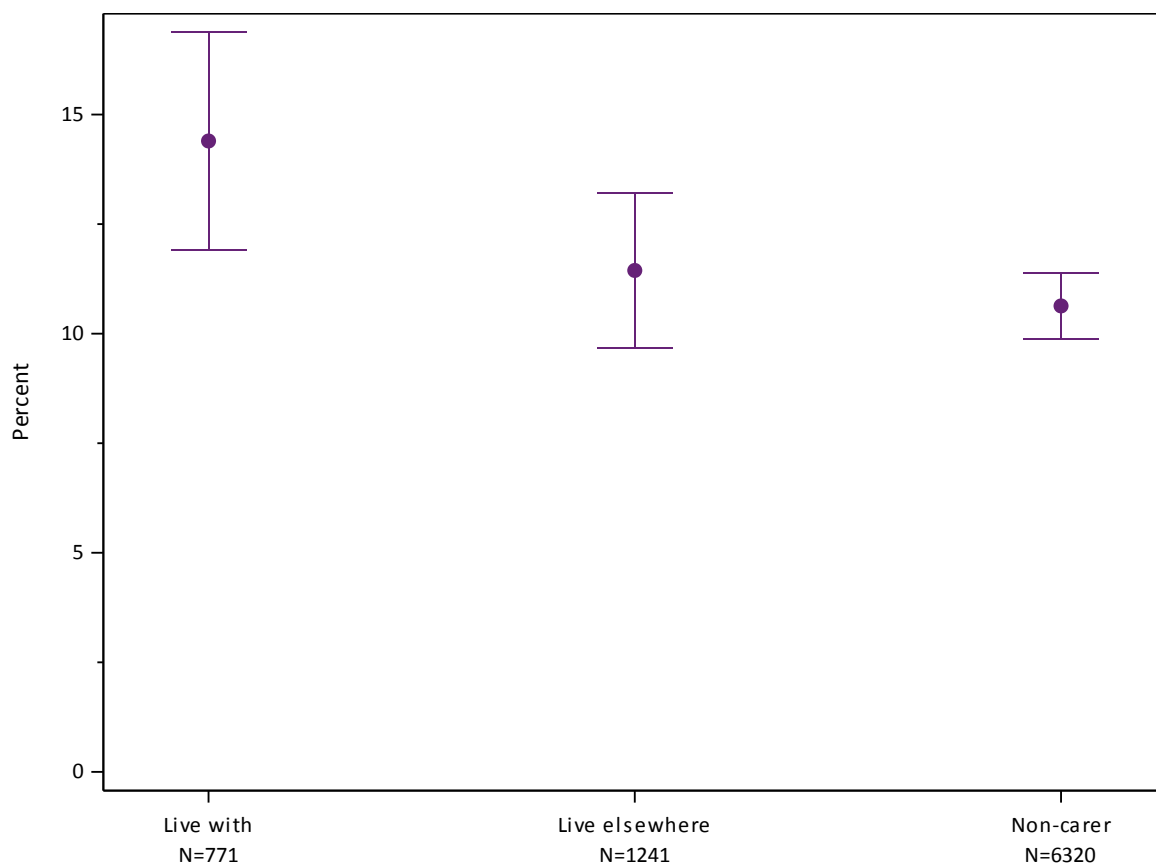


Figure 5-8 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and depression (percentage and 95% confidence interval).

Key points

- In the 1946-51 cohort, caregivers aged 65-70 who lived with the person they cared had poorer self-reported health compared with other caregivers and non-caregivers.
- A higher percentage of caregivers aged 65-70 years who lived with the person they cared for were obese than other caregivers and non-caregivers.
- From the age of 53-58, women living with the person they cared for tended to be less physically active than caregivers living elsewhere and non-caregivers.
- A higher percentage of caregivers living with the person they cared for were non-drinkers and a lower percentage were low risk drinkers compared to caregivers living elsewhere and non-caregivers.
- There was a higher percentage of smokers amongst caregivers born in 1946-51 who lived with the person they cared for than caregivers living elsewhere and non-caregivers, but only between the ages of 53 and 67.
- Adherence to guidelines for fruit intake was lower for caregivers who lived with the person they cared for than caregivers living elsewhere to the person they cared for and non-caregivers.
- There was no difference in adherence to guidelines for vegetable intake between caregivers and non-caregivers.
- A higher percentage of caregivers living with the person they cared for reported three or more chronic conditions and fewer had no chronic conditions than caregivers living elsewhere and non-caregivers.
- Caregivers living with the person they cared for had higher levels of stress than caregivers living elsewhere and non-caregivers.
- A higher percentage of caregivers reported anxiety than non-caregivers.
- A higher percentage of caregivers living with the person they cared for reported depression than caregivers living elsewhere and non-caregivers.

5.2 Caregiving and health service use: General Practitioner and specialist visits, Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) services and screening services

Figure 5-9 shows percentages of women at Survey 8 categorized by caregiver status and the number of self-reported visits to general practitioners during the previous 12 months. At Survey 8, caregivers living with the person they cared for had a higher percentage (by 5-6%) of five or more visits to general practitioners compared with caregivers living elsewhere or non-caregivers. This finding was also found (with the percentage differences ranging from 6-10%) at Surveys 2 to 7. In contrast, there was no difference between caregiving groups and non-caregivers for self-reported specialist visits, and this was also found across Surveys 2 to 7.

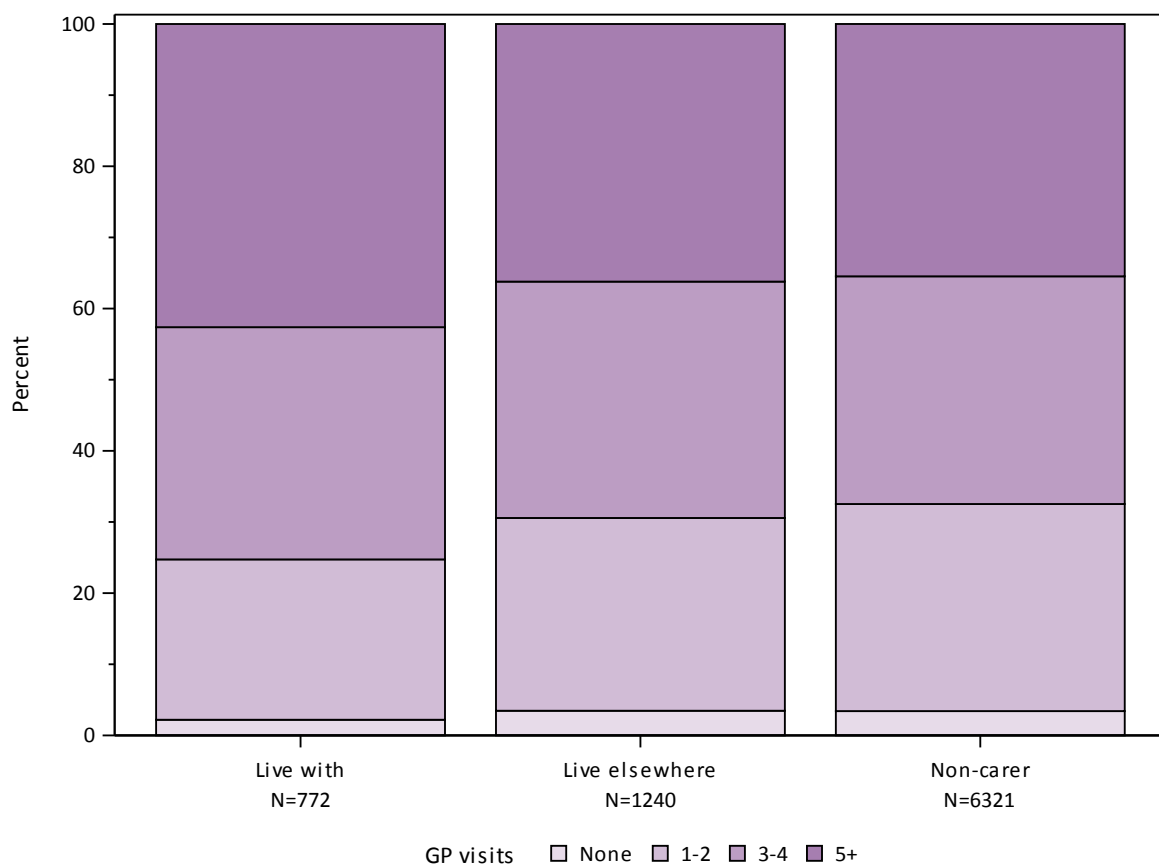


Figure 5-9 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and self-reported general practitioner visits.

5.2.1. MBS services (unreferred visits) and PBS scripts by women in the 1946-51 cohort

The mean number of unreferred MBS services (predominantly general practitioner services) was compared between caregivers and non-caregivers. The time period included in these analyses was as follows: For Survey 8 the data were from the 2015 calendar year as this was the last year we had MBS data for. For all earlier surveys the data are for a 3-year period centred on the survey year. At Survey 8, caregivers who lived with the person they cared for had a mean of 8.8 services in the previous 12 months (Figure 5-10). This was significantly higher than caregivers living elsewhere to the person they cared for and non-caregivers (both had a mean of 7.5). At all previous Surveys from 2 to 7 caregivers living with the person they cared for had a significantly higher mean number of MBS services. Note, the mean number of unreferred MBS services for all women increased over time but at each survey they were highest for live in caregivers (for example, at Survey 2 when the women were aged 47-52, mean MBS services were 6.7, 4.9 and 4.9 for live-in caregivers, live elsewhere caregivers and non-caregivers, respectively).

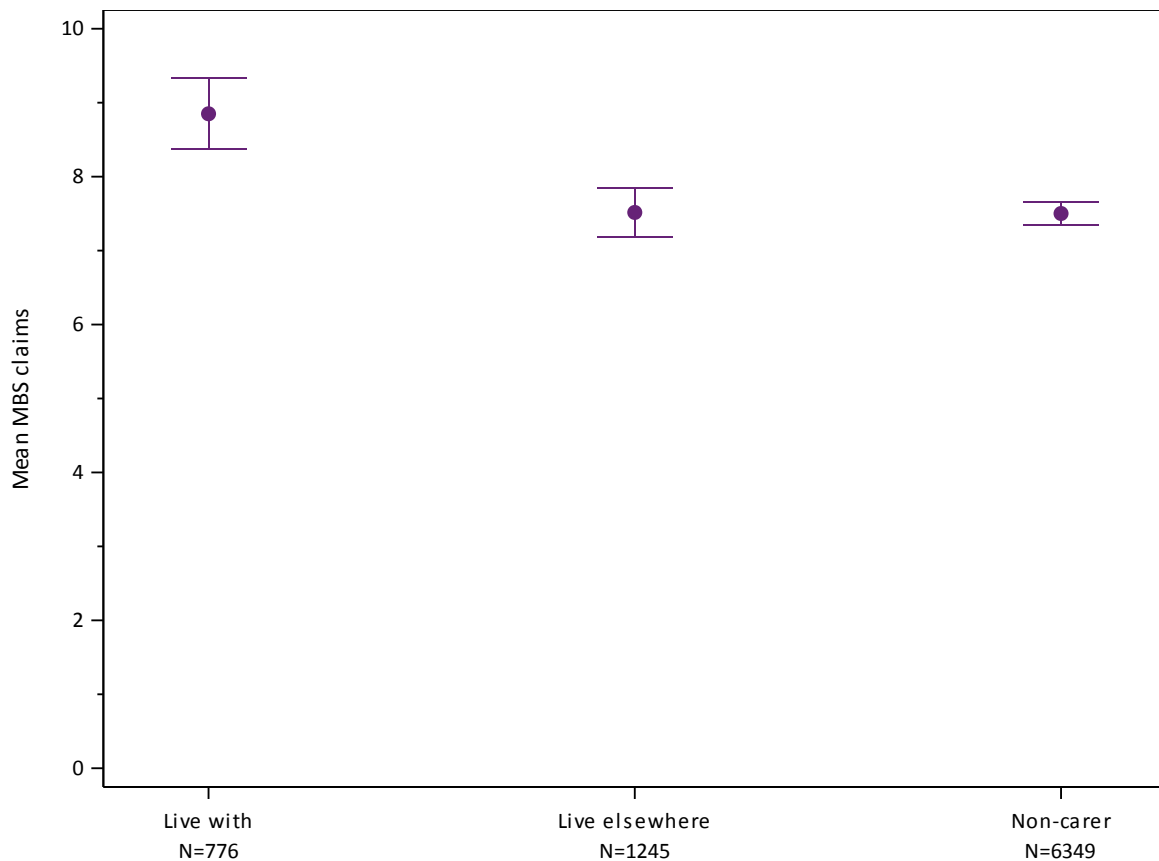


Figure 5-10 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and mean number of unreferred MBS services (mean and 95% confidence interval).

The analysis of PBS data was for the mean number of scripts filled in the previous 3 years to Survey 8 (2013-2015) (Figure 5-11). This analysis revealed a similar pattern to that of MBS services, with a higher mean number of scripts filled by caregivers living with the person they cared for (mean of 28.3) compared with caregivers living elsewhere (23) and non-caregivers (24.5). Data from PBS scripts filled prior to mid-2012 was not complete and therefore was not analysed.

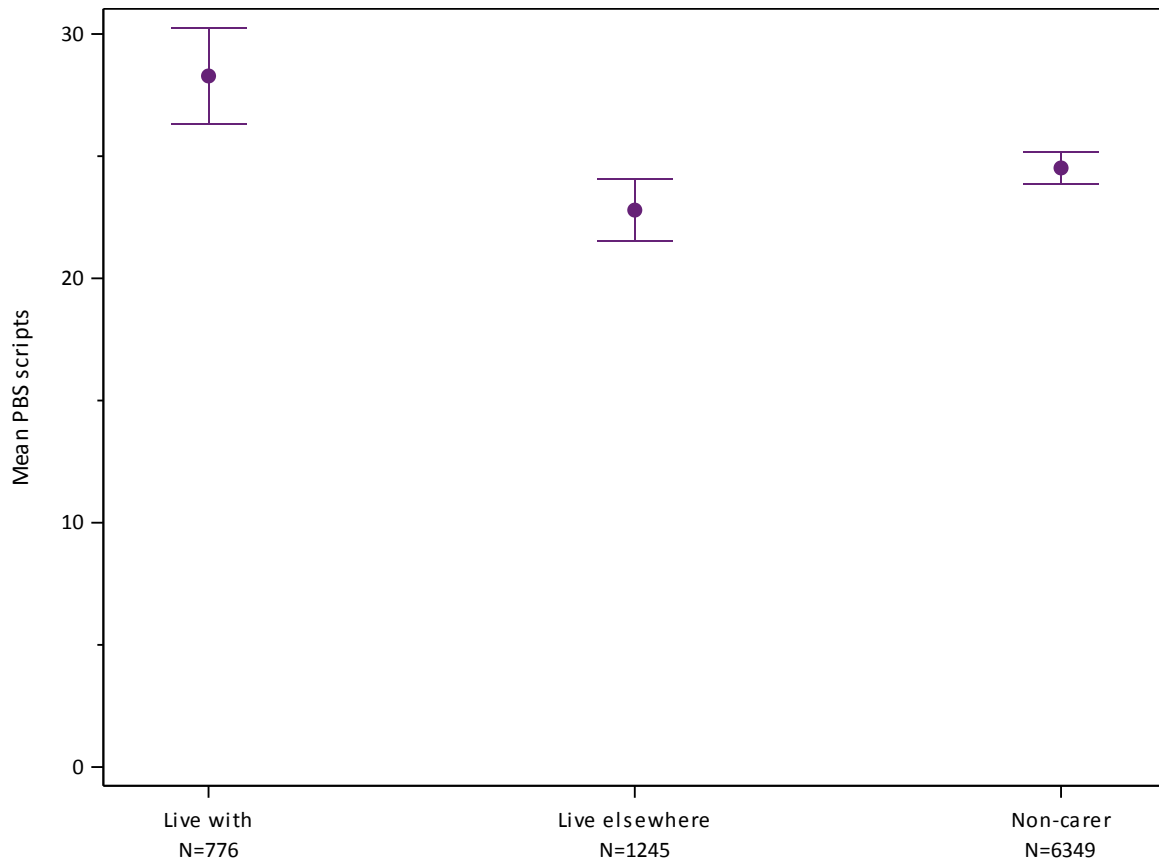


Figure 5-11 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status and mean number of PBS scripts filled (mean and 95% confidence interval).

5.2.2. Use of screening services by women in the 1946-51 cohort: Pap tests and mammograms

At Survey 6 when aged 62 to 67 caregivers who lived elsewhere to the person they cared for and non-caregivers adhered more to recommendations for having a pap test every two years, 61% and 59% respectively, compared with caregivers living with the person they cared for (54%). There was no difference at Survey 6 between caregivers and non-caregivers with adherence to mammograms (adherence to having had a mammogram in the last two years ranged between 79-84%).

Key points

- Caregivers living with the person they cared for had more visits to the general practitioner, had a higher number of prescriptions filled, and were less likely to adhere to pap test recommendations than caregivers living elsewhere or non-caregivers.

5.3 Caregiving by women in the 1973-78 cohort and associations with health, health behaviours and health service use

This section presents an overview of the associations between caregiving by women in this cohort and health, health behaviours and health service use at Survey 7 when the women were aged 37 to 42. For these women, the associations were broadly similar to those found for the 1946-51 cohort, that is those caring for someone they lived with had worse health, poorer health related behaviours and greater use of health services than women caring for someone not living with them and non-caregivers.

The significant associations reflected a higher percentage reporting anxiety (19% of live-in caregivers compared with 11-12% in the other groups), depression (28% compared with 15%), and fair or poor self-rated health (20% compared with 10%). A higher percentage of caregivers living with the person they cared for were also overweight or obese (64% compared with 50-55%), and sedentary (20% compared with 13%) than those caring for someone living elsewhere and non-caregivers. For perceived stress, mean scores were highest for women who cared for someone who lived with them (mean 1.1 (95% confidence interval 1.1, 1.2) or lived elsewhere (1.1 (0.9, 1.1)) than non-caregivers (0.8 (0.8, 0.8)).

A higher percentage of live-in caregivers reported five or more visits to general practitioner (42%) compared with those not living with the person they cared for and non-caregivers (27-28%) and a lower percentage of one to two visits (26% as compared with 37-39%, respectively). Live-in caregivers also reported more visits to a specialist (14%) compared with caregivers not living with the person they cared for (8%). For number of unreferral MBS services, women who cared for someone who lived with them had a higher mean number (7.0, 95% CI 6.4, 7.6) than women who cared for someone who lived elsewhere (5.4 (4.9, 6.0)) or did not provide care (4.8 (4.7, 4.9)). Similarly, a higher mean number of PBS scripts were filled by women who cared for someone who lived with them (11.4 (10.0, 12.9) than by women who cared for someone who lived elsewhere (7.1 (5.6, 8.5)) or did not provide care (6.4 (6.0, 6.7)). There were no significant differences between caregivers and non-caregivers

for smoking or drug use (questions asking about illicit drugs), alcohol consumption or adherence to dietary guidelines for fruit and vegetable consumption.

Key points

- In the 1973-78 cohort, caregivers living with the person they cared for had poorer health and health-related behaviours, and greater use of health services than women caring for someone living elsewhere and non-caregivers.
- More caregivers living with the person they cared for reported anxiety and depression, and poorer health than caregivers who lived elsewhere and non-caregivers.
- A higher percentage of live-in caregivers were overweight or obese and had sedentary lifestyles than caregivers who lived elsewhere and non-caregivers.
- Caregivers living with the person they cared for also made more visits to the general practitioner and specialists, and filled more prescriptions than caregivers who lived elsewhere and non-caregivers.
- There was no difference between caregivers and non-caregivers for specific lifestyle behaviours such as smoking, drug use, alcohol consumption and adherence to dietary guidelines.

5.4 Caregiving by women in the 1921-26 cohort and associations with health, health behaviours and health service use

This section presents an overview of the associations between caregiving by women in this cohort and health, health behaviour and health service use at Survey 4 when the women were aged 79 to 84. For women born 1921-26 the associations were broadly similar to those found for women in the 1946-51 cohort, although not as strong or consistent.

Women who were not living with the person they cared for reported better self-rated health (that is, a higher percentage reporting very good health (32% versus 22-25%) and fewer reporting fair or poor health (21% versus around 33%) compared with live-in caregivers and non-caregivers, respectively). Similarly, they reported being more physically active (a higher percentage reporting high activity (22% versus 14-15%) and fewer who were sedentary (32% versus 43-46%) compared with live-in caregivers or non-caregivers, respectively). Women who cared for someone who lived with them and non-caregivers were more likely to be obese (16% and 15%, respectively) compared to women who cared for someone who lived elsewhere (11%). No differences were found between caregivers and non-caregivers on self-reported anxiety or depression or on the number of unreferral MBS services.

5.4.1. Caregiving by women in the 1921-26 cohort and their own self-care needs

At all surveys the women are asked whether they regularly need help with daily tasks because of long-term illness or disability. Their responses were analysed by whether the women also cared for any other person with a long-term illness, disability or frailty. At all of Surveys 2 to 6, among non-caregivers there was the highest percentage who required help with their own daily tasks (increasing from 11% in Survey 2, when aged 73 to 78, to 23% in Survey 6 when aged 85-90). At all surveys, caregivers who lived with the person they cared for had a higher percentage of needing help (percentages ranged from 9-14%) compared with caregivers living elsewhere (percentages ranged from 4-10%). Figure 5-12 shows data from Survey 4 in 2005 (when the women were aged 79-84) when caregiving prevalence for the women in this cohort was highest.

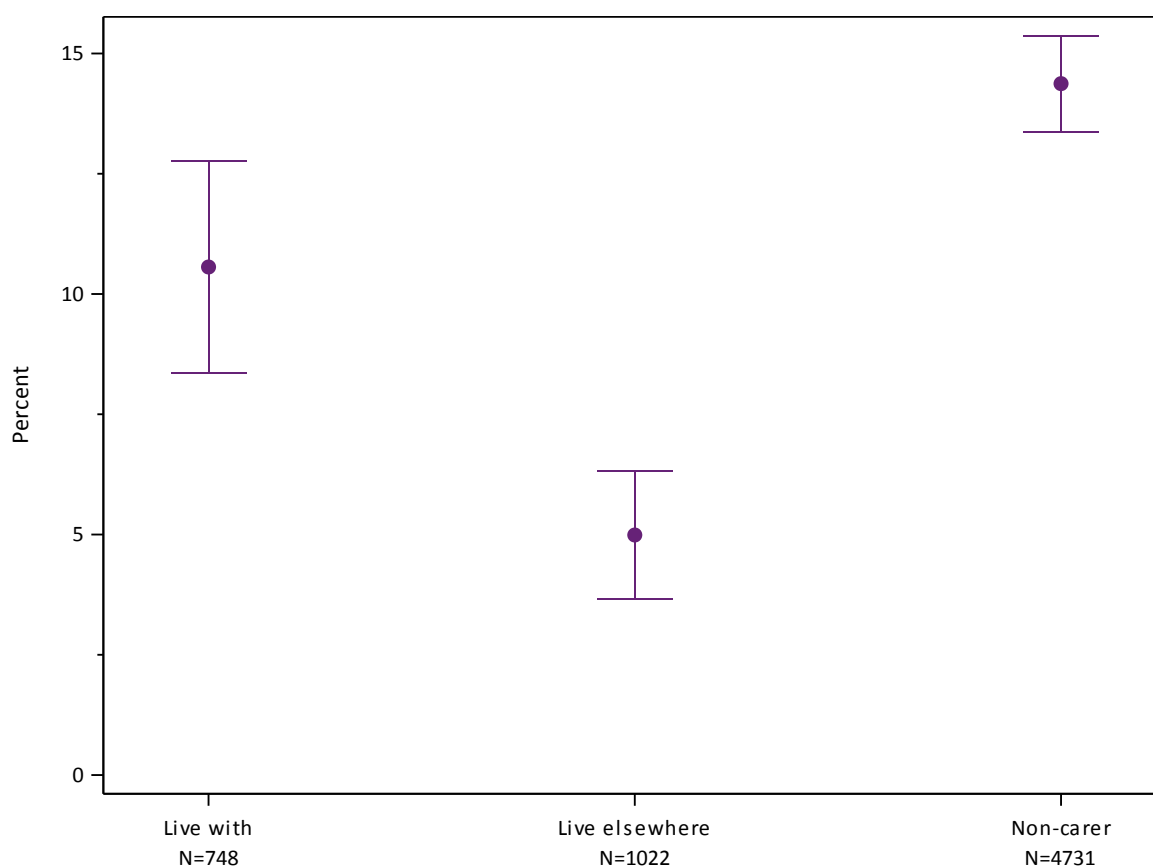


Figure 5-12 Percentage of women in the 1921-26 cohort at Survey 4, by caregiving status and whether they required assistance with their own daily tasks because of long-term illness or disability (percentage and 95% confidence interval).

Key points

- Caregivers aged 79 to 84 years and not living with the person they cared for had better self-rated health and were more physically active than live-in caregivers and non-caregivers.
- Caregivers who lived with the person they cared for were more likely to be obese than caregivers who lived elsewhere and non-caregivers.
- There were no differences in self-reported anxiety and depression, and MBS service use between caregivers and non-caregivers.
- Amongst the women aged 79 to 84 years, non-caregivers had the highest percentage who required help with their own daily tasks, followed by live-in caregivers, and caregivers living elsewhere.

5.5 Providing and needing care: A qualitative examination of free-text comments from ALSWH participants

“All things considered, my husband and I seem to manage quite well, but we do get frustrated with the ageing process!!!”

*Comment by an ALSWH participant from the
1921-26 cohort at Survey 4 in 2005*

The ALSWH quantitative data demonstrate the association between both needing and providing care. As women age, the likelihood of needing care increases, just as the likelihood of their peers needing care increases. The quantitative data have demonstrated that for older women, the person they are most likely to care for is their spouse. The ALSWH qualitative data were analysed to find out more about the experiences of women who need care and support and also provide care to those that depend on them. In particular, the data were

investigated to explore the aspects of both providing and needing care that were problematic and to identify factors that might facilitate caregiving under these circumstances.

For this analysis, we defined women who were providing and needing care as women who, either implicitly or explicitly, reported needing care or support themselves (e.g., needing someone to drive them to the supermarket), as well as reporting providing care to others. The 1946-51 and 1921-26 cohorts were included in this analysis. The sampling frame for this analysis included all surveys of the 1921-26 cohort and Survey 8 of the 1946-51 cohort where:

Women who had responded ‘yes’ to the question that asks about regularly providing care and assistance to others **and** ‘yes’ to the question about needing care themselves, **and** had provided a free-text comment.

Relevant free-text comments were identified from the sampling frame (see [Appendix A](#) for details). Of the 746 comments in the sampling frame, 162 were deemed to be relevant. The longitudinal data (that is, free-text comments from all surveys) for the included participants were collated. In total, there were 791 longitudinal comments from 119 women across both cohorts.

5.5.1. Results

The key themes arising from this analysis include: *giving and receiving care* (caring for partner, care for each other), *‘having help helps’* (e.g., formal care services, informal care provided by family), *her health* (e.g., own health issues, neglect of one’s own health), *housing* (supported and independent accommodation), and *how she feels* (e.g., sad and lonely, tired). This analysis suggests that providing care to someone while needing care is often challenging and difficult. In addition, providing care became increasingly difficult over time, as both the women and those people being cared for aged, and as health deteriorated further. This was particularly evident for the 1921-26 cohort, who were well into their 90s at the most recent surveys.

Overwhelmingly, and in keeping with the quantitative results, the person the women reported caring for most often was their spouse, who in these data was always a husband.

“Owing to the onset of Alzheimer’s disease (my husband being the sufferer), life in retirement has become quite sad. I looked after him for several years but the disease progressed to such an extent that home care became impossible and he was assessed to become a nursing home resident. I visit him every second day, but I am becoming very restricted physically as a result of gross osteo-arthritis. I think that the stress and trauma resulting from the sale of our home, the subsequent relocation to a unit and the grieving which has taken place since my husband’s admittance to the nursing home, have exacerbated my health problems...”

“During the last year my husband has been in a great deal of arthritic pain mostly in his left shoulder. He has in the last 3 weeks had a shoulder replacement which has been very successful but will restrict him for some considerable time until it is properly healed. Also he has now a very painful ankle from the same cause. The extra work and

having to do all the driving has been a big strain for me as in [year] I had a hysterectomy and the removal of a large benign tumour. 12 days later I had another operation for the removal of a piece of the small intestine which had blocked. This has made the answers to many questions apart from the norm. Normally I would walk for 30 mins most days and I am much more tired than I would be otherwise.”

Less commonly, women reported caring for other relations, including their siblings and children.

“In [year] I had extensive spinal injuries resulting in 10 weeks almost bedridden both at home and hospital. Since [date] I have had numerous tests for an inability to walk or stand. With physio treatment and perseverance I have improved greatly. A number of questions are very negative, as for the past month my daughter has been staying with us after major surgery, unable to do much for herself. We have been practically house bound.”

“My 91 Y.O. sister lives with me. She manages all things personal- toilet shower- Medication-Dressing- Doctor's visits I prepare meals. We have assistance with house cleaning, washing, ironing & shopping.”

Sometimes providing this care was difficult and frustrating, particularly as the women watched their husband's age and their health deteriorate over time.

“Both my husband and I live in residential low care accommodation. I'm perfectly happy here but my husband is not (after two years here he still hates it). He refuses to ask for carers help so I am his sole carer, eg dressing, what to wear, drying after shower; tying shoelaces; getting him into bed etc (we have separate rooms). Very frustrating and upsetting at times - although up until two years he was a most agreeable and loving partner.”

“I have found it very hard to answer everything in this survey. My husband had a stroke over 10 years ago. I have been looking after him. He is 83 in May. He has gone from walking stick to a frame to a wheelchair. He can just move along with me holding him and it is getting harder every day. I'm not complaining, he's my love. So sorry about the survey, everything is true but you can see it was not easy for me to fill in.”

The women also reported ill health themselves, and deteriorating health conditions over time. Although these health issues sometimes posed difficulties to providing care, most women continued to provide care for as long as it was needed, despite increasing tiredness or pain. Some women neglected their own health conditions to care for their husbands.

“[year] - Frontal sinus obliteration (sic). [year] - Bowel surgery to remove polyps and haemorrhoids. For over ten years I have been the carer for my husband who has a number of chronic illnesses (Vet Affairs, EDA provision, and Gold Card). When answering some of the questions in this survey I had difficulty separating my personal

health from the caring role. Eg. I know I am tired from the caring role...My activities are quite restricted as I am not free to leave home freely...I have a carer for respite care for 3 hours each week. If you require further clarification please telephone me at my home."

"My husband was diagnosed with Alzheimer's last year and is in the early stage. At 90 years of age he is very frail physically and no longer drives, shops or cooks. However, I am managing to care for him. Respite care one day a week and weekly help with heavy cleaning helps. My osteo arthritis has worsened, but so far I am coping."

"Women's Health Australia [date]. My health is alright except for rheumatized (sic) arthritis which is getting progressively worse. I have hesitated to see a specialist as I can still get around with care. Can still garden, sort of; and care for husband and house. Husband has had prostate cancer 6 years ago and doesn't need the worry of me having operations. I find your newsletters of great interest. Yours Sincerely."

When providing care in their own homes became too challenging, the women reported that their husbands moved into assisted care. The women often, but not always, also moved into care with their husbands.

"I hope I have filled survey in right. All I can say is I am a very sad lady because I have had to put my only love of 59 wonderful years into a hospital. He has been there 2 1/2 years now. I feel I have let him down. He can't understand why. The trouble is he can't even stand, so how can I give him the care he needs. I go and see him every day but it does not make you feel any better. I hope you don't mind me writing this note. Maybe it will help me to sleep better tonight. I can't change things. It is part of life. Thank you for this page."

"Had a hip replacement 2 years ago in the city, made a good recovery. Live in retirement village as husband has memory problem and I wasn't able to give him all the care he needed. I manage but am not too happy living alone. Sorry have taken so long to complete."

"During the last 12 months, my husband's health has necessitated a move into a Hostel with high & low care. [Husband] is now high care & totally dependent. I have to use a walker, & I can't drive anymore which limits a lot of things. The care is excellent & friendly as are all the other residents- it just takes time to adjust."

For many, however, staying in their own homes as long as possible was important. To do this, many utilised formal and informal care. Formal care often took the form of help with domestic chores, respite care, and preparing meals, while informal care was often provided by family.

"My partner has dementia. It has been difficult on my own but now he is on a package (4) and the help and support i am receiving is such a godsend and i don't feel isolated now. I get 6 hours me time and 5 hours cleaning assistance. I can go off and on my

own and do whatever I like knowing the pressure of caring is on someone else for those hours. Gov't is subsidising us so we can afford the aid. I have a massage about once and month and it's great."

"My husband is disabled and gets home care. He is showered each day and i get once a fortnight home cleaning - floors washed, carpets vacuumed and bathrooms cleaned. This is a very great help to me as I have damaged tendons in both shoulders, and sclerosis of the spine etc, so my body is not as strong as it was, so thankfully this help is provided for us, by very pleasant helpers and carers...I do not want to put my husband in a nursing home, and will do my best to keep him at home. I get physio on my back and shoulders occasionally, which relieves some of the pain. The arthritis in my hands stops me from doing most things, and my writing is not good, so i hope you can read this thank you for your interest."

"My husband turned 90 years of age in [year] - he is a twin. I turn 90 years of age on the [date]. My husband had to sell his car 7 years ago owing to macular degeneration, so we rely on community transport to drive us to our medical appointments and on our daughter who gives up her Saturday mornings to take us to do our big heavy shopping, or get haircuts - otherwise we use our mobility scooters to get to the local shops."

Although many of the women reported very difficult circumstances in which they provide care while managing their own health issues, some spoke about their relationships with their husbands, noting that they provide care for each other as they age.

"I'm 76 years old, still happily married for nearly 56 years, and as a married couple we help each other often as much as possible with housework, gardening, cooking. My husband is 78 years old and very healthy, he still does drive the car, (I can drive but don't feel confident.) We do shopping together, go to church and oldies club, help others as much as we can. I'm sure we have been really blessed in our lives by our Heavenly Father."

5.5.2. Caring over time: an example from the longitudinal data

Providing care became more challenging and demanding over time as women dealt with not only their husband's deteriorating health issues, but also their own, often increasing, health concerns. Below are the comments from a participant from the 1921-26 cohort. She commented at nearly every survey over a period of approximately 18 years (Survey 2 in 1999 until the 10th 6 monthly survey). These comments are reflective of the broader cohort, where over time women share their health issues, caring duties and experiences of ageing. By her final comment, the participant was in her 90s.

Survey 1 (1996) *No comment*

Survey 2 (1999) *"arthritis is getting worse. Torn tendons in my shoulders very painful I can have an operation by (sic) my doctor tells me it's rarely a success? Sorry I am late replying always busy with my hobby (orchid growing) and family."*

Survey 3 (2002) *"...My health is alright except for rheumatized (sic) arthritis which is getting progressively (sic) worse. I have hesitated to see a specialist as I can still get around with care. Can still garden, sort of; and care for husband and house. Husband has had prostate cancer 6 years ago and doesn't need the worry of me having operations. I find your newsletters of great interest...."*

Survey 4 (2005) *"Thank you for taking an interest in women's health. Arthritis is getting very severe over the last 12 months. I had a knee replacement last [date]. Eight weeks later had another spell of a fortnight in hospital with 2 crushed vertebrae, spine just collapses, not an accident. Since then have had a lot of back pain. Try to keep mobile and independent."*

Survey 5 (2008) *"I have had crushed vertebrae in the last 4 years due to osteoporosis and it is giving me a lot of pain in the back arms and legs, so I am not as active as I used to be."*

In their first few surveys, many of the women commented on their own health conditions. Aged between 70-75 years at Survey 1, most women were dealing with health issues of varying severity and their comments were about learning to cope with these conditions.

Survey 6 (2011) *"In [year] I fell turning off a tap timer and fractured my pelvis in 2 places was in [named] hospital for 2 1/2 weeks. 5 weeks later was flown to [named] hospital/private with Flying Doctor with gall stones in tube between gall bladder and small intestine had 2 operations in 2 days. Then heart decided to fibrillate (sic). it is still not right I am on oxygen at home and [husband] has a permanent cathetar (sic) so I am very busy. keeping place and him in working order. We have some help with him, showering etc 3 times a week meals on wheels - and a cleaner for some work once a fortnight. [named care provider] supplies help with showering and D.V.A. He is happy at home so I am too. to have him still with me. 66 years this year. He will be 90 in July. Sorry I'm late with this but I have slowed down a lot with Arthritis and Oestio-porosis (sic) pain."*

Survey 6MF1 *"I had a fall in [year] - fractured my pelvis in two places and had two gallstone operations in [named] Medical - in two days and my heart started to fibrillate. I am now on Warfarin. Rheumatoid arthritis, osteoporosis are much worse. I am still caring for 90 year old husband with help from [named care service] and Women's Health."*

Survey 6MF2 *"I am carer for my husband. Have Meals on Wheels. Husband has permanent catheter, prostate cancer and on oxygen. DVA help for him though [named care provider]. I have rheumatoid arthritis and osteoporosis so am slowing up but still manage (sort of) with Health [named] and help from my daughter for surgery visits and shopping, even though she is working full time."*

Over time the women reported deteriorating health conditions and simultaneously, an increase in their caring duties. Although they may have mentioned their husband's health condition in earlier surveys, as the women aged their comments became focused on not only managing their own deteriorating health, but also the health of their husband. Many reported now requiring formal help and support to remain in their own homes, such as Meals on Wheels, as well as informal support from their families.

Survey 6MF3 *"In the last two months have been in [named] Hospital over a month with bad dizzy turns and low haemoglobin (sic) and two units blood transfusions - tests proved negative. Taken at [named] Hospital. Osteoporosis and rheumatoid arthritis getting worse. Have cataract forming in eyes. Booked in for more tests next year."*

Survey 6MF4 *"I am beginning to have nuerouse (sic) dizzy spinning turns and then falling - so far the doctor hasn't found the cause. Have called ambulance and been hospitalised. Husband has to be put in respite while I am in."*

Survey 6MF5 *"My husband died [date] - 92 years old. I nursed him at home with cancer for 17 years. [Husband] and I were married 68 years. My health is not good now - dizzy turns. Problems with osteoporosis, rheumatoid arthritis. I am having physiotherapy - is helping a little. I am a DVA client with help from [care provider]."*

As their health continued to deteriorate, the women reported utilising respite care services for their husbands while they themselves received care. Many women reported the death of their husbands after a long period of illness, and their comments tended to return to their own deteriorating health.

Survey 6MF6 *"I had a cateract (sic) removed from right eye at HOSPITAL [date]. No sight in left eye so remained in HOSPITAL to recuperate. 5 weeks eye drops curtsey (sic) my daughter and [named service provider] nurses. I am able to remain at home with the aid of D.V.A and [named service provider] so far. Excuse, writing eye drops are blurring my eye."*

Survey 6MF7 *"Since my husband dies [date] I have DVA gold card so am getting some help. Physio who is helping my dizzy spinning times. I have not fallen flat on my back since starting and [named] to take me in, no public transport here. Cleaning 1.5 hrs once a fortnight and podiatrist every 10 weeks. Also getting [named service provider] pack 1.5hrs everyday and 1 hr a fortnight for cleaning."*

Survey 6MF8 *"Reumathoid arthiritis (sic) osteoporosis getting much worse fluid in legs need double medication now, and tablets flusimide (sic) causing dizziness"*

Survey 6MF9 *"Rheumatoid arthritis osteoporosis slowly deteriorating. I am receiving help from [service] 5 days a week for 30 minutes a day (20 minutes for a shower, 10 minutes for domestic assistance, 2 days from D.V.A) plus 1 hour a week cleaning alternate weekly [named] D.V.A. Also help from D.V.A to get to physiotherapist."*

Survey 6MF10 *“I am gradually getting worse with Rumathoid (sic) arthritis and Osteo Arthritis. Have fibulation (sic) of heart since [year] changed my blood thinner to the new xarelto tabs, don't need to go for blood tests. Have physio regularly, its keeping my spinning heads from putting me flat on my back. Taxi takes me in for it care of DVA. I have gold card now my husband has passed away. [Named service provider] girl comes in 1/2 hr every morning (20 minute showers 10 min domestic) 1 hr a week cleaning”*

No further comments

5.5.3. Conclusions from the qualitative analysis

Overall, the women in this analysis demonstrated that both providing care to someone and needing care themselves, can be very difficult and challenging. Despite dealing with their own health issues, many women continued to provide care, most often to their husband, over many years, for as long as they possibly could. For many, it was important to remain in their own homes as long as possible. Formal and informal care was imperative to being able to remain at home and many women reported taking advantage of the services available to them. When the burden of caring became impossible, the women reported that their husbands moved to assisted care, and some women moved into the same facility at the same time. Despite a reduction in direct caring, the caring duties did not cease when husbands moved into assisted living accommodation.

Many women reported caring for their husbands over a long period of time, and many women outlived their husbands by years. While the death of their husband after decades of marriage was understandably a period of grief and adjustment, the death of their husband also meant the loss of their primary support network, and the person that cared for them on a daily basis.

Key points

- Ensuring that women have sufficient personal and emotional care when they become widowed is essential to their ongoing health and ability to live independently.
- Formal and informal care assists women to not only care for their husbands but also for themselves. Most women reported being able to access the care they required.
- Many women reported the desire to remain independent and in their own homes as long as possible, and ensuring that there are services available to facilitate this is important.
- As most women reported that the person they cared for was their spouse, some caring burden for these women, who are also in need of assistance, could be alleviated by a coordinated approach. This might include a couple's care plan, rather than individual care plans, potentially provided by different administering bodies (e.g., DVA and State-based community services).

5.6 Previous research from the ALSWH

5.6.1. Thoughts about 'life not being worth living' and 'self-harm' in caregivers in the 1946-51 cohort

In 2014, O'Dwyer et al. reported on an analysis of death thoughts and self-harm in caregivers from the 1946-51 cohort. Using data from 3077 caregivers and 7451 non-caregivers at Survey 5 (when the women were aged 56-61), the authors analysed responses to survey questions which asked whether the women had felt that 'life wasn't worth living', and if they had 'ever deliberately hurt themselves or done anything that they knew might have harmed or even killed them?' Significantly more caregivers (7%) had felt life was not worth living in the previous week compared with non-caregivers (5.7%) but there was no difference between caregivers and non-caregivers on self-harm (about 1% in each group). Caregivers with thoughts about life not being worth living had poorer physical and mental health, higher levels of anxiety, lower levels of optimism, and reported less social support. When all these psychosocial variables were included simultaneously in a logistic regression analysis, social support, mental health, caregiver satisfaction, and depressive symptoms significantly predicted thoughts about life not being worth living. Caregivers with clinically significant depressive symptoms were four times more likely (odds ratio 3.95) to experience thoughts about life not being worth living than those without. Caregivers who were satisfied with their

role were 50% less likely (odds ratio 0.56) to have experienced thoughts about life not being worth living than those who were dissatisfied. The authors concluded that caregiver dissatisfaction could be a potentially modifiable risk factor for suicide-related thoughts and behaviours in caregivers, although more research would be required to identify the factors that contribute to this sense of dissatisfaction (O'Dwyer et al., 2014).

5.6.2. Associations between intimate partner violence and the physical and mental health of women in the 1946-51 cohort

In 2017, Ferreira et al., reported on the analysis of the health of caregivers who reported having experienced intimate partner violence (see abstract in [Appendix A](#)). The aim of the analysis was to investigate if women with a history of having experienced intimate partner violence who also undertook caregiving would experience worse mental health (depressive symptoms, stress, overall mental health) and physical health-related quality of life compared to those without caregiving roles. The analysis included 8453 women from the 1946-51 cohort who had completed Surveys 1 to 6 (that is, when they were aged from 45-64). Thirteen percent of the 8453 women had a history of intimate partner violence and 32% of the women identified as caregivers. Nearly one in 20 women (4.5%) had experienced both. Independently, caregiving and intimate partner violence were associated with worse physical health, increased depressive symptoms and higher stress in women. When the researchers compared these two different and stressful life events, they found the impact on the women's health was almost the same, even though one was perpetrated against the individual (violence) and one was undertaken with a degree of personal control (caregiving). Women who had both a history of intimate partner violence and caregiving had twice the likelihood of having higher stress, more depressive symptoms and poorer physical health than women with intimate partner violence or caregiving alone. The association between poor health, caregiving and the experience of intimate partner violence was reduced when women had better personal resources like resilience and social support to draw on for support. The authors concluded that the findings underscored the need to understand the drivers of poor health, for clinicians to ask about life circumstances of women patients experiencing poor health, and for the provision of referral pathways for complex cases.

6. Caring for multiple generations

This section presents data from women in the 1973-78, 1946-51 and 1921-26 cohorts who reported providing care for children/grandchildren as well as for any other person because of their long-term illness, disability or frailty. For women in the 1973-78 and 1946-51 cohorts this combination of caregiving is often termed 'sandwich caregiving' or 'dual caregiving' (Carers UK, 2012), because they are caring for both younger and older generations. As such, the effects on their health may be different to those who provide care for one generation only. Where appropriate the data are further analysed by whether the caregivers lived with the person they cared for or elsewhere. Associations between caring for multiple generations and impacts on selected measures of health, health behaviours and health service use are also presented. The chapter concludes with an analysis of free-text comments from women who reported providing care to multiple generations.

6.1 Sandwich generation caregiving by women in the 1973-78 cohort

Figure 6-1 shows the percentage of women in the 1973-78 cohort at Survey 7 (when they were aged 37-42) who were caring for any other person who was ill, disabled or frail, by the number of children they have. The percentage of women at this age with children who were caring for any other person who was ill, disabled or frail was low (about 11%). The figure also shows that young women caring for someone they lived with were likely to have more children (33% have 3 or more children compared with 25% of those caring for someone elsewhere or non-caregivers). Similar significant associations were found at Survey 3 (when the women were aged 25-30) and Survey 4 (28-33 years), although the living situation of the caregivers was not specified. Caregivers had more children compared with non-caregivers.

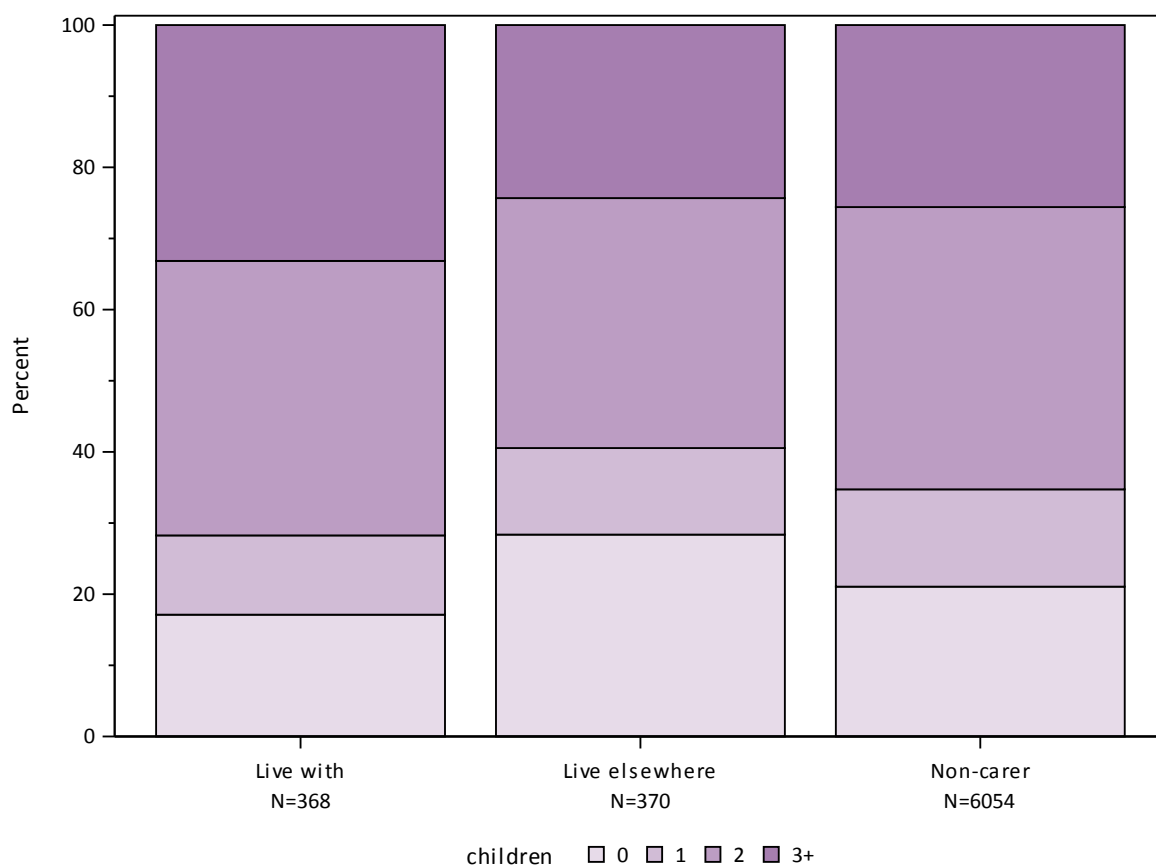


Figure 6-1 Percentage of women in the 1973-78 cohort at Survey 7, by the number of children they have, who were caring for any other person due to their long-term illness, disability or frailty. The graph is further stratified by whether they live with the ill, disabled or frail person they care for or elsewhere.

6.1.1. Sandwich generation caregiving by women in the 1946-51 cohort

Figure 6-2 shows the percentage of women in the 1946-51 cohort at Survey 8 (when aged 65-70) who were caring for any other person due to their long-term illness, disability or frailty and also providing care for a grandchild/other child. Approximately 25% of women in the 1946-51 cohort provided both these types of care at Survey 8. The graph is stratified by whether they lived with the person who was ill, disabled or frail, or elsewhere. The figure shows that more women caring for someone they lived with also provided daily care for a grandchild/other child compared with non-caregivers (by a percentage difference of around 3%). Caregivers not living with the person they cared for were more likely to provide weekly care to a grandchild/other child compared with caregivers living with the person they cared for (percentage difference 7%). Data from earlier surveys revealed similar significant associations.

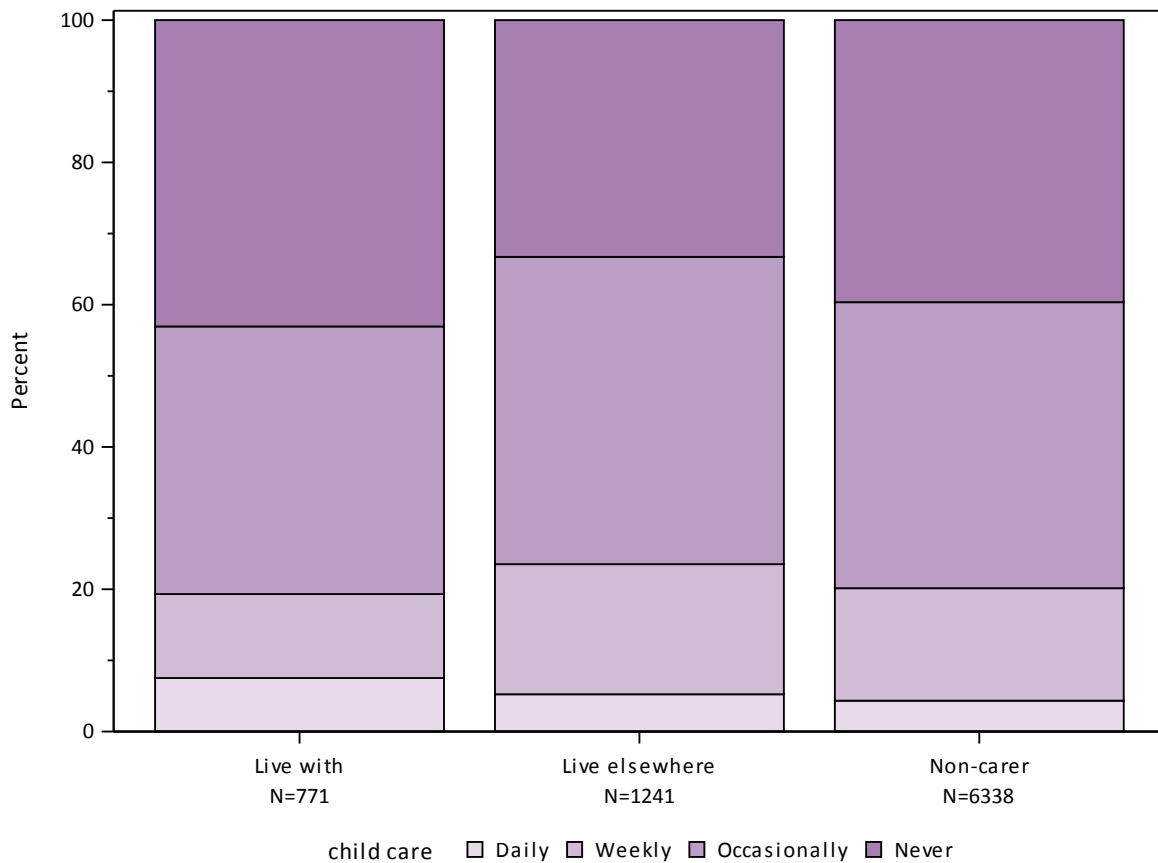


Figure 6-2 Percentage of women in the 1946-51 cohort at Survey 8, by whether they provide care for any other person due to their long-term illness, disability or frailty as well as providing care for a grandchild or other child. The graph is further stratified by whether they lived with the ill, disabled or frail person they care for or elsewhere.

6.1.2. Multiple generation caregiving by women in the 1921-26 cohort

Figure 6-3 shows the percentage of women in the 1921-26 cohort at Survey 4 in 2005 (when aged 79-84) who were caring for any other person due to their long-term illness, disability or frailty and also providing care for a grandchild/other child. Overall, 10% (or just over 700 women) provided both these types of care at Survey 4. The figure shows that more women caring for someone they did not live with also provided occasional care for a grandchild/other child (39% compared with 27% and 25% of caregivers living with the person they cared for and non-caregivers, respectively). Data from earlier surveys revealed similar significant associations. However, in Surveys 5 to 6, when the women were aged 82 to 90, very few were providing multiple generation care (5% at Survey 5, 2% at Survey 6).

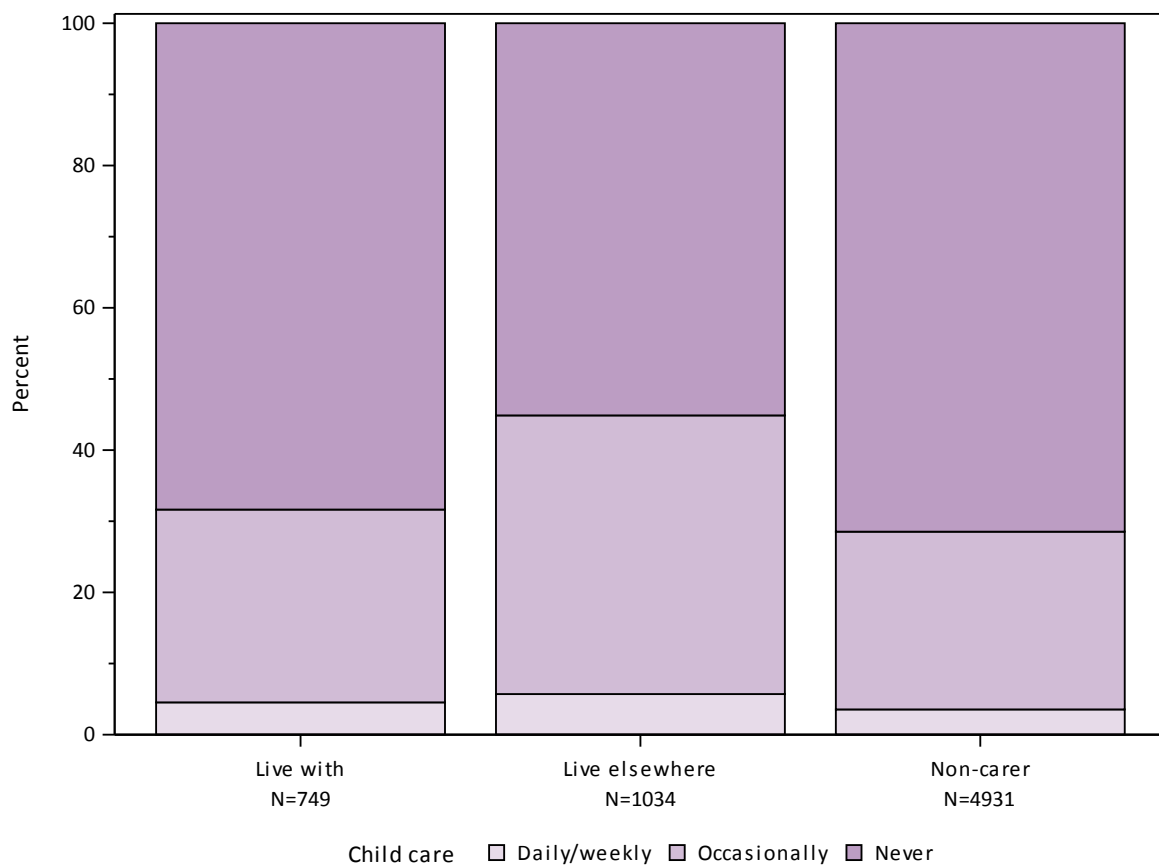


Figure 6-3 Percentage of women in the 1921-26 cohort at Survey 4, by whether they provide care for any other person due to their long-term illness, disability or frailty as well as providing care for a grandchild or other child. The graph is further stratified by whether they lived with the ill, disabled or frail person they care for or elsewhere.

6.2 Sandwich generation caregiving and impacts on health, health behaviours and health service use

The next section presents a summary of analyses comparing six groupings of women (based on caregiving status) and selected measures of health, health behaviours and health service use. The groupings were chosen to best examine the potential effects of 'sandwich caregiving', versus single generation caregiving, versus no caregiving.

The groups were:

- Providing child care plus live-in care for any other person due to their long-term illness, disability or frailty
- Providing child care plus caring for any other person due to their long-term illness, disability or frailty who lives elsewhere
- Only providing child care
- Only providing live-in care for any other person due to their long-term illness, disability or frailty
- Only providing care for any other person due to their long-term illness, disability or frailty who lives elsewhere
- Not providing care

For the 1946-51 and 1973-78 cohorts, data from the last available surveys were used. The health measures analysed were self-reported depression, self-rated health, visits to a general practitioner, physical activity, alcohol consumption and perceived stress.

For the 1921-26 cohort data from Survey 4, conducted in 2005 when the women were aged 79 to 84, were used as this was when the prevalence of caregiving was highest in this cohort. For this oldest cohort, data on self-rated health, visits to a general practitioner and physical activity are presented.

6.2.1. Sandwich generation caregiving by women in the 1946-51 cohort and self-reported depression

Figure 6-4 shows a dichotomy of self-rated depression prevalence that may principally reflect the burden associated with caring for someone who is ill, disabled or frail. When women were caregiving for these individuals their self-rated depression was higher, particularly when they were living with the person and also providing care for a child (18% reported depression). In comparison, women caring for children appeared to have lower self-rated depression (8-9%).

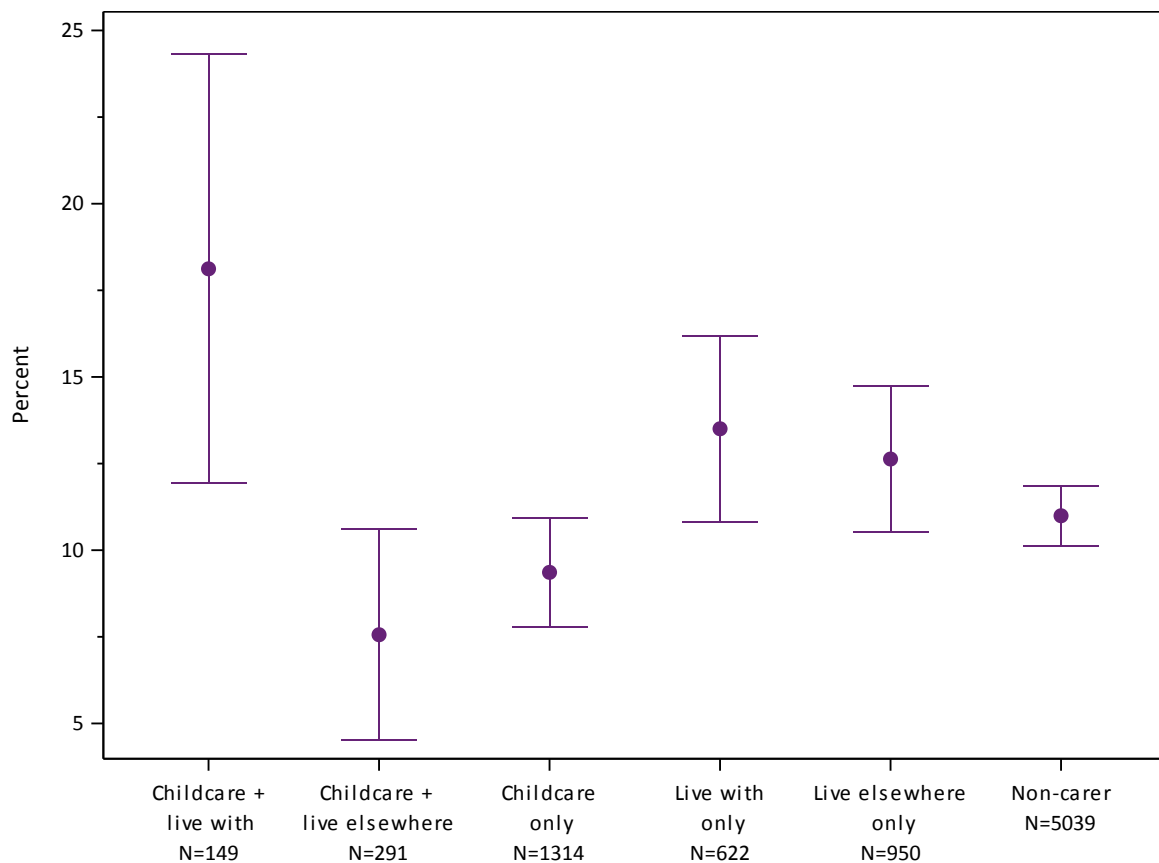


Figure 6-4 Mean percentages (with their 95% confidence interval) for self-reported depression in women in the 1946-51 cohort at Survey 8, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving).

6.2.2. Sandwich generation caregiving by women in the 1946-51 cohort and self-rated health

Figure 6-5 shows that at Survey 8, significantly fewer women in this cohort who cared for both children and someone due to their long-term illness, disability or frailty who lived with them rated their health as very good or excellent (32%) compared to women in the other caregiver groups or non-caregivers (42-50% rated their health as very good or excellent).

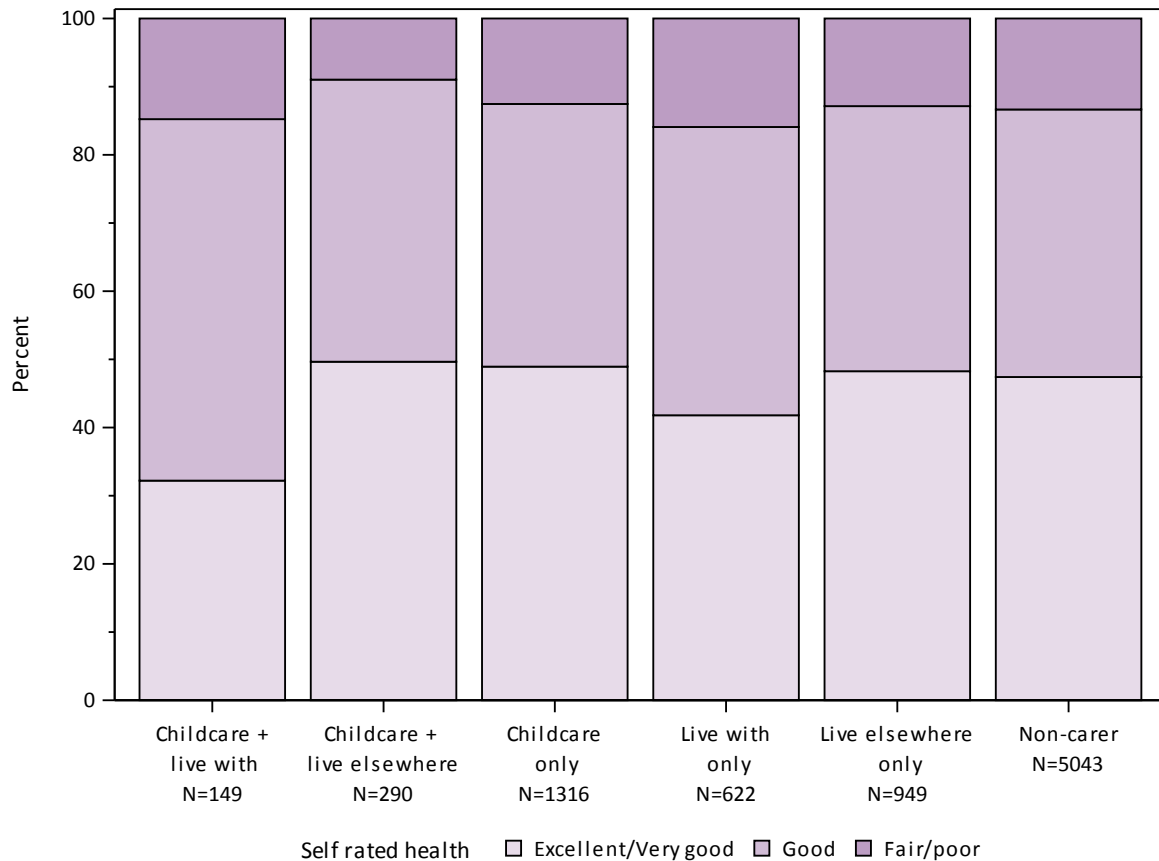


Figure 6-5 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by self-rated health.

6.2.3. Sandwich generation caregiving by women in the 1946-51 cohort and self-reported visits to a general practitioner

At Survey 8, women who cared for someone due to their long-term illness, disability or frailty who lived with them and also provided child care reported significantly more visits (5 or more) to the general practitioner (41-49%) compared with women in the other caregiver groups or non-caregivers (34-36%) (Figure 6-6).

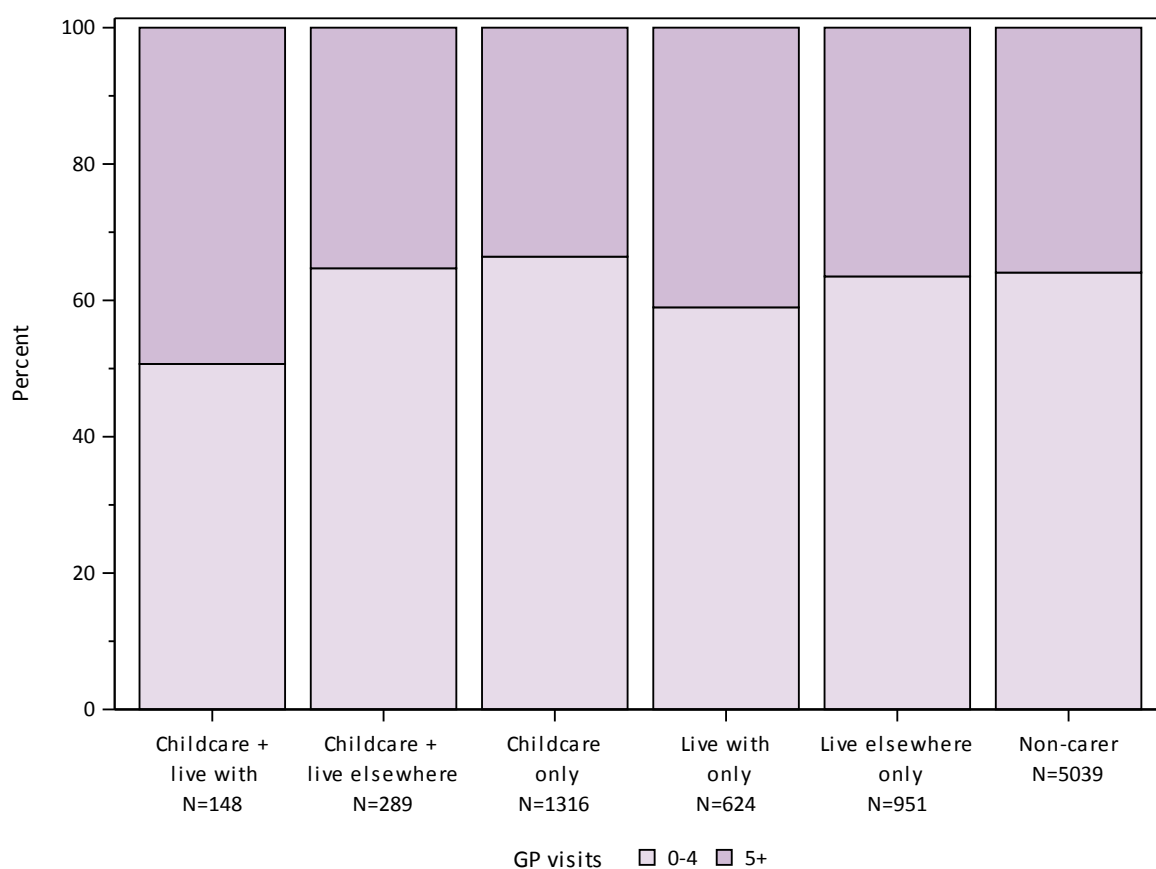


Figure 6-6 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by number of self-reported visits to a general practitioner.

6.2.4. Sandwich generation caregiving by women in the 1946-51 cohort and physical activity

At Survey 8, significantly more women who cared for someone due to their long-term illness, disability or frailty who lived with them and also provided child care, along with women who cared for someone due to their long-term illness, disability or frailty who lived with them but did not provide child care reported being inactive (low physical activity/sedentary behaviour) (43%) compared with women in the other caregiver groups or non-caregivers (33-37%) (Figure 6-7).

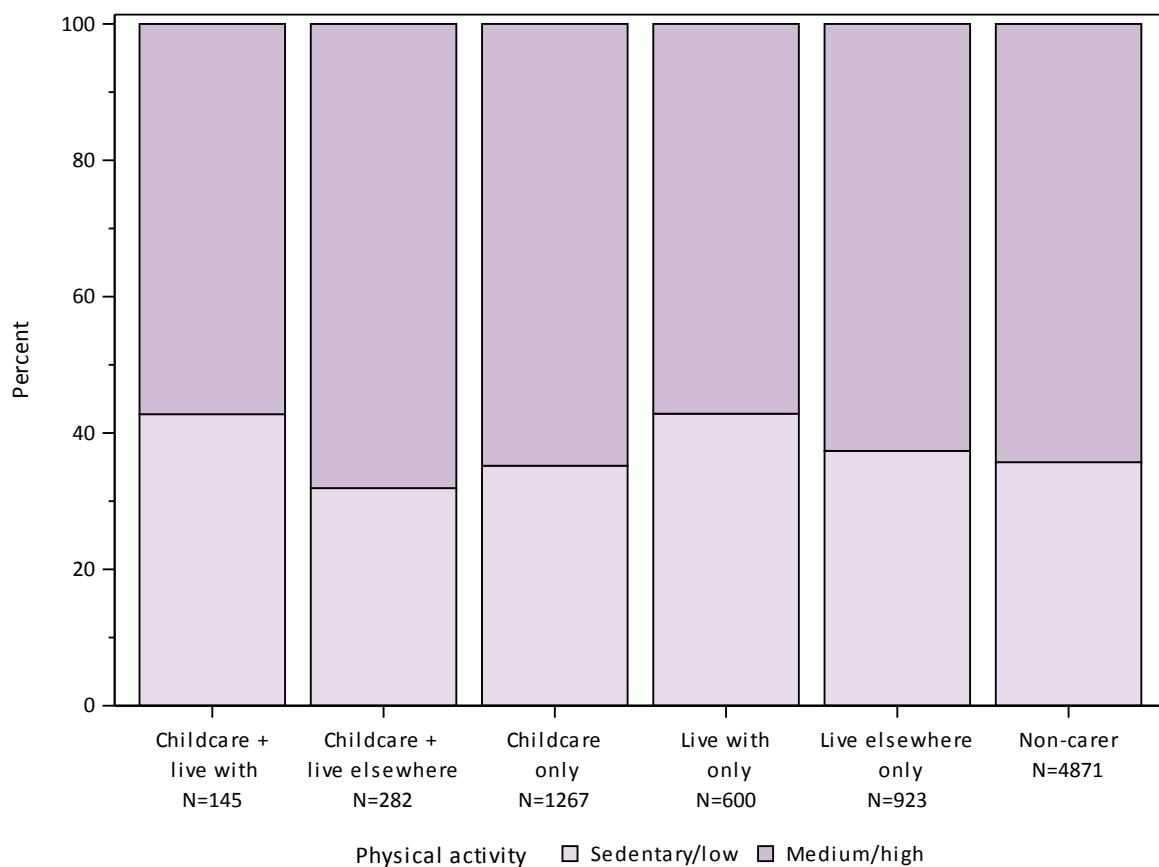


Figure 6-7 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by physical activity.

6.2.5. Sandwich generation caregiving by women in the 1946-51 cohort and alcohol consumption

Figure 6-8 shows that at Survey 8, significantly more women who cared for someone due to their long-term illness, disability or frailty who lived with them and also provided child care, along with women who cared for someone due to their long-term illness, disability or frailty who lived with them but did not provide child care reported being a non-drinker (23-30%) compared with women in the other caregiver groups or non-caregivers (12-17%).

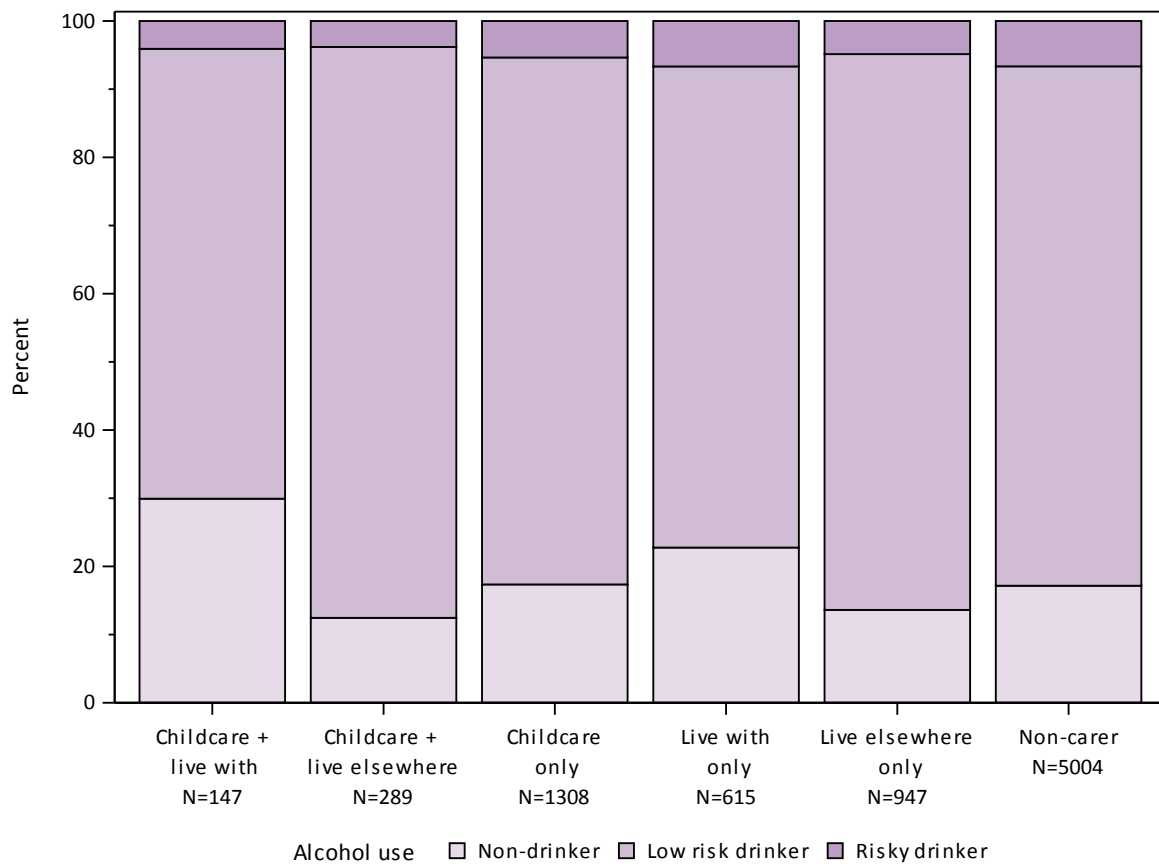


Figure 6-8 Percentage of women in the 1946-51 cohort at Survey 8, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by alcohol consumption.

6.2.6. Sandwich generation caregiving by women in the 1946-51 cohort and perceived stress

At Survey 8, the highest mean scores for perceived stress were reported by women who lived with the ill, disabled or frail person they cared for and also provided care for their grandchild/other child (mean score 0.76). The lowest mean scores for perceived stress were in women who provided care for their grandchild/other child only (0.48) and in non-caregivers (0.44). Providing care for grandchildren or other people's children did not appear to create additional stress, over and above that associated with caregiving for an ill, disabled or frail person, particularly for live-in care.

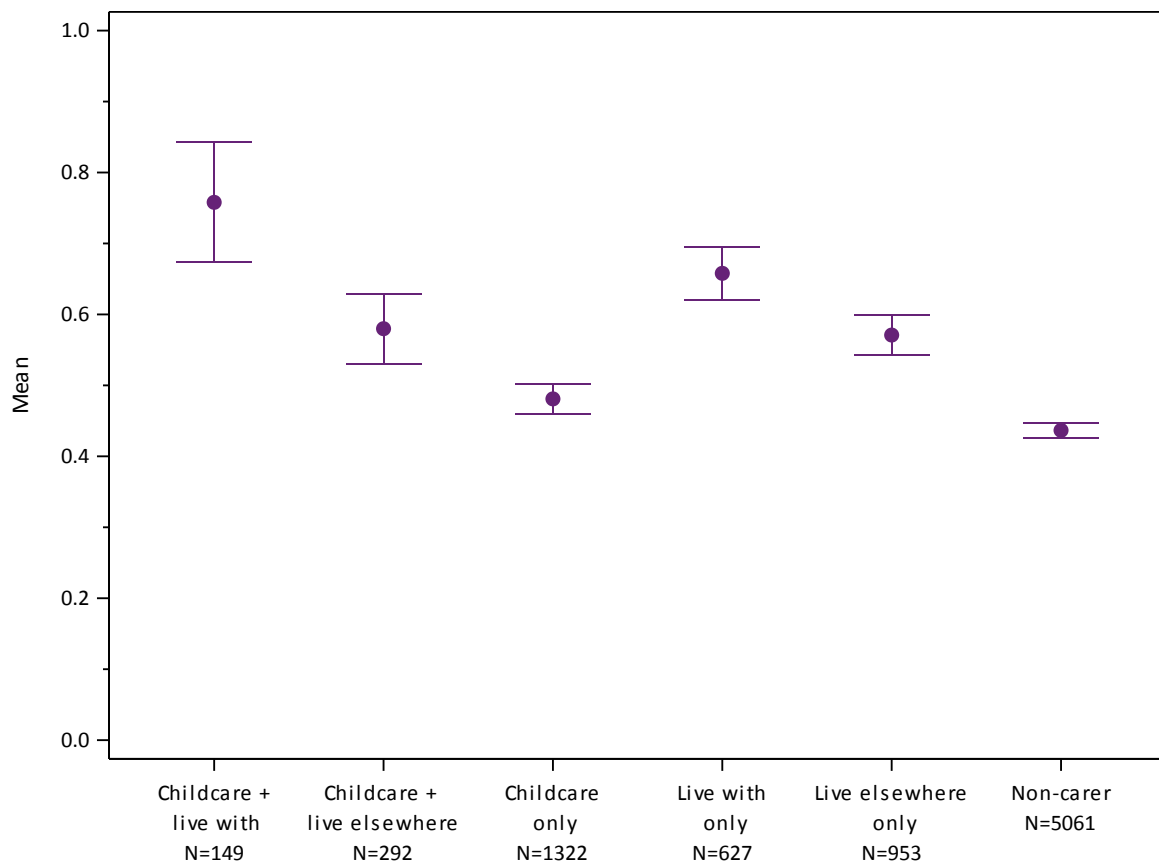


Figure 6-9 Mean scores (with their 95% confidence interval) for perceived stress of women in the 1946-51 cohort at Survey 8, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving).

6.2.7. Sandwich generation caregiving by women in the 1973-78 cohort and self-reported depression

A significantly higher percentage of women who cared for someone they lived with reported being depressed (41%) compared with all other caregivers and non-caregivers (14-26%). Women providing care for children only were the least likely group to report depression (14%).

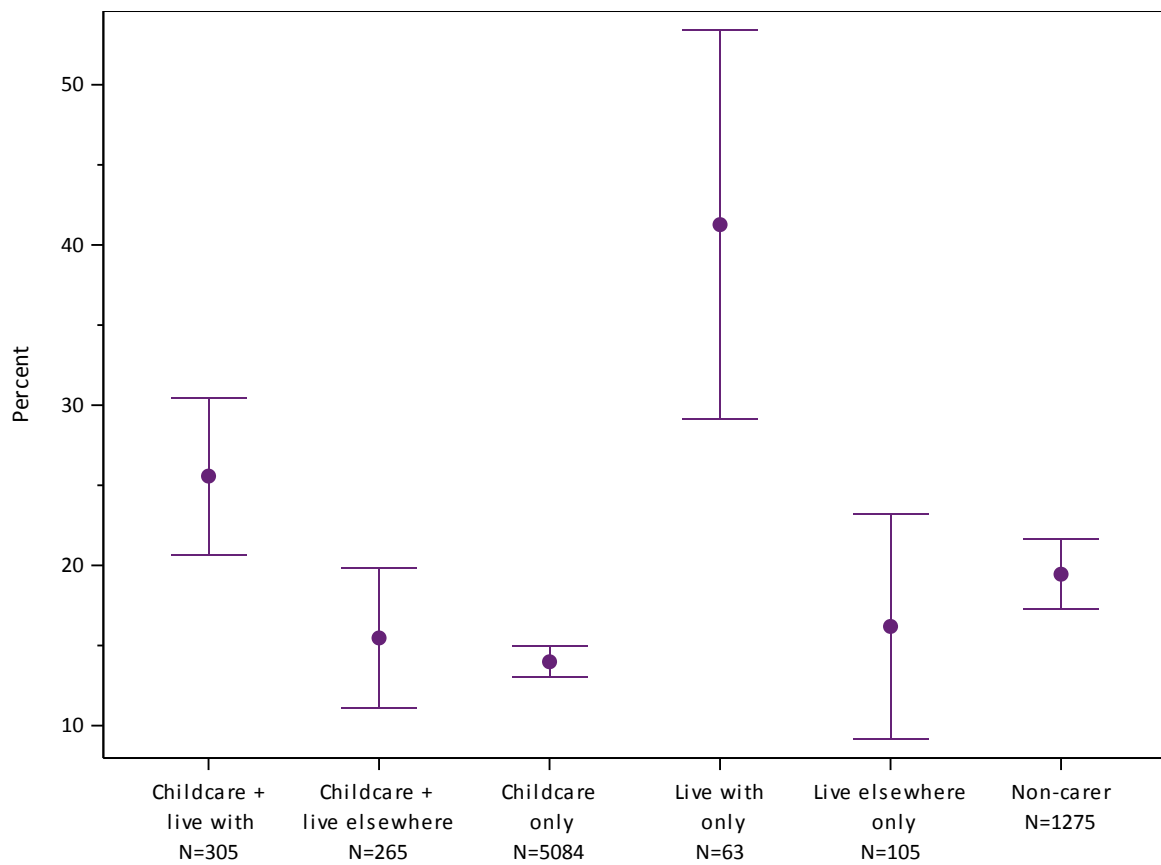


Figure 6-10 Mean percentages (with their 95% confidence interval) for self-reported depression in women in the 1973-78 cohort at Survey 7, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving).

6.2.8. Sandwich generation caregiving by women in the 1973-78 cohort and self-rated health

Figure 6-11 shows that at Survey 7, women who cared for someone due to their long-term illness, disability or frailty who lived with them were significantly more likely to rate their health as fair or poor (32%) compared with women in the other caregiver groups or non-caregivers (9-17%). Women caring for children only and those caring for someone who was ill, disabled or frail who did not live with them were the least likely groups to report fair or poor health (9%).

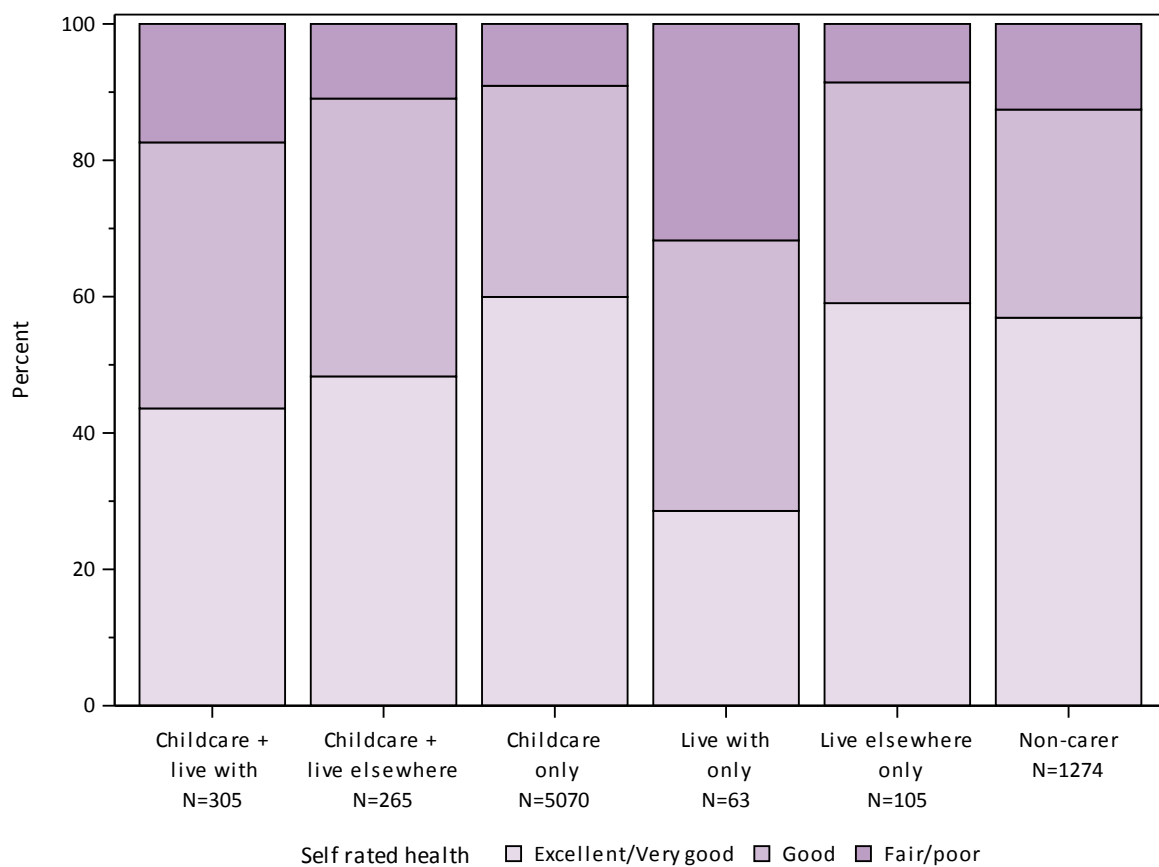


Figure 6-11 Percentage of women in the 1973-78 cohort at Survey 7, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by self-rated health.

6.2.9. Sandwich generation caregiving by women in the 1973-78 cohort and self-reported visits to a general practitioner

At Survey 7, significantly more visits (5 or more) to the general practitioner were reported by women who cared for someone due to their long-term illness, disability or frailty who lived with them and also provided child care (51%) and by women who lived with an ill, disabled or frail person they cared for but did not provide any child care (40%). In comparison, 26 to 31% of women in the other caregiver groups or non-caregivers reported five or more visits (Figure 6-12).

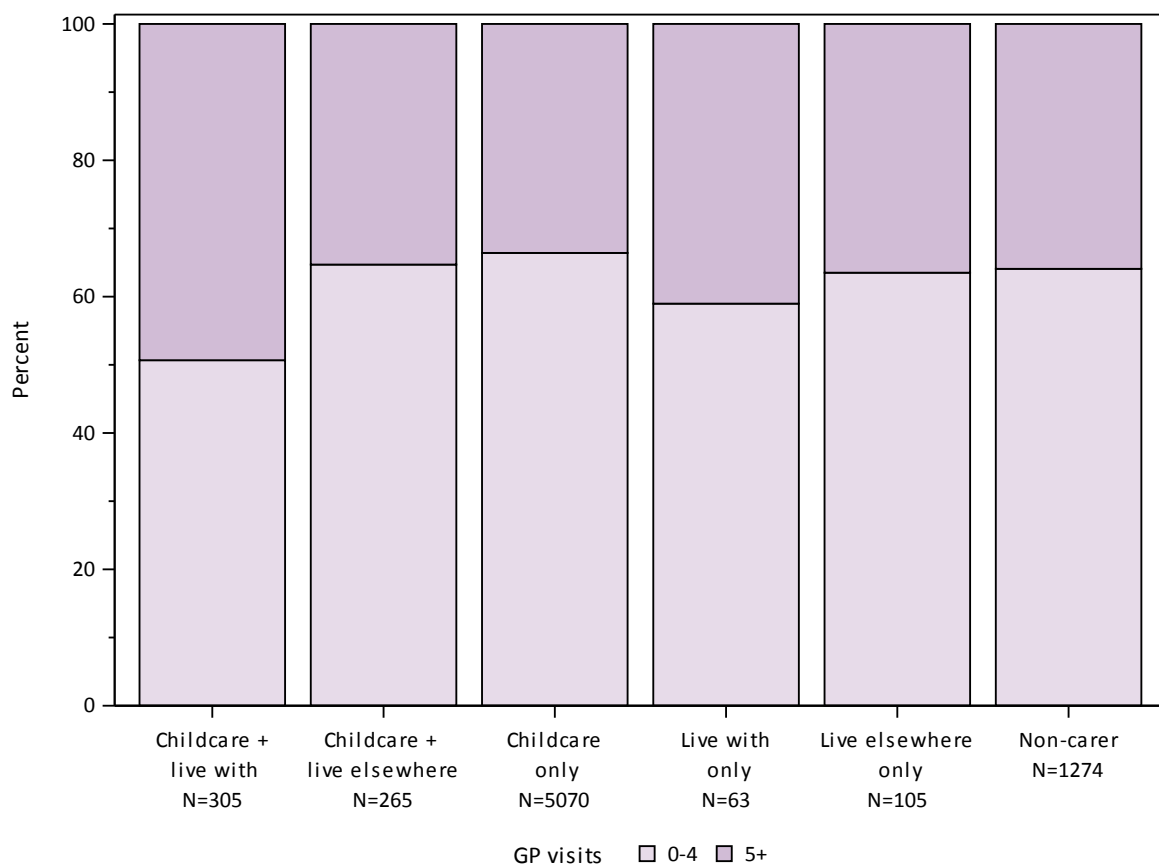


Figure 6-12 Percentage of women in the 1973-78 cohort at Survey 7, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by number of self-reported visits to a general practitioner.

6.2.10. Sandwich generation caregiving by women in the 1973-78 cohort and physical activity

Figure 6-13 shows that at Survey 7, significantly fewer women who cared for someone due to their long-term illness, disability or frailty who did not live with them or who did not provide this care reported being inactive (low physical activity/sedentary) (34-35%) compared with women in the other caregiver groups (45-52%). Significantly fewer women who provided child care only reported being inactive (45%) than women who provided child care but also provided care for someone due to their long-term illness, disability or frailty who lived with them (52%).

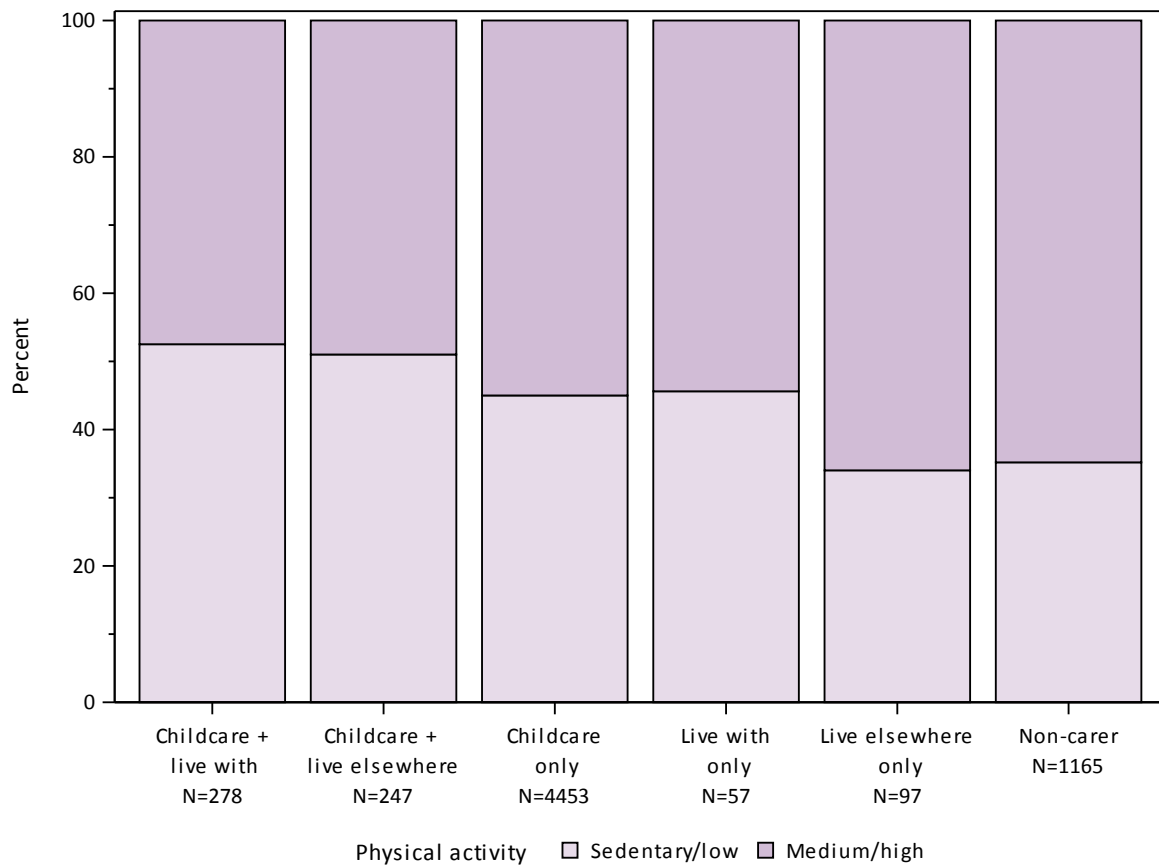


Figure 6-13 Percentage of women in the 1973-78 cohort at Survey 7, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by physical activity.

6.2.11. Sandwich generation caregiving by women in the 1973-78 cohort and alcohol consumption

There was no significance difference between women in the six caregiving/non-caregiving groups by their pattern of alcohol consumption at Survey 7.

6.2.12. Sandwich generation caregiving by women in the 1973-78 cohort and perceived stress

At Survey 7, mean scores for perceived stress were lowest in non-caregivers (0.77) and women who provided child care only (0.82). These percentages were significantly different to the mean scores for perceived stress in women in the other caregiving groups (0.95-1.13).

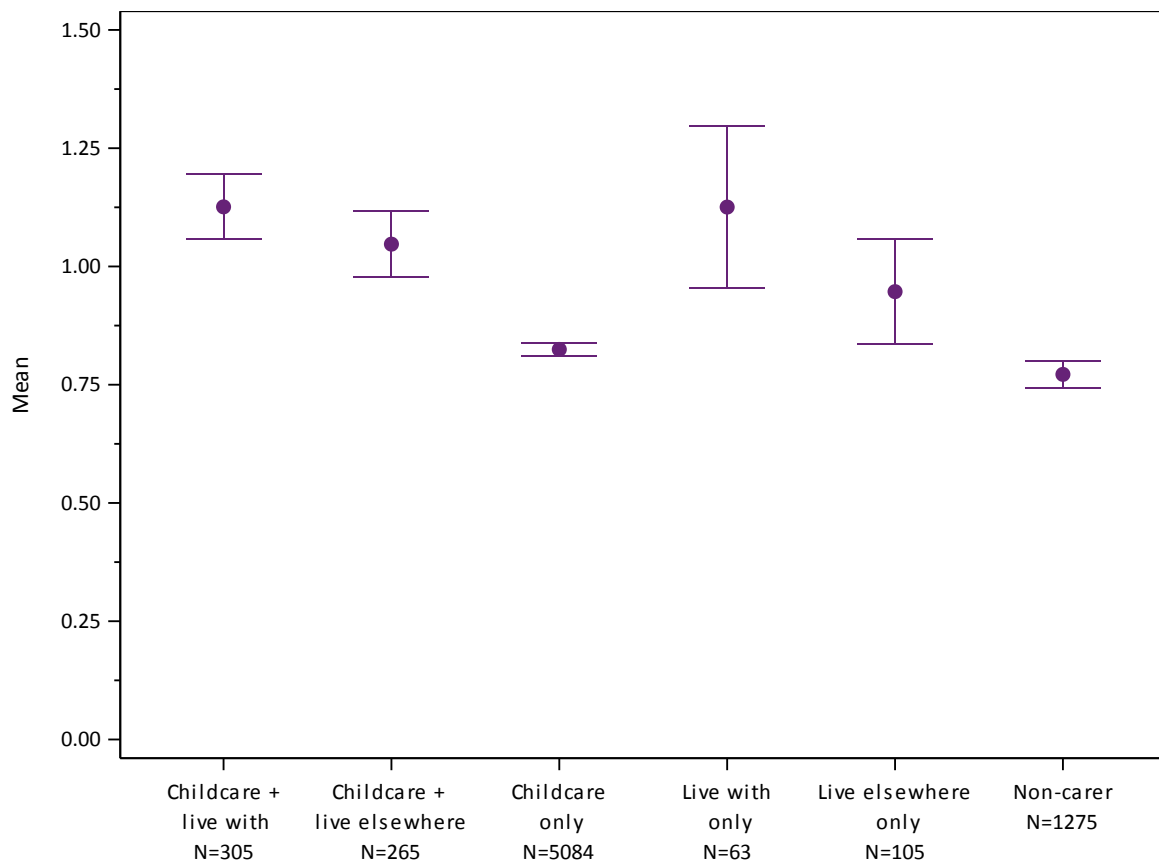


Figure 6-14 Mean scores (with their 95% confidence interval) for perceived stress of women in the 1973-78 cohort at Survey 7, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving).

6.2.13. Caregiving by women in the 1921-26 cohort for multiple generations and self-rated health

At Survey 4 when the women were aged 79-84, the highest prevalence of fair or poor self-rated health was reported by women who either were providing care to another person due to their long-term illness, disability or frailty who lived with them (33%) or were not providing any type of care (35%). This apparent paradox reflects not only the impact of live-in caregiving but also the effect of poor health in determining whether women were able to provide care.

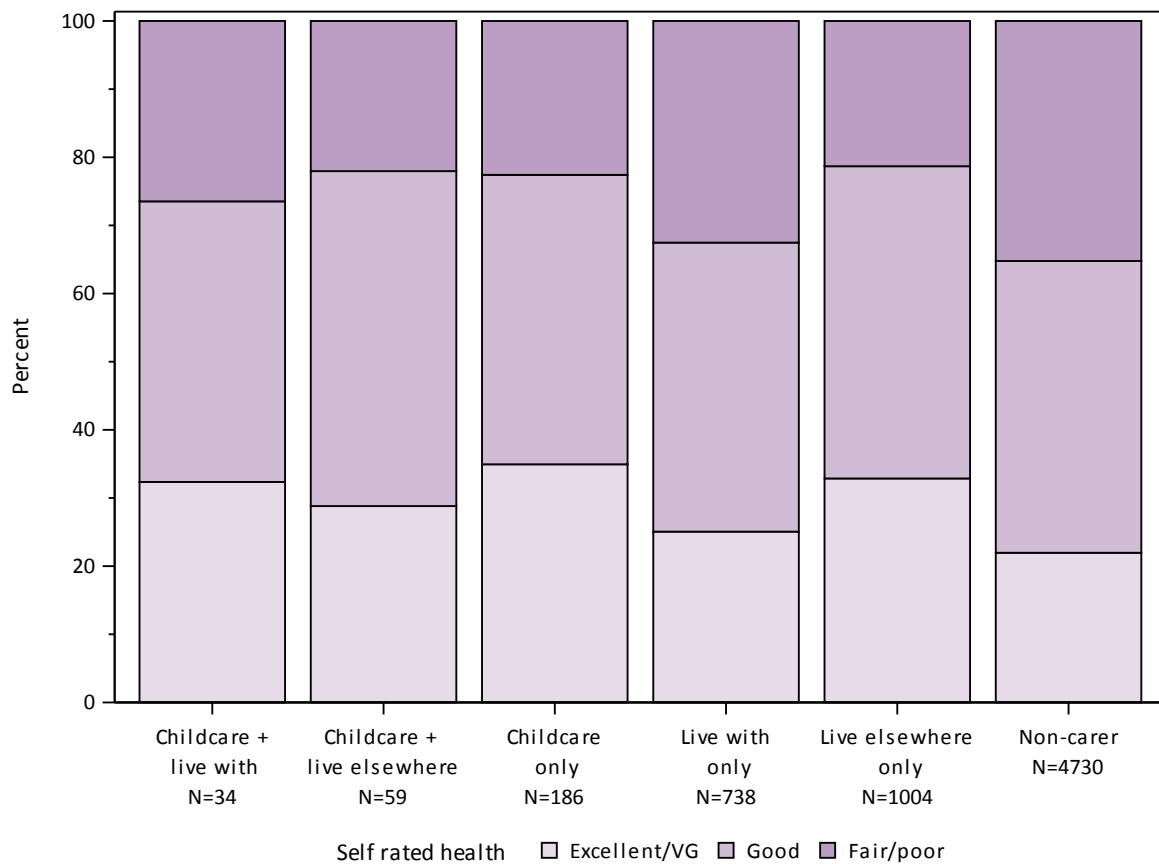


Figure 6-15 Percentage of women in the 1921-26 cohort at Survey 4, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by self-rated health.

6.2.14. Caregiving by women in the 1921-26 cohort for multiple generations and self-reported visits to a general practitioner

At Survey 4, significantly fewer visits to the general practitioner were reported by women who cared for someone due to their long-term illness, disability or frailty who lived with them as well as providing child care (63% reported 0-4 visits, 37% reported 5+ visits) compared with women who provided less caregiving or did not provide this type of care/care for grandchildren/other children (between 54-64% reported 5+ visits) (Figure 6-16). These results reflect the better health of women aged in their late 70s and early 80s who are providing multi-generational care.

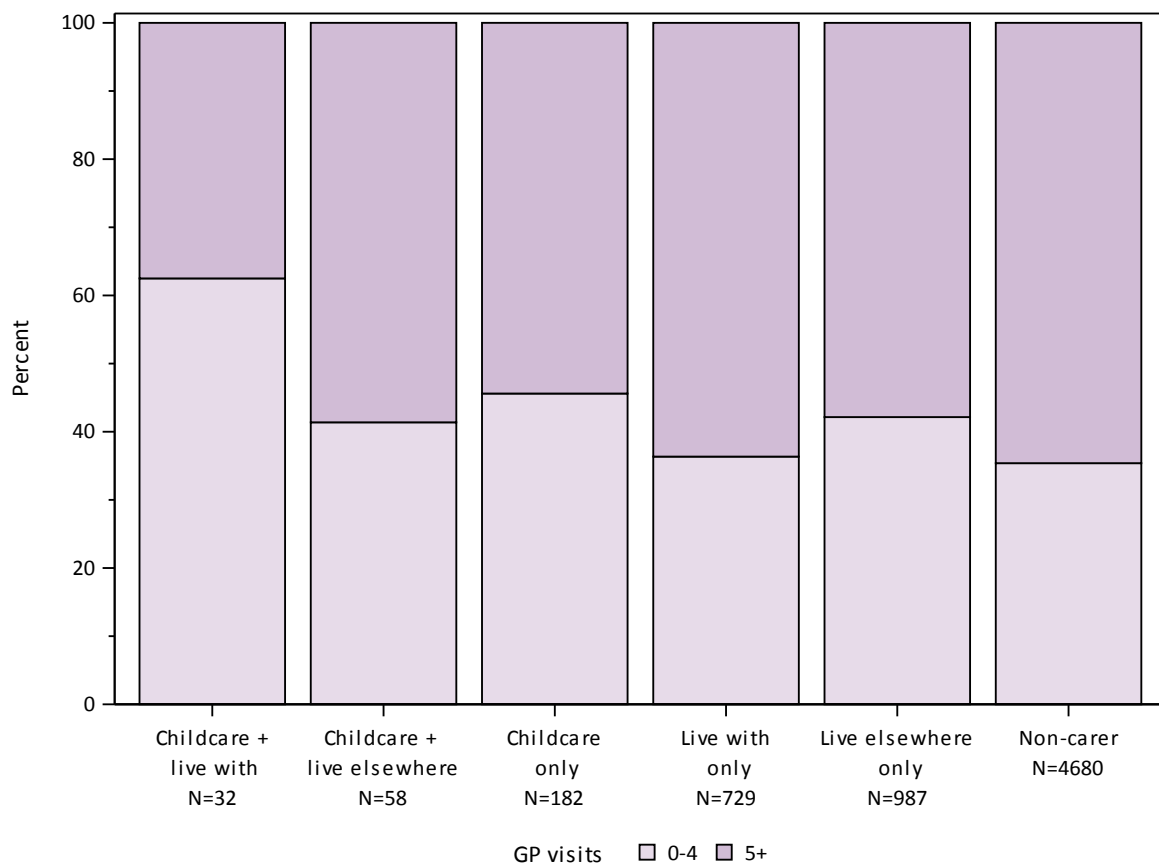


Figure 6-16 Percentage of women in the 1921-26 cohort at Survey 4, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by number of self-reported visits to a general practitioner.

6.2.15. Caregiving by women in the 1921-26 cohort for multiple generations and physical activity

Figure 6-17 shows that at Survey 4, the women reporting the highest levels of physical activity were those who were providing care to an ill, disabled or frail person who did not live with them (42%) and women who were providing care to an ill, disabled or frail person who did not live with them as well as providing care for a grandchild/other child (42%). Women who provided care for ill, disabled or frail people who lived with them, provided care for grandchildren/other children only or who did not provide any care reported lower participation in medium or high levels of physical activity (30-35%).

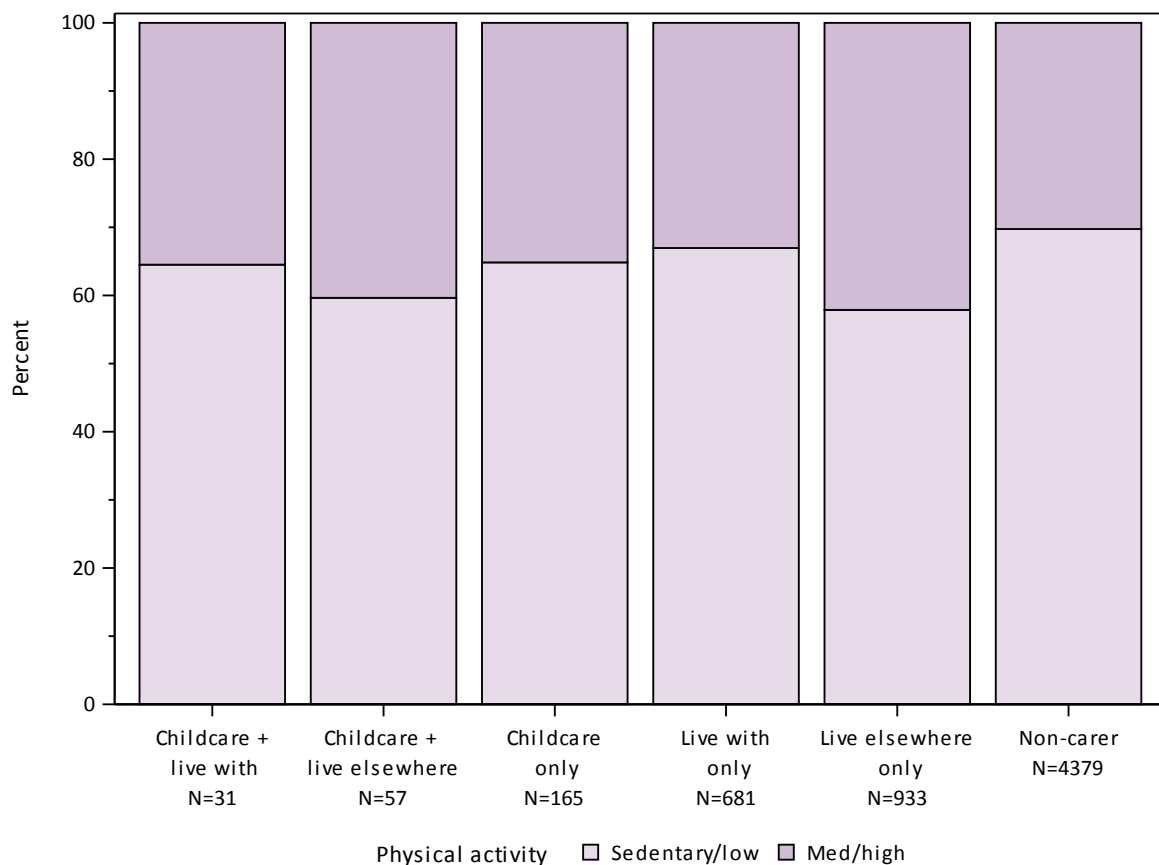


Figure 6-17 Percentage of women in the 1921-26 cohort at Survey 4, by caregiving status ('sandwich' caregiving, other caregiving, non-caregiving) and by physical activity.

Key points

- In the 1973-78 and 1946-51 cohorts, women caring for someone they lived with were more likely to have more children or provide daily care for a grandchild or other child than caregivers who lived elsewhere and non-caregivers.
- Women in the 1946-51 cohort who provided child care and live-in care for someone who was ill, disabled or frail were more likely to report having depression, made more visits to the general practitioner, had a higher perceived level of stress and were less likely to rate their health as very good or excellent than non-caregivers and caregivers who provided other types of care.
- Live-in caregivers in the 1946-51 cohort, regardless of whether or not they provided child care, tended to be non-drinkers and to report being inactive compared to women in other caregiver groups and non-caregivers.
- Women in the 1973-78 cohort who only looked after children or were non-caregivers had the lowest levels of perceived stress and were less likely to report having depression than other caregiver groups and non-caregivers.
- Women in the 1973-78 cohort who were 37-42 years were more likely to have a sedentary lifestyle if they provided child care and cared for another person due to illness, disability or frailty.
- In the 1921-26 cohort, live-in caregivers and non-caregivers were more likely to report fair or poor self-rated health.
- Live-in caregivers who were aged in their 80s and who also provided child care had fewer visits to the general practitioner than all other caregiving groups and non-caregivers.
- Caregivers in the 1921-26 cohort who did not live with the person they cared for had the highest levels of physical activity than other caregiver groups and non-caregivers, regardless of whether or not they provided child care.

6.3 Caregiving for multiple generations: A qualitative examination of free-text comments from ALSWH participants

“I now find myself in the position of being the sandwich generation.”

Comment by an ALSWH participant from the 1946-51 cohort at Survey 6 in 2010

The quantitative ALSWH data demonstrated that more than half of women born 1946-51 were ‘sandwich caregivers’. These women reported high levels of stress and depression, so it is important to understand more about the lived experience of women in this situation. ALSWH qualitative data were examined to determine how these experiences might be influencing their health and wellbeing and to identify factors that help women to manage these multiple caregiving roles.

For the purpose of this section, we understood ‘children’ to be people under the age of 18 years (e.g., the participant’s grandchildren), as well as participant’s dependent adult children. A ‘sandwich caregiver’ was defined as someone who reported providing care for children and other adults. As such, the cohorts born 1946-51 and 1973-78 were selected for this analysis, as these age groups are most likely to be in this position. The most recent surveys for these cohorts (Survey 8 and Survey 7, respectively) were chosen as the initial sampling frame, with the following criteria:

- Women who responded ‘yes’ to the question about regularly providing care for children **and** ‘yes’ to the question about providing care to other people, **and** who provided a free-text comment at the end of their cohorts’ most recent survey formed the sampling frame.

Of the 715 comments included in the sampling frame, only 28 mentioned experiences of caregiving for both a child and an adult (see [Appendix A](#)). Therefore, the sampling frame was expanded to include four additional surveys (Surveys 6 and 7 of the 1946-51 cohort, and 5 and 6 of the 1973-78 cohort). After this expansion, a total of 98 comments were included in the sample. The longitudinal data, that is, free-text comments from all surveys, were collated. In total, there were 439 longitudinal comments from 93 women across both cohorts.

6.3.1. Results

The key themes for this analysis are: *how they feel* (e.g., lonely, busy, exhausted), *people they care for* (e.g., husband, daughter, mother), *what they do to cope* (e.g., take time to themselves), and *providing care* (e.g., babysitting, or checking in on elderly parents). This analysis suggests that being a 'sandwich caregiver' is often difficult and challenging, and that the women engaging in these roles make sacrifices in their lives to care for others. Although caregiving duties fluctuate, many women provide care for their families over many years, with some women reporting providing care and support for three generations (their parents, children and grandchildren) at the same time. Many women reported lacking time to focus on their own health and wellbeing, and it seemed there was a lack of support beyond the family unit to assist with this care.

Overall, women reported providing care and support to a wide range of different people, spanning multiple generations. These people were often related to the women in some way, and were usually their parents, husbands, children and grandchildren, although caregiving for extended family members (e.g., aunt, nephew or sister) was also reported. Care provided to spouses, children and one or both parents was often due to illness, disability or problems associated with ageing, while grandchildren were often cared for to provide support for children (so they could return to work, or undergo medical treatment, for example).

"My health is good, except for an emotional problem which has occurred from my daughter being diagnosed with bowel cancer and having a 5 month old baby. During her low days and treatment of chemotherapy I travel over 100km to be with her and generally spend weeks away from home."

"Some of the information provided could be misunderstood. My situation is one in flux. Since [year] I have experienced one of my children being diagnosed twice with a savage childhood cancer and then my husband with prostate cancer. So this effects all areas of your life, emotional, physical, mentally, financially. Support networks and so on. Thank you for the work that you are trying to achieve."

"...I still care for our 26yr old autistic son at home (he has severe behavioural problems) and I also give as much emotional and domestic support as I can to my lonely father..."

"Although my health has remained great i now find myself in the position of being the sandwich generation. Children and wonderful grandchildren on one side and extremely demanding parents on the other (three visits to hospital in the last two months for my 91 year old mother and a 96 year old father who can't cope. This adds to stress and anxiety levels being somewhat raised..."

Although all of the women reported multigenerational caregiving, some reported providing care and support for three generations of family simultaneously: their parents, children and grandchildren.

“Sorry this is late was going along really well, then my daughter who had leukaemia when young has been told she has a brain tumour so with that and looking after grandchildren – working, looking after my mom. Although she is quite well needs checking and being with every day. She is 90 in June. Plus one thing and another I thought it best to just mail this off as is. Will try to do better next time...”

“I look after my mother who has dementia and a grandson 1 day/wk and provide support to 4 grown children and their wives. At times I feel that there are not enough hours in the day to do all that needs to be done”

Providing care encompassed a variety of roles. Most often, the women reported regular babysitting of grandchildren, or frequently checking in on their elderly parents.

“I'm not sure if this will be of any help. I work school cleaning 3 1/2 hrs 5 days a week. My father is in a nursing home with Parkinson disease I spend 2 mornings a week (take him for walks in his wheel chair etc) (approx 3 hrs each time). Babysit my two youngest grandchildren 1 full day 9am-7-8pm and youngest 2 full days (my husband cares for them whilst I am at work). Have forgotten how to sleep full night last 3 years or so (due to menopause) and wrist and finger joints hurt at times. (information only - not complaining, have great husband and family).”

“...Life for the past eight years has been travelling weekly to my parents, 115km each way for 3 days as well as school pick ups of 6yo granddaughter (50km) round trip, twice a week. Dad at 94 is still doing well at home and the thought of driving each week for another 6 years is daunting. It was sucking me dry...”

However, providing care could also require significant lifestyle changes. This included housing arrangements, where the women reported caring for extra people in their homes for a number of years, or permanently, as well as relocating or travelling long distances to provide care.

“...Also during that time frame, my daughter and her partner (now her husband) and 2 sons now aged nearly 2yrs and nearly 4yrs came to live with us and stayed with us for 14 months. We then had 7 people in the house instead of the usual 3. This caused problems for us due to stress (severe/arguments (my husband and I rarely argued) and the 2 boys had 5 people telling them what to do instead of just 2 (their mum and dad). My daughter and family now live just around the corner from me (4-5 mins walk). We still see a lot of them, but at least have our own space back and my husband and I are back on normal terms together...”

“We are renting privately while we renovate our investment property, which we intend to live in next year. My parents chose to sell their home as they could no longer maintain it due to age/illness/surgery, and have moved in with my family. We will turn our block of units into a 5 bedroom home, large enough to accommodate all of us comfortably.”

“My 37 year old daughter was diagnosed with breast cancer in [year]. I have temporarily relocated from [state] to [state] to assist in her care...”

For others, providing care meant a change in their paid work situation, by retiring or taking leave from paid work to care, or by taking on additional work as part of their caregiving duties.

“My recent retirement was not by choice my husband's deteriorating health since I was 53 years caused further reductions in paid work until his health and my exhaustion increased which culminated into retirement from paid work. Since then other factors e.g. grown children's needs grandchildren's needs and parent's needs as well as partners needs have well and truly filled the paid work gap...”

“[This year] has brought my family and self some 'blows' so far that have contributed to some unsettled months:... Mother-in-law diagnosed with a bowel carcinoma with no chance of operation or other treatment...Father-in-law died suddenly at home...Son broke shin bone - sprial (sic) fracture.... Self - removal of 2 wisdom teeth. I have had to take indefinite leave from part-time position I held as a carer to my mother-in-law, who is 84 years, physically frail and really unable to cope well after death of husband - married for 56 years, understandable.”

“Mum is going through Chemotherapy at the moment to treat breast cancer. She's had a mastectomy (sic), and is very sick with the chemo. She has a [named] business still running, so I'm driving up to their house most weekends (3hr drive, 6hr return) to work in the [business] and clean her house, take her to appointments, visiting her in hospital, etc. Working every day, looking after my three kids and my friend's 3 kids (we juggle school pickups and care, making dinners, etc so we can both work), running the school Fete, and trying to keep my house clean and spend quality time with my husband and kids - no wonder I'm bloody exhausted!!!!”

For those providing care and engaging in paid work, being an employee was another role to integrate with their caring responsibilities.

“... my husband was made redundant, so I have had to find paid work. I did training and now work in aged care as clinical assistant. As well as this my mother developed cancer and died after a 6 month battle, I helped her daily and was with her when she passed away in the hospice. My daughter has been in and out of hospital, battling rejection of her kidney transplant, I take her to her appointments and now she has a fracture and more appointments to deal with. I do my paid work around this. My daughter-in-law has mental health problems and I care for my grandchildren with sleep-over and picking up and dropping off at school, and try to keep the peace in the family. I have a lot of stress to deal with, I go one day at a time now I can't think further ahead than that. However I am happy I have my health and can help others and my faith in god and the hope for a better future under the rule of the kingdom keeps me going.”

Feeling stressed and tired was common. For some, providing care was mentally and physically draining, adversely impacting their health and wellbeing.

"...I recently met with a group of women in my age group about an entirely unrelated matter and found that all of us were experiencing anxiety and stress, much more than in the past, due to increasing family pressures e.g. Grown children, grandchildren parents and partner is this a new phenomenon? I'm sure it impacts on this cohorts health, therefore is it factored into the survey's questions enough?"

"Caring for husband with cancer. I have a chronic back injury. my daughter and her 6 children are back living with us, only had 2 months break after 9 years of living with us, very stressful situation."

"The questions have been asked at a time that I have experienced great distress due to my father's terminal illness. He passed away a fortnight ago. I have also spent the last 12 months being pregnant/having a newborn. I feel the answers for diet, exercise and emotional wellbeing are not accurate - as I've experienced extreme situations in the past 12 months. Normally I'm very diet and exercise conscious - my dissatisfaction with my body image is due to all the weight I gained during pregnancy."

Other women acknowledged their health, but spoke about this as secondary to their caregiving responsibilities.

"...Our daughter who had leukemia when she was 32, now 41 is still having health problems more stress for us all + her. She does have support from Doc [NAME] wonderful but lucky we have a great big family and we all look after everyone very fortunate. Have wonderful grandchildren. We all live close to each other. Yes I do know I need to lose weight and it will happen."

Although providing multigenerational care was often difficult and challenging, many reported loss and sadness at the death of the person or people they were caring for.

"I feel that my anxiety and depression is probably due to retiring from work to care for my husband which I did for 3 years before he died. He had a cardiac arrest and I resuscitated him but he only lived for 11 days. At the time both my sons were working overseas but were able to come home when [husband] had the arrest. After he died my Mum who was 92 became unwell and I moved into care for her until she had to go into permanent care - about 21 months. She lived 12 months and I used to spend every afternoon with her. She only died in November so I'm still trying to adjust to living by myself and not having anyone to look after. I find that I'm OK if keep busy but over the weekends I get down. Hope this explains my situation a little."

Others reported being content with their family life, despite its inherent challenges.

"My apologies for lateness. I have been away for the last 7 months helping my beautiful daughter and my 3 wonderful grandchild as my daughter battles breast

cancer...Her battle is big and ongoing, but it is winnable, no negative thoughts allowed. My whole outlook on life, health has radically changed since beginning this journey. I also look after my other three grandchildren at home as their mother is working and studying. Small grandchildren keep you both young and very fit. So in all life is very challenging, but fulfilling. I could not do what I'm doing without the support of my husband."

Having support available for their own needs was an important coping strategy for many women. Often this was provided by partners. Having time to themselves, thinking positively and spending time with grandchildren were other important coping strategies noted by participants.

"...I find that if I have some timeout to myself I tend to calm down a little. I always manage to bounce back even if only a little bit sometimes. I love to read and I also do a lot of things on the computer - write letters, type up gym programs for my daughter who is a coach and help my grandchildren set up different programs on the computer that they use for school. My husband and I also go out 1-2 a week depending on how my back, Achilles' tendon is. We enjoy going to see stage shows and we still go on cruises, one being 35 nights last year and one for 17 nights this year."

"...On the bright side, I have been blessed with 8 Grandchildren, 7 in the last 6 years. They really do give me the desire to keep going at times!"

"...You just never know what life will throw at you but if you keep on smiling and battle on you can get through it!!!"

Overall, women reported that multigenerational caregiving was difficult, challenging and often tiring. As one participant from the 1946-51 cohort said:

"...However between helping our daughter raise the 2 gorgeous girls, also supporting her through a dreadful divorce (words can't describe what her ex-husband is putting her through), together with the daily challenges of my mother with Alzheimer's supportive, beautiful husband and I have very little free time to enjoy our 60's - we didn't in our wildest dreams think we would be in this situation at our age, having worked so hard together for the past 41 years.... All of the above is taking a huge toll on our physical, mental and emotional wellbeing I can't see it ending anytime soon - its 24/7 stress. No wonder our generation is referred to as: 'the sandwich' generation!"

6.3.2. Caring over time: an example from the longitudinal data

For many women, multigenerational caregiving was difficult, tiring and continued over time. Being a 'sandwich caregiver' often meant providing care and support to ageing parents and unwell children. As a consequence, many women reported feeling stressed at juggling the different aspects of the caregiving role. Multigenerational caregiving was not static over time, however, with caregiving duties increasing or decreasing depending on the needs of the

people concerned. In the below narrative, a woman from the 1946-51 cohort shares her experiences of providing care over a 20 year time period, from Survey 1 in 1996 until Survey 8 in 2016.

Survey 1 (1996) *I hope my response to your survey is not too late to be of some assistance to you, but I do have an aversion to questionnaires as I have filled out so many over the years regarding my son's disability. It is also because of his intellectual disability and extremely challenging behaviours I do not have much spare time in fact this was completed 1 am and he has only just gone to sleep! Having to physically restrain him at times may also have a bearing on my physical deterioration, not excluding emotional stress when the future is always a worry to aging parents. We do not have overnight respite and have not been away from the family home on vacation for 20 years. However, my part-time job and weekly art class help my emotional and mental health enormously. I also try to retain a good sense of humour in most situations and this attitude tends to relieve stress.*

Survey 2 (1998) *Over the last year I have experienced "blackouts" of up to a couple of minutes duration accompanied by hot flushes (I did not faint or fall even while standing or sitting) until I started taking maxisoy plus (pretorius) and 500mg evening primrose oil twice daily. My doctor took blood tests but doesn't recommend hrt as my eostrogen level is normal, she did, however, recommend that I continue with the above natural treatment and relax more often!*

Survey 3 (2001) *January 2000 - overactive thyroid (greves (sic) disease - hereditary condition) treated with radioactive iodine. Also ct scans revealed insulinomas (benign tumours) -> February - major operation - 1/2 pancrias (sic) removed. Current medication 150mcgm daily thyroxine. I am regarded as cured and feel quite healthy, although I am more anxious about my health and have experienced panic attacks, however I do go to the doctor more often for reassurance and this has helped. My future health is uncertain - the surgeon said I could develop more inaulinomas (sic) which could result in more pancreas being removed and therefore I could become diabetic. Our intellectually disabled son (23 yrs old) whom we love dearly, still needs constant supervision because of his challenging behaviours and this is very timing. We also worry about his future - he is currently on a behaviour modification programme and hope he will become more independent - accommodating for*

disabled clients needing high support is very difficult to obtain and we don't think he will be able to leave home for a few years yet.

Prior to becoming a 'sandwich caregiver', comments were focused on her own health and wellbeing and some of the issues with her son. As with many women in the 1946-51 cohort, these comments were often about the effects of illnesses and ageing on the body. Many women already had caring duties, and reported these along with their health and wellbeing.

Survey 4 (2004) *During the last twelve months:- my lovely mother died, after an 8 month period of being ill with multiple myeloma (sic) and undergoing chemotherapy. My 28yr old daughter has recently had a cancerous growth (a dermato fibroma-sarcoma) removed from her leg. I still care for our 26yr old autistic son at home (he has severe behavioural problems) and I also give as much emotional and domestic support as I can to my lonely father. I have experienced extreme grief, worry and stress over a long period of time; I have had a breast cancer "scare", and ongoing checkups for kidney problems, i.e. some bleeding and high calcium levels (urine). However, I enjoy attending an art class every week - and try to find time to do some at home - it helps me cope emotionally!*

As the women reported engaging in multigenerational caring, their comments became more focused on the people they cared for, and the impact of these caring roles on their health. The women often reported stress and fatigue, but balanced this with comments about how they cope with their caring demand.

Survey 5 (2007) *About six months ago I developed major foot problems (metatarsalgia and planter guscutus (sic))-probably caused genetics, footwear and walking on too many hard surfaces eg. Shopping centres, at workplace, etc. -podiatrist has recommended more comfortable footwear and orthotics to help relieve this painful condition, also medication when needed. Also, my husband and I still have our 29 year old autistic son living with us, which is often stressful, we have been told, there is no supported accommodation available for him.*

Survey 6 (2010) *Sorry for late return of questionnaire. I have been looking after my father who has had a terminal illness (diagnosed 11 months ago with AML) and subsequently, passed away two weeks ago. I also have an autistic adult son (32) who still lives at home and has challenging behaviours: and I regularly visit an elderly aunt (90) who is currently in hospital with a*

broken pelvis (after a fall). During this time, [date] I decided I could not cope with my part-time job as well as my duties as a carer and consequently retired from paid work. I must say I do miss having my own income and social contacts at work.

Multigenerational caring often continued over many years, although these duties could intensify or decrease over time. Providing care over many years appeared to be stressful for many, with comments focused on the challenges of caring, their feelings of stress or inability to cope, and less about engaging in activities that had reduced this stress in the past. It is also noteworthy that for women caring for adult children, fear for the future for their children was a common and ongoing concern.

Survey 7 (2013) No response

Survey 8 (2016) *The person who I care for in the family home has a moderate intellectual disability and severe autism (adult son aged 38 years). We are currently going through the process of planning for NDIS funding which is somewhat stressful, especially as department of ageing and disability / and all community services are being transferred to private providers. When talking to other mothers with adult children with disabilities we all agree that 'we have to live forever' as we do not trust current or future arrangements to care for our children with the same level of care that we give them. There is also a scarcity of supported accommodation and housing available for them.*

6.3.3. Conclusions from the qualitative analysis

Multigenerational caring, or being a 'sandwich caregiver', is often challenging and stressful. Although caring duties fluctuate, many women provided care for their families over many years, with some women reporting providing care and support for three generations (their parents, children and grandchildren) at the same time. Many women reported lacking time to focus on their own health and wellbeing, and it seemed there was a lack of support beyond the family unit to assist with this care.

Key points

- More accessible and affordable child care options for parents returning to work may reduce the burden on grandparents of caring for their grandchildren.
- More research is needed to investigate the impact of long-term multigenerational caregiving among those who are reaching retirement age, and who are experiencing their own age-related health issues.
- While child care and respite care may be available to caregivers, these are rarely, if ever, offered as a coordinated support service. The complex support needs of caregivers in this position warrant assessment at the individual level.

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8. Appendix A

8.1 Questions on caregiving used in ALSWH surveys

8.1.1. CHILD CARE

| Question | Cohort | When asked |
|--|---|--|
| Do you have children living with you (your own, your partner's, fostered, etc.)? Yes/No OR Who lives with you? (response options included own children/someone else's children) OR Which of the following best describes the household you live in? (response options include Self and partner/spouse with child/children; self with child/children) | 1973-78 | Survey 1 (age 18-23) Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |
| If you have children living with you, how many are: <ul style="list-style-type: none"> • Under 12 months • 12 months – 5 years • 6-12 years • 13-16 years | <u>Response options:</u> <ul style="list-style-type: none"> • None • One • Two • Three • Four or more • Do not have children living with me | 1973-78 Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |
| Most parents need someone to care for their children when they cannot. How satisfied are you with your child care arrangements? <ul style="list-style-type: none"> • Very satisfied • Satisfied • Dissatisfied • Very dissatisfied | 1973-78 | Survey 1 (age 18-23) Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) |

| Question | Cohort | When asked |
|---|---|---|
| <ul style="list-style-type: none"> • Not applicable/No children living with me | | |
| <p>Are you happy with YOUR SHARE of the following tasks and activities: Child care</p> <ul style="list-style-type: none"> • Happy the way it is • Would like other family members to do more • Would prefer another arrangement • Not applicable | 1973-78 | Survey 1 (age 18-23) Survey 3 (age 25-30) Survey 4 (age 28-33) |
| <p>Whether you use childcare or not, please answer the following questions:</p> <ul style="list-style-type: none"> • Is formal child care located in an area convenient for you? (Survey 5) • Are formal child care places available for you? • Is the cost of formal child care a problem for you? • Is informal child care available for you? • Do you ever use child care (formal or informal) <p>In a normal week, how often do you usually use child care? (formal and/or informal)</p> | <p><u>Response options:</u></p> <ul style="list-style-type: none"> • Yes • No • Don't Know • Do not have children living with me • Don't use this type of childcare <p><u>Response options:</u></p> <ul style="list-style-type: none"> • less than 5 hours • 5-10 hours • 11-20 hours • 21-30 hours • 31-39 hours • more than 40 hours | 1973-78 Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |

| Question | Cohort | When asked |
|---|----------------|---|
| <p>In general, how satisfied are you with the amount of child care you use? (Formal care/Informal care)</p> | | <p>Survey 4 (age 28-33)</p> |
| <p>Thinking about the birth of your last child:</p> <ul style="list-style-type: none"> • Were you entitled to paid maternity leave? • Did you take paid maternity leave? • Were you entitled to unpaid maternity leave? • Did you take unpaid maternity leave? <p>After the birth of your last child, how soon did you go back to work?</p> | <p>1973-78</p> | <p>Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39)</p> <p>Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39)</p> |

| Question | Cohort | When asked |
|---|---------|----------------------|
| At the time of the birth or adoption of your youngest child, were you employed (or self-employed), even if you were on leave? | 1973-78 | Survey 7 (age 37-42) |
| <p><u>Response options:</u></p> <ul style="list-style-type: none"> • Have not given birth or adopted • Yes, full-time work (35+ hours/week) • Yes, part-time work (less than 35 hours/week) Yes, casual/temp work (irregular hours) • No, but I was looking for work • I was not in the paid workforce | | |
| Did you take leave from your paid work (including self-employment) for the birth or adoption of your youngest child? Yes/No | 1973-78 | Survey 7 (age 37-42) |
| Please write down the number of weeks you took as leave from your paid work (including self-employment) before and after the birth or adoption of your youngest child. | 1973-78 | Survey 7 (age 37-42) |
| <p>Paid leave:</p> <ul style="list-style-type: none"> • Employer-paid parental leave • Government paid parental leave • Annual leave OR Long service leave • Sick leave <p>Unpaid leave:</p> | | |
| Did you start, or return to, paid work (including self-employment) within 12-13 months of the birth or adoption of your youngest child? | 1973-78 | Survey 7 (age 37-42) |
| <p><u>Response options:</u></p> <ul style="list-style-type: none"> • Yes, full-time work (35+ hours/week) | | |

| Question | Cohort | When asked |
|--|--|--|
| | | |
| <ul style="list-style-type: none"> • Yes, part-time work (less than 35 hours/week) • Yes, casual/temp work (irregular hours) • No, my job was no longer available • No, I chose not to return to work | | |
| <p>In relation to your youngest child, how satisfied were you with the following arrangements?</p> | <p>a) Parental leave arrangements b) Return to work arrangements</p> | <p>1973-78</p> <p>Survey 7 (age 37-42)</p> |
| <p>Do you regularly provide (unpaid) care for grandchildren or other people's children?</p> <p>Response options:</p> <ul style="list-style-type: none"> • Yes, daily • Yes, weekly • Yes, occasionally • No, never | <p>1946-51</p> | <p>Survey 1 (age 45-50) Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70)</p> |
| | <p>1921-26</p> | <p>Survey 2 (age 73-78) Survey 3 (age 76-81) Survey 4 (age 79-84) Survey 5 (age 82-87) Survey 6 (age 85-90)</p> |

8.1.2. CAREGIVING FOR OTHERS

| Question | Cohort | When |
|---|---------|--|
| <p>Do you regularly provide care or assistance (e.g., personal care, transport) to any other person because of their long-term illness, disability or frailty? (Response: Yes/No)</p> <p>*At some surveys, the response options were:</p> <ul style="list-style-type: none"> • For someone who lives with you Yes/No • For someone who lives elsewhere Yes/No | 1973-78 | Survey 1 (age 18-23) Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39)* Survey 7 (age 37-42)* |
| | 1946-51 | Survey 1 (age 45-50) Survey 2 (age 47-52)* Survey 3 (age 50-55) * Survey 4 (age 53-58) * Survey 5 (age 56-61) * Survey 6 (age 59-64) * Survey 7 (age 62-67) * Survey 8 (age 65-70)* |
| | 1921-26 | Survey 1 (age 70-75) Survey 2 (age 73-78)* Survey 3 (age 76-81) * Survey 4 (age 79-84) * Survey 5 (age 82-87) * Survey 6 (age 85-90) * Six MF surveys (age 85 +)* |
| <p>How many people with a long-term illness, disability or frailty do you regularly provide care for? Response options (<i>Mark one only</i>):</p> | 1973-78 | Survey 6 (age 34-39) Survey 7 (age 37-42) |

| Question | Cohort | When |
|--|---------|--|
| <ul style="list-style-type: none"> • One person • More than one person | | |
| | 1946-51 | Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |
| | 1921-26 | Survey 2 (age 73-78) |
| How often in total do you provide this care or assistance? Response options (<i>Mark one only</i>): <ul style="list-style-type: none"> • Every day • Several times a week • Once a week • Once every few weeks • Less often | 1973-78 | Survey 6 (age 34-39) Survey 7 (age 37-42) |
| | 1946-51 | Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |
| | 1921-26 | Survey 2 (age 73-78) |

| Question | Cohort | When |
|--|---------|--|
| <p>How much time do you usually spend providing such care or assistance on each occasion? Response (<i>Mark one only</i>):</p> <ul style="list-style-type: none"> • All day and night • All day • All night • Several hours • About an hour | 1973-78 | Survey 6 (age 34-39) Survey 7 (age 37-42) |
| | 1946-51 | Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |
| | 1921-26 | Survey 2 (age 73-78) |
| <p>Does the person you care for have any of the following major medical conditions or disabilities? If you care for more than 1 person please select the person you have cared for the longest and complete the question about that person. Response options (<i>Mark all that apply</i>):</p> <ul style="list-style-type: none"> • Alzheimer’s disease/dementia • Cancer • Frailty in old age • Heart condition • Mental health problem (e.g., depression, anxiety) • Visual impairment • Respiratory conditions (e.g., asthma, emphysema) • Stroke • Other reason (please specify...) | 1946-51 | Survey 7 (age 62-67) Survey 8 (age 65-70) <i>*Note:</i> a longer list of 20 options was used in Survey 7 , however due to low responses only items that were selected by more than 5% of women at Survey 7 were retained as separate categories for Survey 8. (All omitted items would be picked up by the ‘other reason’ option). |

| Question | Cohort | When |
|--|---------|--|
| <p>What is your relationship to the person you care for? If you care for more than 1 person please answer for the person you care for the most. (<i>Mark one only</i>)</p> <ul style="list-style-type: none"> • Spouse/partner • Child • Parent/parent-in-law • Grandchild • Sibling/sibling-in-law • Friend • Neighbour • Other (please specify...) | 1946-51 | Survey 8 (age 65-70) |
| <p>If you do not provide care or assistance to any person with a long term illness, disability or frailty, is it because you</p> <ul style="list-style-type: none"> • Used to care for someone in the last 3 years, but they passed away or moved into a nursing home or other residential care facility • Use to care for someone in the last 3 years, but stopped caring for them for another reason (please specify) • Have never provided care or assistance • Other reason (please specify) | 1946-51 | Survey 7 (age 62-67) Survey 8 (age 65-70) |

8.1.3. SELF RATED HEALTH

| Question | Cohort | When |
|--|---------|--|
| In general, would you say your health is: <ul style="list-style-type: none"> • Excellent • Very Good • Good • Fair • Poor | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |
| In the last 3 years, have you been diagnosed or treated for depression? | 1973-78 | Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |
| | 1946-51 | Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |
| | 1921-26 | Survey 2 (age 73-78) Survey 3 (age 76-81) Survey 4 (age 79-84) Survey 5 (age 82-87) Survey 6 (age 85-90) |

| Question | Cohort | When |
|---|---------|--|
| <p>Below is a list of how you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK. (Response options: Rarely or none of the time, less than one day; Some or a little of the time, 1-2 days; Occasionally or a moderate amount of the time, 3-4 days; most or all of the time, 5-7 days).</p> <ul style="list-style-type: none"> • I was bothered by things that don't usually bother me • I had trouble keeping my mind on what I was doing • I felt depressed • I felt that everything I did was an effort • I felt hopeful about the future • I felt fearful • My sleep was restless • I was happy • I felt lonely • I could not 'get going' | 1973-78 | Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |
| | 1946-51 | Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |
| <p>In the last 3 years, have you been diagnosed or treated for anxiety?</p> | 1973-78 | Survey 2 (age 22-27) Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |
| | 1946-51 | Survey 2 (age 47-52) Survey 3 (age 50-55) Survey 4 (age 53-58) Survey 5 (age 56-61) |

| Question | Cohort | When |
|--|---------|--|
| | | Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |
| | 1921-26 | Survey 2 (age 73-78) Survey 3 (age 76-81) Survey 4 (age 79-84) Survey 5 (age 82-87) Survey 6 (age 85-90) |
| <p>Over the last 12 months, how stressed have you felt about the following areas of your life:</p> <ul style="list-style-type: none"> • Own health • Health of other family members • Work/Employment • Living Arrangements • Study • Money • Relationship with parents • Relationship with partner/spouse • Relationship with other family members • Relationship with friends • Motherhood/children | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | Survey 1 (age 70-75) Survey 2 (age 73-78) Not asked at any further surveys |

8.1.4. LIFESTYLE

| Question | Cohort | When |
|---|---------|--|
| How often do you currently smoke cigarettes, or any tobacco products? Daily, at least weekly (but not daily), less often than weekly, Not at all. | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | Survey 2 (age 73-78) |
| Which of the following best describes your smoking status now? (<i>Mark one only</i>) <ul style="list-style-type: none"> • I have never smoked • I used to smoke • I now smoke occasionally • I now smoke regularly | 1921-26 | Survey 1 (age 70-75) Not asked at Surveys 3 - 5 Survey 6 (age 85-90) |
| In your lifetime, would you have smoked 100 cigarettes or less? (Yes/No) | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| How often do you usually drink alcohol? <ul style="list-style-type: none"> • Never • Rarely • Less than once a week • 3-4 days a week • 5-6 days a week • Every day | 1973-78 | All surveys |
| | 1946-51 | All surveys *At Survey 3, alcohol questions were asked in a different format, as part of a food frequency questionnaire |

| Question | Cohort | When |
|---|---------|--|
| | 1921-26 | Survey 1 (age 70-75) Survey 2 (age 73-78) Survey 3 (age 76-81) Not asked at Surveys 4 and 5 Survey 6 (age 85-90) |
| <p>On a day when you drink alcohol, how many drinks do you usually have?</p> <ul style="list-style-type: none"> • 1-2 • 3 or 4 • 5-8 • 9 or more | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | Survey 1 (age 70-75) Survey 2 (age 73-78) Survey 3 (age 76-81) Not asked at Surveys 4 and 5 Survey 6 (age 85-90) |
| <p>How often do you have 5 or more drinks on one occasion?</p> <ul style="list-style-type: none"> • Never • less than once a month • about once a month • about once a week • more than once a week. | 1973-78 | All surveys |
| | 1946-51 | All surveys, except Survey 3 (age 50-55) |
| | 1921-26 | Survey 1 (age 70-75) Not asked at further surveys |

| Question | Cohort | When |
|---|---------|-------------|
| <p>How many time did you do each (of the following) type of activity last week? (Only count the number of times the activity lasted for longer than 10 minutes).</p> <ul style="list-style-type: none"> • Walking briskly for recreation or exercise, or to get from place to place) • Moderate leisure activity (like social tennis, moderate exercise classes, recreational swimming, dancing) • Vigorous leisure activity (that makes you breathe harder or puff and pant, like aerobics, competitive sport, vigorous cycling, running, swimming) • Vigorous household or garden chores (that make you breather harder or puff and pant). <p>How much time did you spend altogether on each?</p> <p>*At Survey 1 (for all cohorts) and in 6MF surveys, this question was asked in a slightly different format.</p> | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |
| How tall are you without shoes? | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |
| How much do you weigh without shoes or clothing? | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |

8.1.5. HEALTH SERVICE USE

| Question | Cohort | When |
|---|---------|---|
| <p>How many times have you consulted a family doctor or another general practitioner for your own health in the last 12 months? (None, 1-2 times, 3-4 times, 5-6 times, 7-12 times, 13-24 times, 25 or more times)</p> | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys, excluding 6MF surveys. |
| <p>How many times have you consulted a specialist doctor for your own health in the last 12 months? (None, 1-2 times, 3-4 times, 5-6 times, 7-12 times, 13-24 times, 25 or more times)</p> <p>*Format changed to: In the last 12 months, have you consulted a specialist doctor? Yes/No</p> | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | Survey 1 (age 70-75) Survey 2 (age 73-78)* Survey 3 (age 76-81)* Survey 4 (age 79-84)* Not asked Surveys 5 and 6 Not asked 6MF Surveys |

8.1.6. SOCIOECONOMIC

| Question | Cohort | When |
|--|---------|--|
| What is your postcode? (Location is then coded as Major Cities, Inner Regional, Outer Regional, Remote/Very Remote) | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |
| What is the highest qualification you have completed? <ul style="list-style-type: none"> • No formal qualifications • School Certificate (Year 10) • Higher School Certificate (Year 12 equivalent) • Trade apprenticeship • Certificate/diploma • University degree • Higher university degree | 1973-78 | All surveys |
| | 1946-51 | Survey 1 (age 45-50) Survey 6 (age 59-64) |
| | 1921-26 | Survey 1 (age 70-75) Not asked at any further surveys |
| In the last week, how much time in total did you spend doing the following things? <ul style="list-style-type: none"> • Full time paid work • Permanent part-time paid work • Casual paid work • Work without pay (e.g., family business). Response options: 1-15 hours, 16-24 hours, 25-34 hours, 35-40 hours, 41-48 hours, 49 hours or more. | 1973-78 | All surveys |
| | 1946-51 | All surveys |

| Question | Cohort | When |
|---|---------|--|
| What is/was your main occupation now? <ul style="list-style-type: none"> • Manager/administrator • Professional • Paraprofessional/associate professional • Tradesperson or related worker • Advanced clerical or service worker • Intermediate clerical, sales/service worker • Intermediate production or transport worker • Elementary clerical, sales or service worker • Labourer or related worker • No paid job • Other | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | Survey 1 (age 70-75) Not asked at any further surveys |
| Please indicate the following description that best fits your life now (<i>Mark one only</i>) <ul style="list-style-type: none"> • I am not retired at all • I am partially retired • I am completely retired from paid work • I gave up paid work over 20 years ago • I have never been in paid work • Other (please specify) <i>If applicable:</i> When did you retire or give up work completely? At what age do you expect to retire from the paid workforce? | 1946-51 | Survey 4 (age 53-58) Survey 5 (age 56-61) Survey 6 (age 59-64) Survey 7 (age 62-67) Survey 8 (age 65-70) |

| Question | Cohort | When |
|---|---------|--|
| Are you currently unemployed and actively seeking work? <ul style="list-style-type: none"> • No • Yes, unemployed for less than 6 months • Yes, Unemployed for 6 months or more. | 1973-78 | Survey 3 (age 25-30) Survey 4 (age 28-33) Survey 5 (age 31-36) Survey 6 (age 34-39) Survey 7 (age 37-42) |
| How do you manage on the income you have available? <ul style="list-style-type: none"> • It is impossible • Difficult all the time • Difficult some of the time • Not too bad • It is easy | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |
| What is your present marital status/living arrangement? <ul style="list-style-type: none"> • Married • De Facto • Separated • Divorced • Widowed • Never Married | 1973-78 | All surveys |
| | 1946-51 | All surveys |
| | 1921-26 | All surveys |

8.2 Notes on qualitative analysis of free text comments

8.2.1. Sampling frame

There were 58,910 free-text comments from ALSWH participants across all four cohorts of women (see Table 8-1). Therefore, reducing the sample for analysis according to responses in the quantitative section of the survey was necessary. This process is akin to identifying a sampling frame from which the data for analysis was drawn (Tavener, Chojenta et al., 2016).

Table 8-1 Number of participant comments across the ALSWH surveys

| ALSWH cohort (birth year) | Survey 1 | Survey 2 | Survey 3 | Survey 4 | Survey 5 | Survey 6 | Survey 7 | Total |
|---|----------|----------|----------|----------|----------|----------|-----------|--------------|
| 1921-26 | 2978 | 4695 | 3955 | 4353 | 2481 | 698 | not held* | 19160 |
| 1946-51 | 2392 | 2058 | 2672 | 2967 | 3731 | 3745 | 3021 | 20586 |
| 1973-78 | 2423 | 1948 | 2266 | 2394 | 2415 | 1656 | 1275 | 14377 |
| 1989-95 | 1415 | 1150 | 740 | 846 | 636 | not held | not held | 4787 |
| Total comments by all participants | | | | | | | | 58910 |

Notes: *Participants from the 1921-26 cohort have received shorter, 6-monthly follow up surveys from Survey 6 onwards. Six monthly follow-up data for the 1921-26 cohort is not included in this count. Table adapted from Tavener et al., 2016.

8.2.2. Method of analysis of qualitative data

Comments were coded using a thematic analysis technique. Thematic analysis, as detailed by Braun & Clarke (2006), is a flexible analysis technique which has successfully been applied to free-text analysis (e.g., Tavener et al., 2016, Wigginton et al., 2016). In brief, thematic analysis involves familiarisation with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.

8.3 Abstracts of ALSWH papers

Lee C & Gramotnev H. (2007). Transitions into and out of caregiving: Health and social characteristics of mid-age Australian women. *Psychology and Health*, 22(2): 193-209.

Family caregiving is frequently associated with significant levels of physical, emotional and financial strain. This article examines the health effects of transitions into and out of caregiving in middle age. We conducted a secondary analysis of data from the Australian Longitudinal Study on Women's Health (ALSWH) to examine changes in caregiving status among middle-aged women over a 3-year period, and the correlates and outcomes of these changes. A total of 9,555 middle-aged Australian women were categorised according to caregiving status at two surveys 3 years apart, as Continuing (2.7%); Stopped (4.9%); Started (3.0%); and Never caregivers (89.4%). Analyses at each time point show poorer physical and emotional health, health service use, health behaviours and lower engagement in the paid workforce among all three caregiver groups, indicating that middle-aged women who are, have been, or will become family caregivers are in poorer health than women who do not have these roles. Middle-aged women in poor health tend to be selected into caregiving, probably because they are less engaged with the paid workforce. Poor health and disengagement from the paid workforce continue even when caregiving stops. Health care providers should be particularly conscious of the needs of middle-aged caregivers, who are likely to be in poor health even before they take on the role.

Berecki J, Lucke J, Hockey R & Dobson A. (2008). Transitions into informal care and out of paid employment of women in their 50's: A study of cause and effect. *Social Science and Medicine*, 67(1): 122-127.

Data from the Australian Longitudinal Study on Women's Health were used to study the order of events leading to informal caregiving and changes in labour force participation in mid-aged women, taking into account health and socio-economic status. This analysis included women who responded to the third (2001) and fourth (2004) surveys and providing data for the caring and employment variables used (n= 9857). Caring was defined as providing care for an ill, frail or disabled person at least seven hours per week. Between 2001 and 2004, the proportion of women caring increased from 12% to 14% (difference 2.3 % [95% CI 1.6 to 3.1 %]). Paid employment participation decreased from 67% to 62% in 2004 (difference -5.2 % [95% CI -6.1 to -4.4 %]). Logistic regression model results showed that taking up caring between 2001 and 2004 was not statistically significantly associated with employment status in 2001. Among women who took up caring, however, hours spent in paid employment in 2001 was negatively associated with hours spent caring in 2004 (rs -0.10, p=0.004). Amongst women working in 2001, taking up caring between 2001 and 2004 was associated with reduced participation in paid employment (OR=1.63 [95% CI 1.34 to 1.98]).

In conclusion, among mid-aged women, transitions into caregiving were irrespective of time spent in paid employment, but were followed by a decrease in labour force participation. Policies could aim to support continuing labour force participation during caregiving by creating flexible working arrangements; re-employment programs could support women who quit work in getting back to paid employment after a period of caregiving

Tooth L & Mishra G. (2014). Socioeconomic factors associated with trajectories of caring by young and mid-aged women: a cohort study. *BMC Public Health*, 14(1): Art. No. 74.

Background: The health and socioeconomic outcomes from being a caregiver are well described. In contrast, the long-term trajectories of caring undertaken by women, and the demographic, socioeconomic status, health status and health behaviour characteristics associated with these trajectories is not well known.

Methods: The data were from the Australian Longitudinal Study on Women's Health. Participants were 14,202 women born 1973–78 followed for 13 years, and 12,282 women born 1946–1951 followed for 9 years. Latent class analyses and multinomial logistic regression were used.

Results: Five distinct trajectories of caring were identified for the younger women: these represented 'ongoing', 'starting', 'never' and 2 types of 'transitional' caring. While traditional indicators of poorer socioeconomic status were associated with trajectories representing 'ongoing' and 'starting' caring, they were not associated with 'transitional' caring trajectories. Three distinct trajectories of caring were identified for the mid-age women: these represented 'ongoing', 'starting' and 'never' caring. For the mid-age women, poorer socioeconomic status indicators were associated with the 'ongoing' caring, but not 'starting' caring.

Conclusions: Women in the 1973–78 cohort showed more varying and transitional caring trajectories compared to those in the 1946–51 cohort, and these trajectories were not associated with traditional socioeconomic indicators. An 'opportunity cost' theory for who become carers does not support young transitional carers or mid-aged women beginning new caring. Health policies, education and awareness campaigns for women carers need to target outside previously identified populations.

O'Dwyer S, Moyle W, Pachana N, Sung B & Barrett S. (2014). Feeling that life is not worth living (death thoughts) among middle-aged, Australian women providing unpaid care. *Maturitas*, 77(4): 375-379.

Objective: To identify the proportion of female carers who experience death thoughts and the factors associated with these thoughts, using data from the Australian Longitudinal Study on Women's Health (ALSWH).

Methods: A cross-sectional analysis of the fifth ALSWH survey was conducted. 10,528 middle-aged women provided data on caring and death thoughts, 3077 were carers and 2005 of those were included in the multivariate analysis.

Results: 7.1% of female carers had felt life was not worth living in the previous week and were classified as having experienced death thoughts, compared with 5.7% of non-carers ($p = .01$). Carers with death thoughts had poorer physical and mental health, higher levels of anxiety, lower levels of optimism, and reported less social support ($p < .01$). In a multivariate model social support, mental health, carer satisfaction, and depressive symptoms significantly predicted death thoughts. Carers with clinically significant depressive symptoms were four times more likely to experience death thoughts than those without. Carers who were satisfied with their role were 50% less likely to have experienced death thoughts than those who were dissatisfied.

Conclusions: A small but significant proportion of female carers experience death thoughts and may be at risk for suicide. These findings add to the growing body of evidence on suicide-related thoughts and behaviours in carers and have implications for health professionals and service providers

Ferreira P, Loxton D & Tooth L. (2017). Intimate personal violence and caregiving: Influences on physical and mental health in middle-aged women. *Maturitas*, 102; 34-40.

Objectives: To investigate if women with a history of having experienced intimate partner violence (IPV) who undertook caregiving would experience worse mental and physical health compared to those without caregiving roles.

Study design and main outcome measures: IPV, caregiving history and data on covariates were collected between 1996 and 2010 from 8453 participants in the Australian Longitudinal Study on Women's Health aged between 45 and 65 over the course of the study. Regression analyses were used to analyse the association of IPV and caregiving (categorised as IPV + caregiving, IPV + no caregiving, no IPV + caregiving, no IPV + no caregiving), with and without adjustment for covariates, on mental and physical health-related quality of life (HRQOL), depressive symptoms and perceived stress, measured in 2010.

Results: Experiencing IPV and being a caregiver was associated with poor health outcomes on three of the four outcomes (depressive symptoms, OR 2.08, 95% CI 1.58, 2.75; stress, OR 2.11, 95% CI 1.55, 2.87; physical HRQOL β -2.39, 95% CI -3.34, -1.44; all $p \leq 0.001$, fully adjusted) compared with not experiencing IPV or caregiving. On these outcomes, IPV and caregiving combined had a stronger association than IPV or caregiving separately. For mental HRQOL, a weaker association was found (OR 1.41 95% CI 1.02, 1.95, fully adjusted, $p = 0.04$).

Conclusions: This paper provides evidence for the cumulative health impact of stressful life events, both those that are perpetrated against an individual (violence) and those undertaken with a degree of personal agency (caregiving). The findings underscore the need to understand the drivers of poor health, for clinicians to ask about life circumstances of patients experiencing poor health, and for the provision of referral pathways for complex cases.

8.4 Instructions for interpreting plot graphs

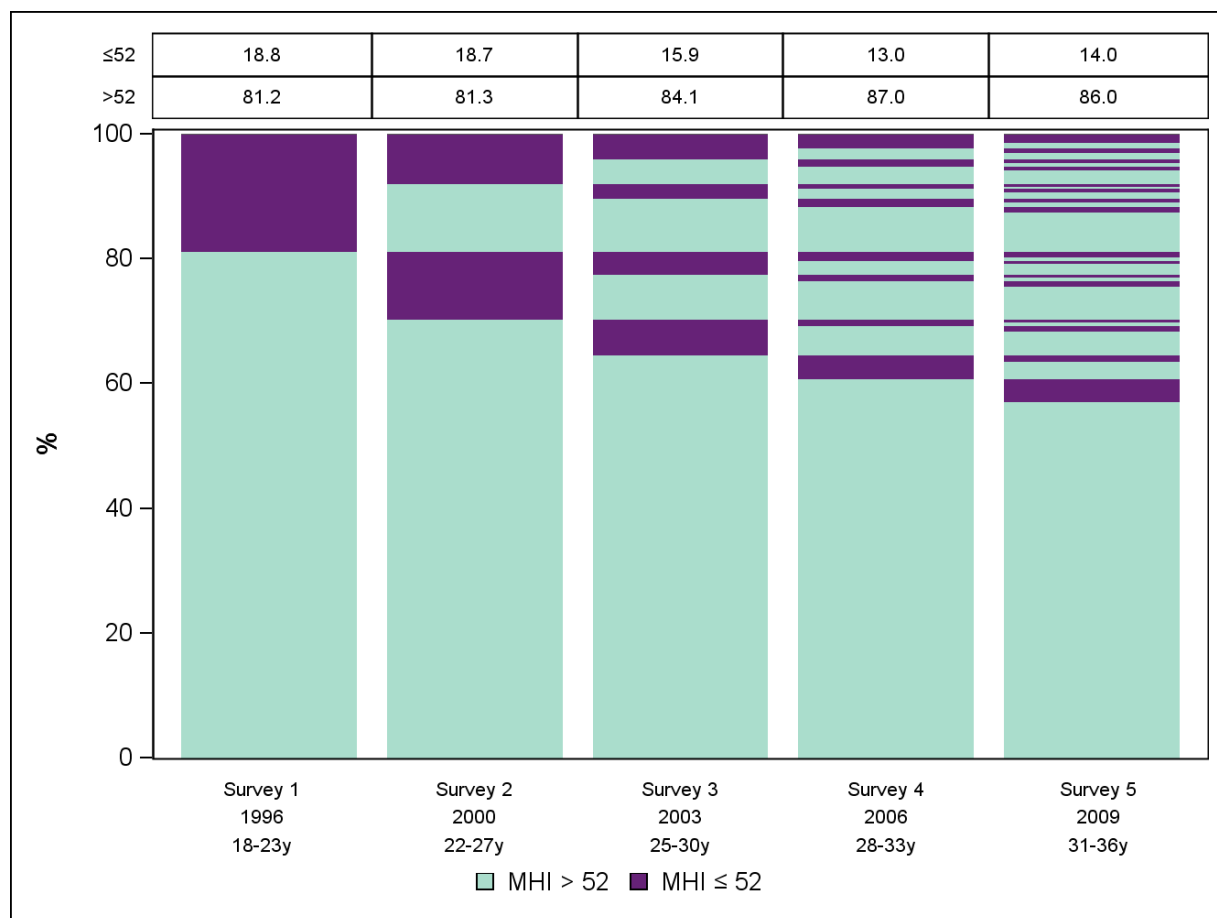


Figure 8-1 Percentage of younger women (born 1973-78) with psychological distress (purple areas) in past four weeks using the SF-36 MHI ≤52.

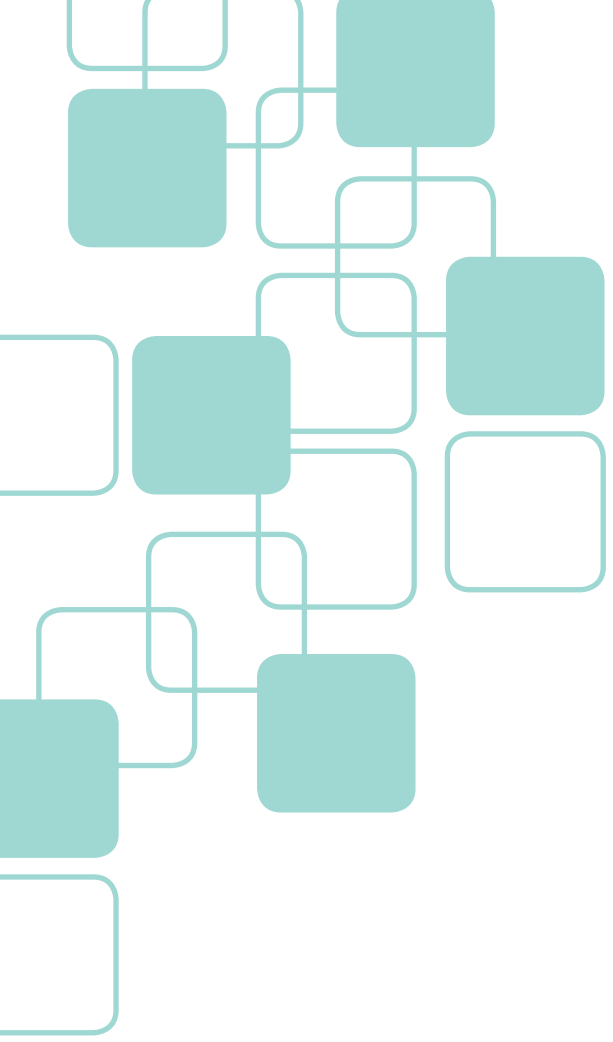
The far left column of Figure 8-1 above shows that Survey 1 in 1996 had more young women with good mental health than poor mental health. This interpretation is based on the green section being considerably greater than the purple section. The key at the bottom of the graph indicates that the green section is made up of women who had a score greater than 52 on the SF-36 Mental Health Index (MHI), indicating good mental health. The table at the top of the far left column reports the proportion of 81.2% women who had a score of greater than 52. The far left column also shows that close to 20% had poor mental health (purple section of far left column) which is also reported in the table on the top of the far left column with the proportion 18.8% having a score of ≥ 52 indicating poor mental health.

In 2000 (Survey 2) the column second from the left is divided into four sections, two purple and two green. The bottom green and purple sections of column two line up with the green section in column one (far left) and describe the mental health status at Survey 2 for women who had good mental health at Survey 1 showing that some women with good mental health in 1996 experienced poor mental health in 2000 while the greater proportion continued to

experience good mental health. The top set of purple and green sections in the column representing Survey 2 lines up with the purple section of column 1 and represents the mental health status at Survey 2 for women who experienced poor mental health at Survey 1. This shows while some women with poor mental health at Survey 1 continued to have poor mental health at Survey 2, many of them went on to experience good mental health at Survey 2.

The column third from the left (the middle column overall) representing Survey 3, collected in 2003, has eight sections, 4 purple and four green. The bottom green and purple sections line up with the bottom green section of Survey 2, indicating that while most women with good mental health at Survey 2 continue to have good mental health at Survey 3, some experience poor mental health, even though they had experienced good mental health at the previous two surveys (2000 and 1996). The green section second from the bottom in the column representing Survey 3, represents women who had good mental health in Survey 1 (green section), poor mental health in Survey 2 (bottom purple section) and good mental health in Survey 3 (second from bottom green section). The green section third from the bottom in the column representing Survey 3 represents women who had poor mental health in Survey 1 (purple section) and good mental health in Surveys 2 and 3. The purple section third from the bottom in the section representing Survey 3 represents women who had poor mental health in Survey 1 (purple section), good mental health in Survey 2 (second from the bottom green section) and poor mental health in Survey 3. The top purple section in Survey 3 represents women who continued to have poor mental health across all of the first three surveys (1996, 2000 and 2003).

These same patterns continue into the next two columns representing Surveys 4 and 5 with the bottom green section in the far right column representing women who had good mental health in Surveys 1, 2, 3, 4, and 5; and the top purple column in the far right column representing women who had poor mental health across all surveys (1996, 2000, 2003, 2007 and 2009).



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