

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



the australian longitudinal
study on women's health

Dr Samantha McKenzie, Dr Leigh Tooth,
Dr Jayne Lucke, Dr Shehara Mendis and
Prof Annette Dobson

Caring for carers: Caring and use of services in women carers born between 1921 and 1926



Detailed report for the Australian Government Department of Health and Ageing
Carers Project, Stage 2, Phase 2

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Summary of findings

- This project was a nested cross-sectional substudy of the Australian Longitudinal Study on Women's Health (ALSWH), involving data from 280 carers who cared for someone who may have used community services. The survey consisted of 53 closed-response questions (some with open-ended components) and 5 open-ended questions. Both the statistical analyses of the quantitative data (from the closed-response questions) and summaries of the text of the open-ended questions are presented in the report.
- The mean age of the carers was 78 years. Most carers were married, lived in a major city or inner regional area, spoke English at home and had a school or intermediate certificate and were not having difficulties managing on their income.
- The demographic profile of the carers in this substudy was similar to that of the 1921-1926 cohort from the ALSWH, except that more women were married in the substudy. This difference was due to most of the older carers in the substudy caring for their husbands. The substudy's carers also had poorer mental and physical health compared to the entire 1921-1926 cohort.
- The Care Activity Index (CAI) classified the 280 carers into three equal groups (lower, middle, higher) according to the level of activities, from the nine activities of daily living in the survey, that they performed for their care recipients. The higher CAI category indicated more frequent caring for more activities.
- The age of the care recipients (mean=83.0 years) was similar across CAI groups.
- In general, carers perceived their lives to be worse due to caring and carers with a higher CAI were most affected.
- The substudy's carers had poorer mental and physical health compared to the entire 1921-1926 cohort.
- Carer strain was measured by the Caregiver Strain Index. Carer strain was related to CAI group: carers with a higher CAI were more likely to be strained than were carers with a lower or middle CAI.
- Developmental burden, as measured by the Caregiver Burden Inventory, describes carers' feelings of being 'out of sync' in their development with respect to their peers. In the substudy, developmental burden was related to CAI group: carers with a higher CAI were more likely to be burdened than were carers with a lower or middle CAI.
- Carers were satisfied with their social support network.
- The carers reported that their needs and those of the people they cared for were generally being met.
- The carers who completed the survey provided the majority of the help for the care recipients compared to other unpaid carers or paid services.
- The use of Meals on Wheels, personal home care, domestic home care and respite care was low. However, when the services were used, the carers reported that they were easy to access, they were of a good quality and that they received as much as they wanted.

- Personal home care had the highest proportion of carers reporting that they received the service less often than they wanted, followed by domestic home care and respite care in descending order. No carers reported that they received Meals on Wheels less often than wanted. Conversely, out of the four services, Meals on Wheels stood out as the service that had the most carers reporting they received it more frequently than wanted.
- The most difficult health service to access for care recipients was 'house calls by the doctor.'
- Nearly half of the carers wrote that no groups or government services had provided significant support to them as carers.
- Carers whose recipients received health services through the Department of Veterans' Affairs commended their helpfulness and availability of services.
- The survey data informed the possible relationship between use of the four highlighted services and the impact of caring. However, further investigation is required to determine the causality of the associations between use of these services and impact on caring.
- The use of respite care was strongly driven by care recipient preference.
- The most common themes of the positive aspects of caring in the written section were 'characteristics of the relationship between the carer and care recipient' and 'personal concerns or attitudes of the carer.' 'Characteristics of the relationship' included companionship, longevity of marriage and reciprocity within the relationship. 'Personal concerns or attitudes of the carer' referred to the carers' outlook on life, providing care, coping and religious beliefs.
- The most discussed theme for the negative aspects of caring in the written section was 'practicalities of the caring situation.' 'Practicalities' covered an extensive range of topics including restrictions on everyday life, lack of holidays and travel, and dissatisfaction with the present situation and repetitious routine.

Possible policy implications

- 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.
- Policies should recognise that carers and their situations are different. Therefore, providing flexible options for respite care may improve care recipient use.
- Carers who were provided with services through the Department of Veterans' Affairs commended them highly. Other non-veterans service providers may be able to model their service delivery and availability after the Department of Veterans' Affairs.
- Food delivery services, such as Meals on Wheels, should offer a wider range of food, including culturally appropriate food, to meet the varied dietary needs of the care recipients.

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Chapter 1 Background

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

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

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

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

Each cohort has a similarly aged pilot study group of women, not included in the main sample, who pilot test the main survey. Each cohort group is surveyed every three years and substudies may be conducted each year for the two groups not involved in a main survey. There are now 12 years of data available. The women born between 1973 and 1978 are being surveyed in 2009 for the fifth time.

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

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

1.2 Background to research on caring

Stage 1: In 2006 and 2007 researchers in the ALSWH team at the University of Queensland were contracted to provide detailed analyses of caring by women born between 1946 and 1951, with particular emphasis on the impact of employment and

other life roles and to develop and pilot a substudy focusing on support needed for mid-aged women who provide care for someone who is frail or disabled. This research is referred to as Stage 1. The results of Stage 1 were delivered in three reports:

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

Stage 2: In 2008 researchers in the ALSWH team at the University of Queensland, were contracted to provide further detailed analyses of caring by women born between 1946 and 1951, and 1921 and 1926. These analyses were to examine the influence of factors such as where carers lived (both in relation to the care recipient and in terms of area of residence) and care recipient needs (such as functional dependency levels) and the frequency and amount of care. The research was to provide evidence to address the following questions:

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

This second report (Phase 2 of Stage 2 research on caring) describes further analysis of data from a substudy of the 1921-1926 cohort funded by a National Health and Medical Research Council of Australia Healthy Ageing Research Program Grant: "How well do health and community services help older people with neurodegenerative disorders and family caregivers." In this report, the substudy is referred to as the 'older carers substudy.' Some of the data from the older carers substudy have already been analysed, resulting in two papers published in 2008 (Lucke et al. 2008; Tooth et al. 2008). Lucke et al. report on a preliminary examination of the health service use and

access by women in rural and urban areas. Tooth et al. describe the effect of the type of impairment (cognitive versus physical) of care recipients on the level of burden and quality of life of elderly carers. The papers are in Appendix 11.1 and Appendix 11.2.

1.3 Aims of this report

This second report, Stage 2, Phase 2, is based on data from the older carers substudy and aims to address the following questions:

1. Carer needs:
 - a. What is the broad impact of caring on women's lives?
 - b. What needs, unmet or under met, can be identified for carers?
2. Intervention/services:
 - a. What types of interventions/services do carers use?
 - b. What patterns of health or community service use are demonstrated?
 - c. What information can be provided on access, information and perception of services that carers use?
 - d. What interventions/services lessen the impact of caring?
 - e. What carer support strategies and interventions assist or could assist employed carers?
 - f. What type/dose/timing of respite interventions are effective in maintaining a caring relationship for the different carer types and settings?

Chapter 2 Context

2.1 Methodology of the older carers substudy of the 1921-1926 cohort

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

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

Of the 305 returned completed surveys, 276 (91%) were from carers who lived with their care recipients, 4 (1%) were from carers who lived elsewhere and 25 (8%) were from carers whose recipients lived in care facilities. For this report, women who cared for someone living in a care facility were excluded from analysis because access to health and community services is not relevant to nursing home participants in the same way as for those living in the community. Therefore, there were data available from 280 women who cared for someone who may have used community services.

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

The survey consisted of 53 closed-response questions (some with open-ended components) and 5 open-ended questions (Appendix 11.3). Both the statistical analyses of the quantitative data (from the closed-response questions) and summaries of the text of the open-ended questions are presented in the report. The main themes of the responses from the open-ended questions are presented and direct quotes are provided as examples where relevant.

The survey was constructed in 14-point font and was written at a grade seven to eight reading level, consistent with the educational levels of Australian women now in their 70s and 80s. The survey content was informed by focus groups and pilot tested.

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

Carer activity index

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

To determine the intensity of caring activities performed by the carer, an index of caring activity for each carer was created by combining the responses to questions that asked whether the care recipient needed help with each activity (Questions 9-17) and how often the carer helped the recipient with the activity (Questions 9-17a; responses ranged from never to every day). (The IADL 'financial management' (Question 18) was not included in this index because the response options were not the same as for the other activities of daily living. In addition, this question would not have provided any additional information to this index because 92% of the carers responded similarly; the carers assisted the care recipients with financial management.)

Firstly, a score was created for each of the nine activities from the survey.

- If the care recipient did not need help with an activity, it was scored as zero.
- If the care recipient did need help with an activity, the score for that activity was determined from the response to item a (as outlined below).
- Questions 9-17 "a" items were scored so that a higher number indicated a higher caring intensity:
 - 0=never
 - 1=hardly ever
 - 2=a few times a month
 - 3=a few times a week
 - 4=every day.

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

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

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

For the current report, the following terminology is used:

Statistically significant — analyses where the associations or differences are statistically significant to the level of $p \leq 0.05$.

Trend / apparent differences — analyses where apparent trends exist. The absence of statistical significance may be due to the small sample size and does not mean that it is not potentially important.

2.2 Demographic profile of carers

The demographic profile of the carers by CAI is presented in Table 1. Of the 280 carers, 276 lived with their care recipients and four lived elsewhere. There were no apparent differences in carer age, marital status, residence, language spoken at home, education, volunteer work, ability to manage on income and health insurance by CAI. The mean age of carers was 78 years. Most carers were married, lived in a major city or inner regional area, spoke English at home, and had a school or intermediate certificate.

Due to the carers' ages, the carers were not likely to be in the labour force and questions about employment were not asked in the substudy's survey or the main ALSWH Survey 3. However, Survey 3 did ask about volunteer work for any community or social organisations. Approximately half of the carers (45%), regardless of CAI group, volunteered for a community or social organisation (Table 1).

Most carers also reported that it was 'not too bad' (55%) or it was 'easy' (25%) to manage on their available income.

Carers, regardless of CAI, were more likely to have private insurance for hospital services (50%) than for ancillary services (38%) or have health services coverage through the Department of Veterans' Affairs (18%).

The demographic profile of the carers in the older carers substudy did not differ from the ALSWH participants born between 1921 and 1926, except for marital status (Appendix 11.4). Nearly all of the women in the older carers substudy were married (92%). However, in the ALSWH, 44% of the women were married and 47% of them were widowed when surveyed in 2002. This difference is due to most of the older carers caring for their husbands.

Table 1 Demographic profile of carers, by CAI

	All Carers (n=280*)	Lower (n=93*)	CAI Middle (n=93*)	Higher (n=93*)
Age (years) [mean (SD)]	78.0 (1.5)	78.0 (1.5)	78.1 (1.5)	77.9 (1.4)
Marital status (%)				
Married	92	91	88	96
De facto	1	1	1	2
Divorced	1	0	2	0
Widowed	5	8	7	2
Never married	1	0	2	0
Residence** (%)				
Major city	40	37	39	44
Inner regional	41	44	45	35
Outer regional	18	18	14	20
Remote	1	1	1	1
Very remote	0	0	1	0
Language (%)				
English	97	97	98	96
Other	3	3	2	4
Education (%)				
No formal qualifications	20	22	15	24
School or intermediate certificate	46	50	45	44
Higher school or leaving certificate	13	13	12	14
Trade / apprenticeship	5	3	7	3
Certificate / diploma	12	7	19	10
University degree	3	5	2	2
University higher degree	1	0	0	3
Volunteer work (%)				
Every day	2	2	1	2
Every week	17	14	21	15
Every month	19	20	20	17
Less than once a month	7	8	8	7
Not at all	55	56	50	59
Manage on available income (%)				
It is impossible	0	0	1	0
It is difficult all the time	5	3	5	5
It is difficult some of the time	15	15	11	18
It is not too bad	55	56	53	57
It is easy	25	26	30	20
Insurance cover† (%)				
Veterans' Affairs cover	18	19	12	23
Private hospital insurance	50	47	56	48
Private ancillary insurance	34	32	38	33

* Actual sample sizes vary for each variable due to missing data.

** Areas of residence were based on the ARIA+ system, which is determined by remoteness based on the distance to the nearest service centre.

† Percentages do not add up to 100 as care recipients could have selected more than one response.

SD=standard deviation.

2.3 Demographic profile of care recipients

Care recipient information by CAI is presented in Table 2. The ages of the care recipients were similar across the CAI groups. There were no apparent differences in carer-care recipient relationship or length of time spent caring by CAI. Most carers cared for their husband/partner (91%). The length of time spent caring ranged from 3 months to 60 years with a median of 5 years.

The carers were asked to identify whether care recipients had the following: stroke, Parkinson's disease, Alzheimer's disease/dementia, multiple sclerosis, arthritis/rheumatism, heart disease or 'other.' The 'other' condition was the most reported condition, regardless of CAI. Some of the predominant 'other' responses included blindness, deafness, cancer, diabetes, posttraumatic stress disorder and depression.

More than half of the carers (55%), regardless of CAI, indicated that the care recipients had Department of Veterans' Affairs coverage for health services while only 29% of recipients had private insurance for hospital services or 17% for ancillary services.

In a paper that was published from the same survey data, the carers were classified by whether they cared for someone with cognitive or physical impairment or both (Tooth et al. 2008; see Appendix 11.2). They classified care recipients as follows: 31% primarily had physical impairment, 9% primarily had cognitive impairment and the majority had both physical and cognitive impairment (58%).

Table 2 Care recipient information, by CAI

	All carers (n=280*)	CAI of carer		
		Lower (n=93*)	Middle (n=93*)	Higher (n=93*)
Age of care receiver (years)	83.0	82.0	83.0	84.0
[median (quartiles)]	(80.0, 86.0)	(79.0, 85.0)	(80.0, 86.0)	(82.0, 87.0)
Length of time caring (years)	5.0	5.0	5.0	5.0
[median (quartiles)]	(3.0, 10.0)	(3.0, 10.0)	(3.0, 10.0)	(3.0, 10.0)
Carer-care recipient relationship (%)				
Husband / partner	91	89	88	96
Brother / sister	2	1	2	1
Son / daughter	6	9	8	2
Other	1	1	2	1
Condition** (%)				
Stroke	26	19	22	37
Parkinson's disease	8	5	4	14
Alzheimer's disease / dementia	19	16	15	24
Multiple sclerosis	0	0	0	1
Arthritis / rheumatism	44	44	45	42
Lung / breathing problems	29	21	30	35
Heart disease	45	48	42	45
Other	61	57	62	65
Insurance cover** (%)				
Veterans' Affairs cover	55	52	54	58
Private hospital insurance	29	31	30	25
Private ancillary insurance	17	16	19	15

*Actual sample sizes vary for each variable due to missing data.

** Percentages do not add up to 100 as care recipients could have selected more than one response.

Chapter 3 Carer needs

3.1 Impact of caring

The carers were asked a series of questions in order to understand the impact of caring on their lives. These questions included the following variables, which were based on responses to individual questions or a series of questions as part of a scale:

- Overall effect of caring (Question 56)
- Health-related quality of life: mental and physical health (Questions 28-38)
- Carer strain (Question 55)
- Carer burden—developmental burden (Question 57)
- Social support: social interaction and satisfaction with social support (Questions 45-54)
- The ‘good’ and ‘not so good’ aspects of caring: written comments (Question 58)

The quantitative impact of caring variables are presented in Table 3. The open-ended responses to Question 58 are presented in Section 3.2 by discussing the main themes present in the written comments from all carers. Direct quotes are provided as examples where relevant.

3.1.1 Overall effect of caring

In Question 56 of the survey, carers were asked whether their lives were ‘a lot worse’, ‘a little worse’, ‘neither better or worse’, ‘a little better’ or ‘a lot better’ from caring. Most carers responded that they either felt ‘neither better or worse’ (41%) or that their lives were ‘a little worse’ (37%) rather than that their lives were positively affected by caring or ‘a lot worse’. However, carers with a lower CAI were statistically significantly more likely to report that their lives were ‘neither better or worse’ (52%) compared to carers with a middle (42%) or higher (30%) CAI. In addition, carers with a higher CAI were statistically significantly more likely to report that their lives were a lot worse (17%) than were carers with a lower (7%) or middle (3%) CAI.

3.1.2 Health-related quality of life

Health-related quality of life was measured by the Medical Outcomes Study Short Form 36 using the two component summary scores representing physical and mental health (Ware et al. 1993). Higher scores indicate better quality of life. There were no apparent differences in mental or physical health across the CAI groups.

The Medical Outcomes Study Short Form 36 was also used in Survey 3 (2002) for the 1921-1926 cohort of the ALSWH. The 1921-1926 cohort of the ALSWH (n=8418) had a mean mental health component score of 51.4 and a mean physical health component score of 48.0, indicating that the substudy’s carers had statistically significantly poorer mental and physical health compared to the entire 1921-1926 cohort.

3.1.3 Carer strain

The Caregiver Strain Index was included in the current survey to measure carer strain and the impact of caring on women’s lives. Scores range from 0 to 13 with a higher score indicating more strain (Robinson 1983). Carers with a higher or middle CAI reported statistically significantly more strain than did carers with a lower CAI.

Table 3 Impact of caring variables, by CAI

	All carers (n=280*)	Lower (n=93*)	CAI Middle (n=93*)	Higher (n=93*)
Overall impact of caring (%)				
A lot better	6	6	6	8
A little better	7	4	4	11
Neither better or worse	41	52	42	30
A little worse	37	31	45	34
A lot worse	9	7	3	17
Mental health component score [Mean (SD)]	46.9 (10.4)	47.9 (9.6)	46.5 (11.1)	46.5 (10.6)
Physical health component score [Mean (SD)]	46.4 (9.0)	47.3 (8.6)	46.8 (8.0)	45.3 (10.3)
Carer strain [Mean (SD)]	4.2 (2.7)	3.1 (2.6)	4.5 (2.5)	5.0 (2.8)
Developmental burden [Mean (SD)]	5.3 (4.2)	3.8 (4.0)	6.3 (4.5)	5.6 (3.6)
Social interaction [Mean (SD)]	8.8 (1.4)	8.8 (1.3)	8.9(1.4)	8.8 (1.5)
Satisfaction with support (%)				
Satisfied	81	83	78	82
Dissatisfied	19	17	22	18

*Actual sample sizes vary for each variable due to missing data.
SD=standard deviation.

3.1.4 Carer burden—developmental burden

Developmental burden was measured by the Caregiver Burden Inventory (Novak & Guest 1989). Developmental burden describes carers' feelings of being 'out of sync' in their development with respect to their peers. Items included "I expected things would be different at this point in my life" and the scale scores range from 0 to 20 with a higher score indicating more developmental burden. In the current sample, carers with a higher or middle CAI reported statistically significantly more developmental burden than did carers with a lower CAI.

3.1.5 Social support

Two subscales of the Duke Social Support Index, social interaction and satisfaction with social support, were used to measure social support in the current study (Powers, Goodger & Byles 2004). Social interaction measured the size and structure of the carers' social network, with scores ranging from 4 to 12. Higher scores indicated more social interaction. There were no apparent differences in social interaction across the CAI groups.

Satisfaction with support measured the perceived satisfaction with the behavioural or emotional support obtained from the social network. Answers were grouped into two categories: satisfied or not satisfied. Most carers, regardless of CAI, were satisfied with their social support network (81%).

3.2 The 'good' and 'not so good' aspects of caring: written comments

There were five open-ended questions in the survey. In one the participants could have written three 'good' and three 'not so good' aspects of caring. Five themes emerged from the data regarding positive and negative aspects of caring: 1) characteristics of the relationship between the carer and care recipient, 2) the personal concerns or attitudes of the carer, 3) characteristics of the care recipient, 4) support provided by family, friends or formal services and 5) the practicalities of the caring situation.

3.2.1 The 'good' aspects of caring

Among the carers, 241 provided 528 responses about the 'good' aspects of caring. Characteristics of the relationship (mentioned by 53% of the carers) and personal concerns or attitudes of the carer (mentioned by 52% of the carers) were the themes most commonly raised. Characteristics of the relationship included companionship, being able to share activities together, longevity of marriage, love, closeness and reciprocity within the relationship. The women most frequently discussed the joy of having companionship with their lifetime partner, often citing the number of years they and their spouse had been together; *'[I'm] so happy to still have him around, with his lovely smile, and that's after 53 years of wedded bliss.'*

Personal concerns or attitudes of the carer referred to the women's outlook on life, providing care, coping and religious beliefs. Some carers took the worldview approach to their situation, commenting on how good their life was, though others may have perceived it as unfortunate. Adopting an optimistic outlook, these women had come to *'[a]ppreciate one's own blessings.'*

The remaining three themes (characteristics of the care recipient, support provided by family, friends or formal services, and practicalities of the caring situation) occurred with roughly equal frequency. Characteristics of the care recipient (mentioned by 37% of the carers) were discussed in terms of endearing personal characteristics, positive aspects of their physical and mental health and the gratitude expressed by the care recipient. The carers cited various facets of their partner's personality that endeared him to her and made the situation easier. These characteristics may have endured from the period before the spouse required assistance; *'[h]is nice nature has not changed.'* Alternatively they may have arisen out of their current situation:

'Since his stroke in March '03 he has become very quiet and gentle, lost a lot of his aggression. Constantly praises me and speaks of his love for me, which didn't always come easily to him in earlier times.'

The support provided by family, friends and formal services (mentioned by 34% of the carers) encompassed the closeness and backing of family and friends that provided reassurance that these women were not alone. As one woman caring for her son wrote, being blessed with a *'loving[,] caring family – helps a lot.'* It also encompassed the helpfulness of the community at large and satisfaction with medical, allied health care and other formal services. These supports were personal motivators who *'help[ed] keep [the carers'] spirits up.'* Allied health care services, the Department of Veterans' Affairs, medical services, friends and neighbours were also mentioned.

Practicalities of the situation (mentioned by 32% of the carers) involved living arrangements, finances, leisure time, having a car and personal gain through enhancing skills or personal qualities such as patience. A number of women were appreciative of being able to take care of their husbands within their own homes:

'Leading as normal a life as possible, together. Visiting someone in hospital rehab, nursing home seems very different from sharing a life together, enjoying our children's visits, etc.'

3.2.2 The 'not so good' aspects of caring

Among the carers, 227 provided 465 responses about the '*not so good*' aspects of caring. When reporting the '*not so good*' aspects of caring, the practicalities of the situation were by far the most discussed (mentioned by 79% of the carers). Characteristics of the relationship (mentioned by 47% of the carers) and personal concerns or attitudes of the carer (mentioned by 42% of the carers) were mentioned to similar extents, while support provided by family, friends or formal services (mentioned by 16% of the carers), and characteristics of the relationship (mentioned by 15% of the carers) were least frequently cited.

About four of every five responses written under the '*not so good*' column related to practicalities of the situation. Practicalities of the situation covered an extensive range of topics with regard to difficulties of caring. These included restrictions on everyday life, such as engaging in personal activities or maintaining a social life; the physical burden of caring, including coping with continual demands; greater responsibility for driving, finances, household chores and decision making; lack of holidays and travel; being fatigued or having sleep interrupted; dissatisfaction with the present situation, which involved living arrangements, experiencing adverse events or being tied to the caring role; lack of personal time; and dissatisfaction with repetitious routine. Restrictions on everyday living were the inconveniences most often cited:

The social side of your life is diminished; my husband cannot enjoy the many things we did together. His blindness prevents his playing golf and enjoying men's company whereby I had my own space with him away.'

Characteristics of the care recipient encompassed their health, abilities and personal characteristics. Carers often wrote about specific features of their spouse or care recipient that made the caring experience more difficult. Also important were features of the care recipients' personalities that were seen to be counterproductive: '*I find it hard to "keep my cool" in the face of constant ill humour and total negativity.'*

Personal concerns or attitudes of the carer referred to feelings of being in a helpless situation; experience of stress, sadness and frustration; and concerns about ageing, health and the future. A number of carers discussed the helplessness, frustration and pain of watching someone they care about endure hardship: '*[h]is deterioration is very slow, but very sure...all of which weighed heavily on my heart...'*

The support provided by family, friends and formal services again covered lack of support or proximity to family; loss of friends; dissatisfaction with medical, allied health care and other public services; and lack of community empathy. While some carers were fortunate enough to be able to call on the support of family and friends, others did not enjoy the same position. They detailed how children, now grown up, no longer lived nearby; others lamented about the difficulty of arranging visits or the absence of family assistance; '*[l]ack of family support...We are financially independent but I would appreciate moral support.'*

When referring to negative characteristics of the relationship, the women wrote about lack of communication or companionship. For many, their relationship with the care

recipient was a source of comfort; this was not universally the case, however. A number of women specifically referred to the deterioration in their relationship, which had occurred after caring began: *'due to my husband's inability to speak, we could not converse. This caused, me especially, sadness as all of our lives we had been very close to one another.'*

Summarising the written comments, restrictions to the carer's personal activities and space were the most frequently cited negative aspects of caring. What is also apparent is the benefit of a positive relationship between the carer and care recipient for the carer's satisfaction and motivation to fulfil the caring role.

3.3 Needs, unmet or undermet, of carers

The needs of carers were determined through several questions in the survey. Carers were asked whether they had a major medical condition or disability, whether the carer needed help with her own daily tasks and whether the carer was satisfied with the help she received. In addition, the carers were asked if 'help was needed, but not provided' for the nine activities of daily living included in the survey (Questions 9-17). The carers were also provided an opportunity to write their responses to 'Are there any services you or the person you care for want, but are not getting?' (Question 25). While the responses to these questions may be directed more toward the needs of the care recipients, unfulfilled needs of the care recipients still may affect the carers and the duties required of them.

Nearly all of the carers (98%) reported having at least one major medical condition or disability, but only 23% of them said that they needed help with their own daily tasks, and of these, 95% were satisfied with the help they received (Table 4). The carers indicated in their written comments that they mainly received help with domestic home care, such as cleaning, gardening, repairs (83% of carers) or transportation (10% of carers), and this help was mostly provided by a service provider (32% of carers), family (29% of carers), local councils (13% of carers) or they were paid for privately (10% of carers). One carer noted that her husband received the service, but that she also benefitted from it: *'As described for my husband - under VA the help I receive for him - which has only been in the past 2 months, has been a wonderful help to me.'*

Table 4 Carers' needs, by CAI

	All Carers (n=280*) (%)	Lower (n=93*) (%)	CAI Middle (n=93*) (%)	Higher (n=93*) (%)
Has medical condition / disability				
Yes	98	100	99	96
No	2	0	1	4
Needs help with daily tasks				
Yes	23	25	20	23
No	77	75	80	77
Satisfied with help received				
Very satisfied	45	40	46	48
Satisfied	50	53	50	48
Dissatisfied	4	7	4	2
Very dissatisfied	1	0	0	2

*Actual sample sizes vary for each variable due to missing data.

Care recipient needs score: the help received or needed by the care recipients

Similar to the CAI, a score was also created for the care recipients to indicate their needs (i.e. the help they received or the help that was needed, but not provided) for the nine activities of daily living. In addition to asking how much help was provided by the carer who completed the survey (item a), the carers were asked how much help was provided by another unpaid carer (item b), a paid service (item c) and how often help was needed but not provided (item d) in Questions 9-17. All items were scored so that a higher number indicated more frequent help received (items a, b and c) or needed (item d).

A total score was created by adding the four item scores for each activity. The total score, the Care Recipient Needs Score, represents the overall need of the care recipients for each activity and takes into account the needs that are being provided (items a, b and c) and those that still need to be provided (item d). The scores themselves are not meaningful; however, they were used to rank the care recipients' needs between services and compare the types of help provided.

The care recipient needs scores are presented in descending order in Figure 1 and indicate that the care recipients needed help with washing, dressing and grooming the most and needed help with eating or drinking the least. The item scores indicated the following:

- The participant/carer most frequently helped with preparing meals and least frequently helped with eating or drinking.
- Other unpaid carers provided help most often with transportation and least often with eating or drinking or toileting.
- Paid services were employed most for washing, dressing and grooming and least for eating or drinking.
- Washing, dressing and grooming was the most reported item for which help was needed but not provided.

The care recipients received the most help from the carer who completed the survey compared to the other sources of help. Other unpaid carers did help with the needs of the care recipients, but not nearly to the extent of the participant carers. In general, the participant carer, other unpaid carers and paid services accounted for most of the care recipient need for each activity.

The percentages of carers who reported that 'help was needed but not provided' for each of the nine activities of daily living ranged from 17% for eating or drinking to 38% for washing, dressing and grooming. However, the pattern of responses differed when the carers wrote their responses to 'Are there any services you or the person who care for want, but are not getting?' In the responses provided, household management, transportation and recreation were the three most frequently reported services that the carers or their recipients wanted but were not getting. Specific home care services that were identified included garden maintenance, repairs, lawn maintenance, rubbish removal, window cleaning and house cleaning.

The difference in the pattern of responses between the closed and open-ended questions may simply be due to the order of the questions. The carers answered the closed questions on activities of daily living before they wrote their responses to the open-ended question. Some of the carers may have felt that they provided sufficient

information on services that were 'needed but not provided' within the activities of daily living questions and did not repeat themselves in written responses.

Additional information on unmet or undermet needs is presented by service in Chapters 4 to 7.

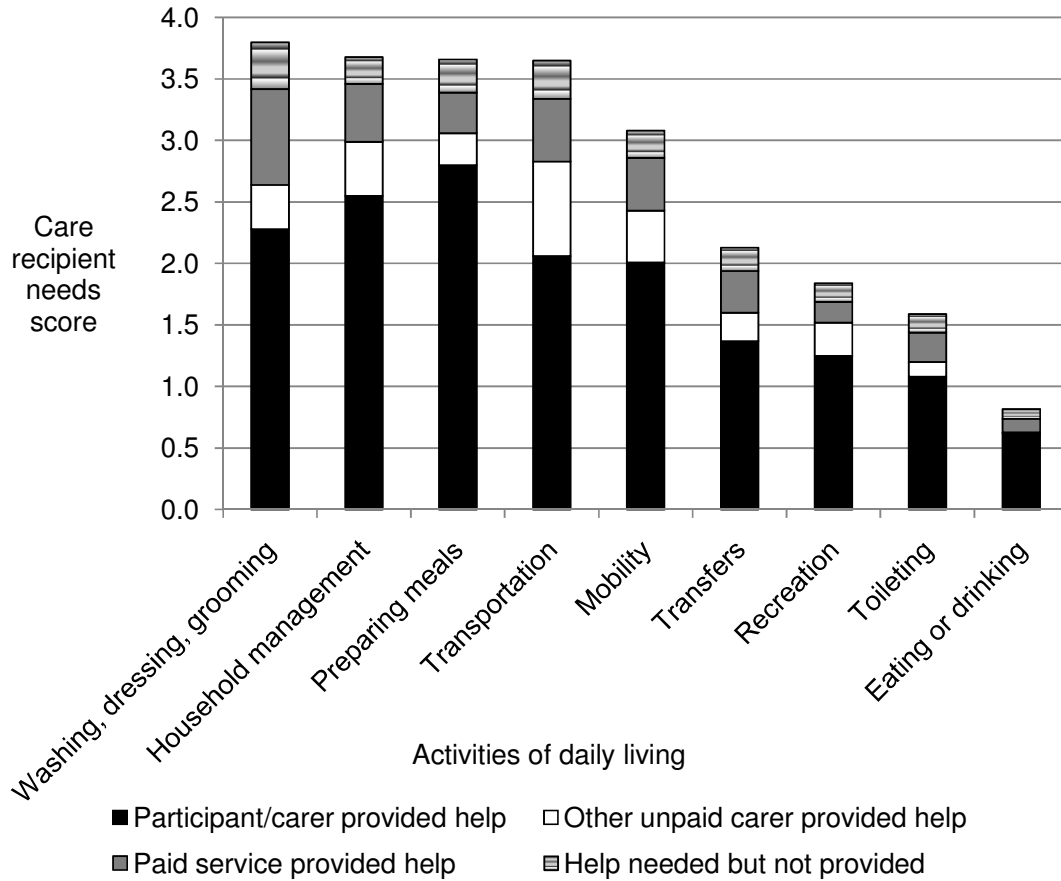


Figure 1 The proportion that each source of help contributed to the total need of care recipients for each activity

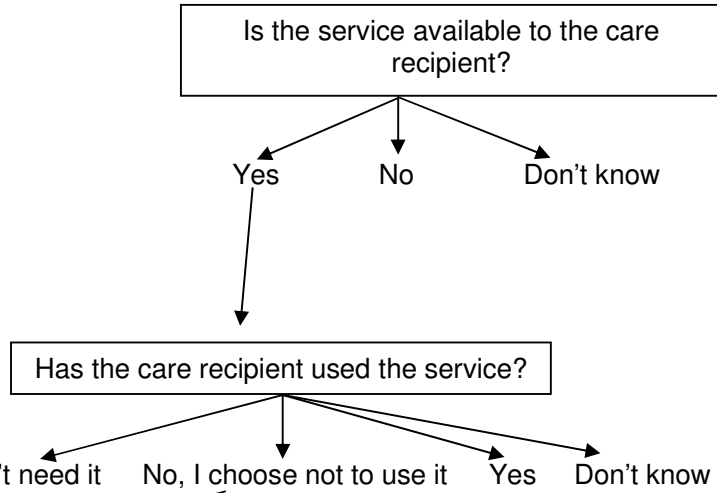
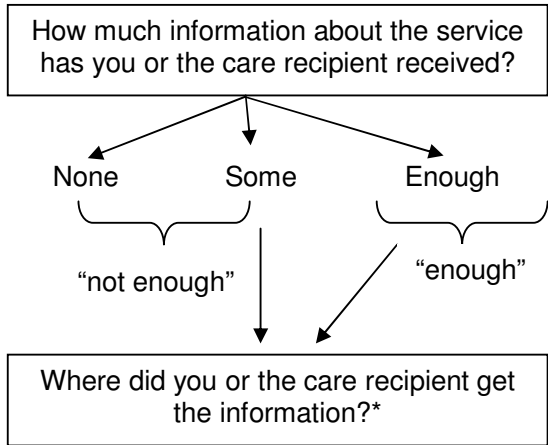
All carers answered questions about the information, availability and use of four services (Meals on Wheels, personal home care, domestic home care and respite care). For each highlighted service, the carers were asked a series of questions and depending on their answers to each item, they were then directed to the next relevant item. Figure 2 shows the progression of the questions asked for each service. The following four chapters (Chapters 4-7) present information by each service. In each chapter, the results from each question are presented in the same order as they were asked in the survey. Quantitative data, by CAI, as well as themes discussed in the written responses for all carers are presented.

Missing data

Missing data occur because respondents skip pages, questions and items unintentionally or because they do not think the items are relevant to them. This is particularly relevant to the service use questions because of the structure of the section in the survey. For instance, in the current survey, 144 carers indicated that respite care was available to them. These 144 carers should have then answered if they had used the service. However, only 99 carers answered the service use question.

Therefore, for each question in the four service chapters, the percentages presented are based on the number of carers who responded to that particular question.

Please refer to Appendix 11.5 for the sample sizes and frequency of responses to each question for all carers.



Can you explain why you chose not to use this service?*

Yes, the care recipient used the service (continuing onto page 25)

Chapter 4 Use of Meals on Wheels

All carers responded to questions about Meals on Wheels, which were introduced by the following statement: 'These questions are about Meals on Wheels or other services delivering meals to your home.'

4.1 Information

All carers reported on the amount of information they received about Meals on Wheels and whether the service was available. Half of the carers (50%) reported that they received enough information and there was no apparent relationship between this and CAI group.

Those carers who had received information on Meals on Wheels were asked to write where they had received the information. About one-third of the carers (n=106) provided 133 responses. Carers mainly received Meals on Wheels information from medical professionals, such as doctors, specialists or nurses, or from hospitals (31% of the carers). Service providers, such as the Department of Veterans' Affairs, were the second most frequently discussed source of information (25% of the carers). In addition, quite a few women had volunteered for Meals on Wheels prior to needing the service themselves (21% of the carers). Local councils (13% of the carers) and friends (9% of the carers) also provided information about Meals on Wheels.

4.2 Availability

There was no apparent relationship between service availability and CAI. A high proportion of all carers (38%), regardless of CAI, did not know if Meals on Wheels was available or reported that the service was not available.

The percentage of carers who reported that Meals on Wheels was not available or did not know if it was (dark grey) compared to the percentage of carers who reported that the service was available (light grey and thatched areas) are presented in Figure 3 for each CAI. Of those carers who reported the service was available, the thatched area indicates the percentage of carers who used the service.

4.3 Use

Those carers who reported that the service was available indicated whether they had used the service. Of those carers who answered the question 'have you used Meals on Wheels?' more than two-thirds (71%) reported that they had used the service, again with no apparent relationship between use and CAI.

Twenty-one carers wrote 24 explanations for why they chose not to use the service. Nearly half of the carers (43%) indicated that the care recipients had dietary needs (poor appetite, liquid diet, allergies) which could not be met by Meals on Wheels. The comments were positive about the service delivery itself (19% of the carers), but 14% of the carers wrote that the food was not satisfactory. Six responses (29% of the carers) indicated that the carer or care recipient made other arrangements, such as receiving cooking help in the home or taking meals at a senior citizens' centre. The remaining two responses (10% of the carers) indicated that their distance from town or the cost of the service were too prohibitive.

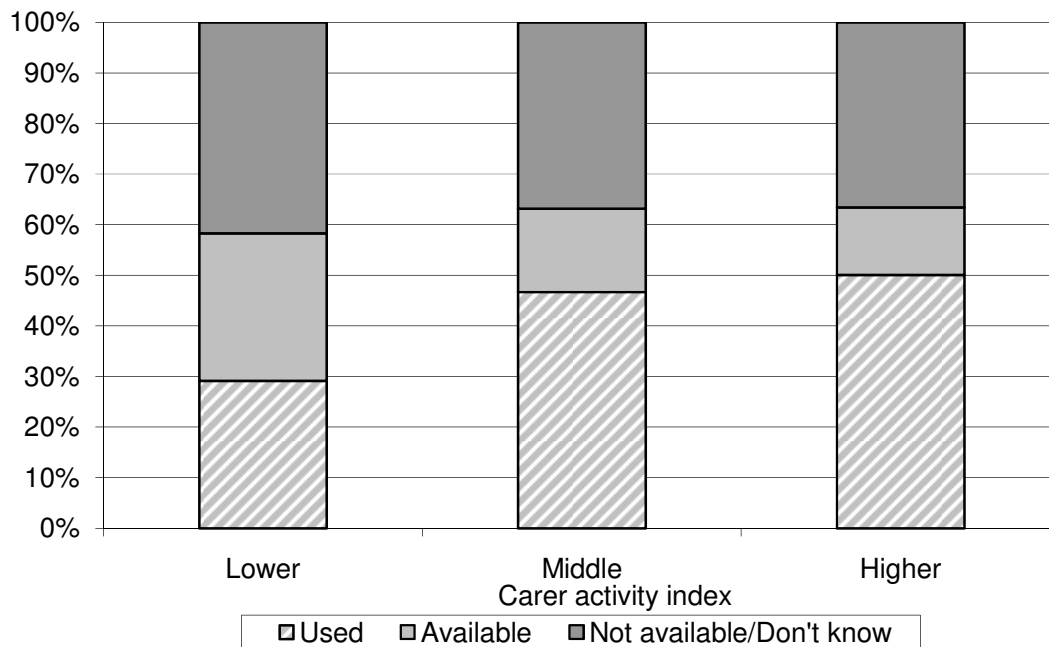


Figure 3 Availability and use of Meals on Wheels for each CAI group

4.4 Accessibility, duration of wait to receive service, frequency and quality

Those carers who reported that they used Meals on Wheels then reported on ease of access, how long it took the service to start after requesting it, how often they used the service, how often they would like to have used the service and the quality of the service. These results are presented by CAI group in Table 5.

- Most carers (97%), regardless of CAI, found that Meals on Wheels was easy to access.
- All carers reported receiving the Meals on Wheels in less than 4 weeks after requesting it with most carers, regardless of CAI, waiting less than 2 weeks (86%). Carers with a middle CAI were more likely to not know how long they waited for the service to start than carers with a lower or higher CAI.
- There was no apparent pattern between the frequency with which the carer received Meals on Wheels and the CAI groups.
- Carers, regardless of CAI, typically wanted to receive Meals on Wheels several days per week or less often rather than every day.
- When comparing the amount of Meals on Wheels services received and wanted, 85% of the carers reported that they received the service as often as they wanted. However, 15% of the carers reported that they received the service more frequently than they wanted. Carers with a lower CAI were more likely to report that they received Meals on Wheels more often than they wanted than carers with a middle or higher CAI.

- Carers with a middle CAI were less likely to rate Meals on Wheels as having a good quality than carers with lower or higher CAIs.

Table 5 Percentages of responses to each quantitative question for those carers who used Meals on Wheels

	All carers (%)	Lower CAI (%)	Middle CAI (%)	Higher CAI (%)
How easy was it to get the service?				
Easy	97	100	100	93
Difficult	3	0	0	7
After requesting it, how long did it take to receive the service?				
Less than 2 weeks	86	100	75	94
2-4 weeks	3	0	6	0
More than 4 weeks	0	0	0	0
Don't know	11	0	19	6
How often do you receive the service?				
Every day	19	0	38	9
Several days per week	57	100	37	64
Once a week or less often	24	0	25	27
How often would you like to receive the service?				
Every day	15	0	25	10
Several days per week	45	50	38	50
Once a week or less often	40	50	37	40
How would you rate the quality of the service?				
Good quality	77	100	55	85
Poor quality	23	0	45	15

In the final question in the series, the carers were asked to write whether they had any comments or complaints about the Meals on Wheels service. The themes found in these responses were similar to those found in the responses to 'why the carers chose not to use the service.' Twenty-two carers provided 40 responses which were generally positive (39% of the carers) rather than negative (25% of the carers). Four comments (14% of the carers) indicated that the service delivery was flexible and adaptable to varying circumstances, while two comments (7% of the carers) mentioned that the service was not available on the weekends or the food arrived too late for her diabetic husband. No comments dealt with positive aspects of the food, but there were five comments (18% of the carers) that the food did not meet cultural needs, was too similar to hospital food, was bland or too seasoned or was generally not appetising.

Eight carers (36%) indicated that their use of the service was short term due to illness or surgery that prevented them from preparing the meals for their care recipient.

Chapter 5 Use of personal home care

All carers responded to questions about personal home care which were introduced by the following statement: 'These questions are about personal home care eg assistance with self care (bathing, dressing) and nursing care (wound care, continence) by someone paid to do this.'

5.1 Information

All carers reported on the amount of information they received about personal home care and whether the service was available. On average, 36% of carers reported that they had not received enough information while 64% had received enough information. Carers with a higher CAI (75%) were statistically significantly more likely to have received enough information than carers with a lower (57%) or middle (60%) CAI.

Those carers who had received information on personal home care were asked to write where they had received the information. The carers (n=172) provided 210 responses. Similar to Meals on Wheels, carers mainly received personal home care information from medical professionals (51% of carers) or from service providers (47% of the carers). Local councils (10% of the carers) and carers' associations and support groups (8% of the carers) also provided information on personal home care.

5.2 Availability

In general, 68% of carers reported that personal home care was available and the remaining 32% did not know if the service was available or reported that it was not available. The likelihood of reporting that personal home care was available statistically significantly increased with CAI: carers with a higher CAI (81%) were more likely to report that personal home care was available than carers with a lower (56%) or middle (65%) CAI.

The percentage of carers who reported that personal home care was not available or did not know if it was (dark grey) compared to the percentage of carers who reported that the service was available (light grey and thatched areas) are presented in Figure 4 for each CAI. Of those carers who reported the service was available, the thatched area indicates the percentage of carers who used the service.

5.3 Use

Those carers who reported that the service was available indicated whether they had used the service. Of those carers who answered the question 'have you used personal home care?' most (86%) reported that they had used the service. There was no apparent relationship between use and CAI.

Twenty-three carers wrote 25 explanations for why they chose not to use the service. The most frequently discussed theme was that the carers and their recipients could manage on their own (43% of the carers) and several particularly indicated that they would do this as long as they could manage: *'I felt I would like to look after my husband myself while I could and to save him embarrassment.'* Care recipient preference (26% of carers) and carer preference (22% of the carers) were also discussed in the written comments. One carer indicated that the care recipient *'[didn't] want strangers seeing*

[him] in the shower” while another referred to the care recipient not being happy to have strangers in the house.

Care recipient preference may have also coincided with carer preference. Two carers noted that they and their care recipient preferred to remain independent and do as much for themselves as possible. In addition, one carer chose not to use personal home care because she preferred ‘to care for [her] husband [her]self.’

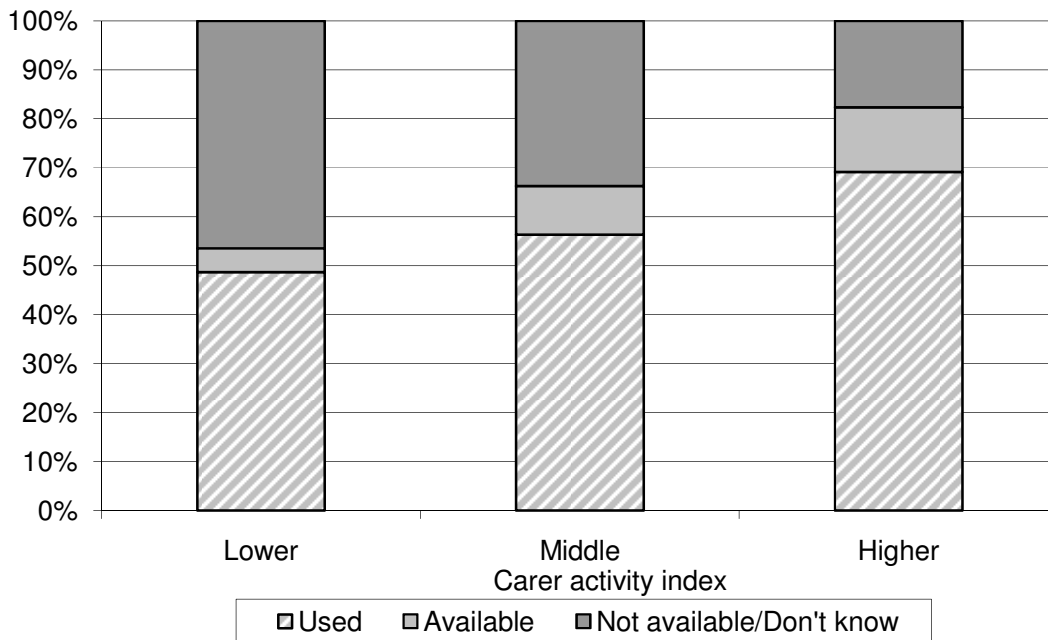


Figure 4 Availability and use of personal home care for each CAI group

5.4 Accessibility, duration of wait to receive service, frequency and quality

Those carers who reported that they used personal home care then reported on ease of access, how long it took the service to start after requesting it, how often they used the service, how often they would like to have used the service and the quality of the service. These results are presented by CAI group in Table 6.

- Most carers (94%), regardless of CAI, found that personal home care was easy to access.
- There were no apparent differences between the CAI groups and how long the carer waited to receive personal home care after requesting it. In general, most carers (76%) reported receiving the service in less than 2 weeks and a minority of carers received the service within 2-4 weeks (12%), more than 4 weeks (1%), or did not know how long it took the service to start (11%). All CAI groups showed a similar pattern.

- Carers generally received, and preferred to receive, personal home care several days a week or less often. Carers with a lower CAI received, and preferred to receive, personal home care less often than carers with a middle or higher CAI.
- Out of 66 carers who reported their current and preferred frequencies of receiving personal home care, 57 (86%) reported that they received the service as often as they wanted. Only 1 carer (2%) reported that she received the service more often than she wanted, and 8 of the carers (12%) received the service less often than they wanted. Carers with a higher CAI were more likely to report that they received personal home care less frequently than they wanted than carers with a lower or middle CAI.
- Most carers (95%), regardless of CAI, reported that the quality of the service was good.

Table 6 Percentages of responses to each quantitative question for those carers who used personal home care

	All carers (%)	Lower CAI (%)	Middle CAI (%)	Higher CAI (%)
How easy was it to get the service?				
Easy	94	94	100	92
Difficult	6	6	0	8
After requesting it, how long did it take to receive the service?				
Less than 2 weeks	76	86	79	72
2-4 weeks	12	7	13	13
More than 4 weeks	1	0	0	2
Don't know	11	7	8	13
How often do you receive the service?				
Every day	14	9	19	13
Several days per week	58	27	57	65
Once a week or less often	28	64	24	22
How often would you like to receive the service?				
Every day	19	9	13	25
Several days per week	58	27	62	65
Once a week or less often	23	64	25	10
How would you rate the quality of the service?				
Good quality	95	94	95	96
Poor quality	5	6	5	4

In the final question in the series, the carers were asked to write whether they had any comments or complaints about the personal home care service. There were more positive comments (60% of the carers) than negative comments (18% of the carers) from the 50 carers who provided 82 responses. Twelve percent of the carers specifically discussed the help the service provided to them or the care recipient. A carer said *'It has saved my husband's life and has been a great mental and physical help for me.'* Another carer indicated that personal home care improved her husband's attitude and gave her a break:

'The great advantage of this young woman who comes for 3/4 hr. ie. 7:15 - 8am, is that my husband enjoys her visit, puts on special behavior patterns, tells her stories about his life and comes out for breakfast, dressed, rubbed, and happy, instead of only having me and telling me how painful every joint is on that particular day--also I can cook the porridge in peace, put on the washing and do my chores.'

Carers (14%) also expressed difficulties with the continuity of service. Continuity problems included personal home care staff changing regularly as well as a lack of continuity in the skills across the staff. The carers also indicated problems with scheduling appointments (staff were overworked and did not have appropriate availability) or staff missed appointment times by several hours or completely:

'The service provided by XX Nursing Agency has been sensitive, professional and reliable, but because of rosters, pressure of work, emergencies, etc a 1pm appointment time becomes a waiting time of up to two hours.'

One carer also noted that the *'time of day is not always convenient (can be any time early or very late so often I have bathed him when they arrive especially if bed is wet).'*

Chapter 6 Use of domestic home care

All carers responded to questions about domestic home care which were introduced by the following statement: 'These questions are about domestic home care such as cleaning, ironing, shopping or gardening by someone paid to do this (that is, home help not including nursing care).'

6.1 Information

All carers reported on the amount of information they received about domestic home care and whether the service was available. On average, 37% of carers reported that they had not received enough information and 63% had received enough information. Carers with a higher CAI (72%) were more likely to have received enough information than carers with a lower (58%) or middle (60%) CAI.

Those carers who had received information on domestic home care were asked to write where they had received the information. The carers (n=169) provided 200 responses. Over half of these carers (56%) indicated that they received information on domestic home care from service providers. Providers that were named included the Department of Veterans' Affairs, non-governmental services and community health programs. Approximately one-quarter of the carers (26%) indicated that medical professionals (including doctors, nurses or hospitals) provided information while 15% of the carers reported that local councils provided them with information. The remaining responses varied and indicated that support groups, carers' associations and friends or family also provided information on domestic home care.

6.2 Availability

There was no apparent relationship between service availability and CAI, with most carers (67%) reporting that domestic home care was available.

The percentage of carers who reported that domestic home care was not available or did not know if it was (dark grey) compared to the percentage of carers who reported that the service was available (light grey and thatched areas) are presented in Figure 5 for each CAI. Of those carers who reported the service was available, the thatched area indicates the percentage of carers who used the service.

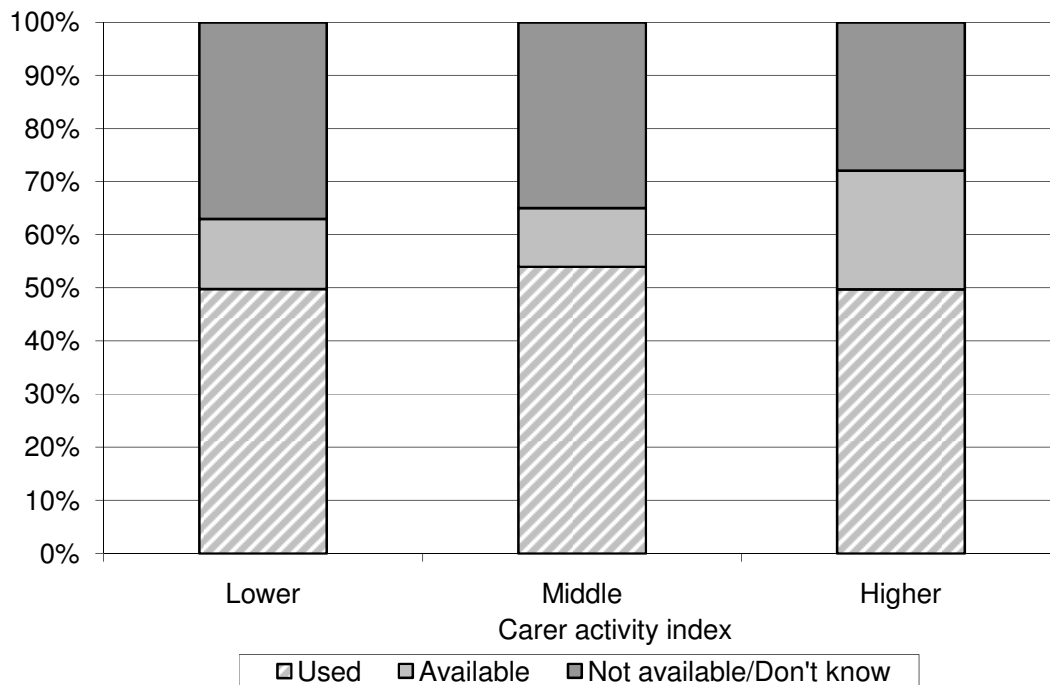


Figure 5 Availability and use of domestic home care for each CAI group

6.3 Use

Those carers who reported that the service was available indicated whether they had used the service. Of those carers who answered the question 'have you used domestic home care?' 76% reported that they had used the service with no apparent relationship between use and CAI.

Over one-third (38%; n=18) of all the carers who wrote a response for why they chose not to use the service (n=47), indicated that they *did* use a domestic home care service. It may be that these carers chose not to use a particular service, but did chose to use other domestic home care services. Twelve of these 18 carers (26% of all the carers) specifically indicated that they paid for the service privately. Fourteen of these 18 carers (29% of all the carers) also specified that they received help with cleaning, gardening or cooking.

The remaining 62% of the carers explained why they chose not to use the service. The most frequent response (23% of the carers) was that the carer was capable of completing the domestic duties. It may be that if a carer could manage, her preference was to do so and therefore not deal with external services. Several carers indicated that completing the domestic duties was their or the care recipients' preference (13% of the carers). This preference may have been because the carer or recipient preferred to have familiar people in the house; 9% of the carers indicated that family or friends helped. One carer indicated that having strangers in the house would not have been suitable:

'Can do housework myself. The anxiety caused by someone in the house cleaning or using a vacuum cleaner when [care recipient] has a headache or is sleeping, (which is a lot of the day) would not be the best idea.'

This carer was also the only carer to indicate that she could not afford a particular service (gardening) for which she would like assistance.

Five carers (11%) also indicated that they would like to use the service, but could not because of availability problems. Only 2 carers (4%) indicated they did not use domestic home care because they were not satisfied with the service that they received.

6.4 Accessibility, duration of wait to receive service, frequency and quality

Those carers who reported that they used domestic home care then reported on ease of access, how long it took the service to start after requesting it, how often they used the service, how often they would like to have used the service and the quality of the service. These results are presented by CAI group in Table 7.

- Most carers (82%) found that domestic home care was easy to access. Carers with a lower CAI were least likely to report that the service was easy to access (72%) while carers with a higher CAI were most likely to report that the service was easy to access (87%). This may reflect the needs-based service sector in which those carers/recipients with greater needs are more likely to receive the service.
- There were no apparent differences between the CAI groups and how long the carer waited to receive domestic home care after requesting it. Generally, most carers, regardless of CAI, received the service within 2 weeks of requesting it. However, carers with a higher CAI were more likely to receive the service more quickly than carers with a middle or lower CAI.
- There was no apparent pattern between the frequency with which the carer received domestic home care and the CAI groups. The majority of carers (95%) received domestic home care once a week or less often.
- Similarly, most carers (84%), regardless of CAI, reported that they wanted to receive the service once a week or less often.
- When comparing the amount of domestic home care received and wanted, most carers (91%) received the service as often as they wanted while 9% of carers received the service less frequently than wanted.
- Approximately three-quarters of all the carers (76%), regardless of CAI, indicated that domestic home care service was of a good quality.

In the final question in the series, the carers were asked to write whether they had any comments or complaints about the domestic home care service. The carers (n=58) provided 83 responses. The comments typically provided clarification of what type of service they received or how frequently they received it (43% of the carers). More of the responses were positive (48% of the carers) rather than negative (29% of the carers). The positive comments commended the quality of service or espoused the virtues of reliable, competent service staff. However, many of these same comments also expressed that some of the service staff that they received were not reliable or helpful: *'some carers are excellent others could not care less'*. This dichotomy emphasizes the need to find a suitable match for each caring situation.

Carers also expressed concerns that the service was restricted (12% of the carers). Restrictions included no availability for rescheduling or emergency services and service staff could not perform some duties (heavy lifting, reaching high places). The carers also mentioned that they would like the frequency of service provision to increase to cover similar additional tasks.

Table 7 Percentages of responses to each quantitative question for those carers who used domestic home care

	All carers (%)	Lower CAI (%)	Middle CAI (%)	Higher CAI (%)
How easy was it to get the service?				
Easy	82	72	85	87
Difficult	18	28	15	13
After requesting it, how long did it take to receive the service?				
Less than 2 weeks	54	42	53	61
2-4 weeks	34	31	41	30
More than 4 weeks	6	12	6	2
Don't know	6	15	0	7
How often do you receive the service?				
Every day	2	0	3	2
Several days per week	3	0	7	2
Once a week or less often	95	100	90	96
How often would you like to receive the service?				
Every day	3	0	4	5
Several days per week	13	15	15	10
Once a week or less often	84	85	81	85
How would you rate the quality of the service?				
Good quality	76	83	68	77
Poor quality	24	17	32	23

Chapter 7 Use of respite care

All carers responded to questions about respite care, which were introduced by the following statement: 'These questions are about respite care, that is, any service provided to give you a break from caring. This service may be provided in your home or in a place where the person you care for can go.'

7.1 Information

All carers reported on the amount of information they received about respite care and whether the service was available. A high proportion of carers (46%) indicated that they did not receive enough information about respite care. Carers with a higher CAI were statistically significantly more likely to report that they received enough information about respite care (71%) than were carers with a middle (48%) or lower CAI (39%).

Those carers (n=143) who indicated that they received information wrote 177 responses about where they received the information. The carers mainly received respite care information from service providers such as respite centres or the Department of Veterans' Affairs (55% of the carers). The second most frequently discussed source of information was medical professionals, such as doctors, specialists or nurses, or from hospitals (36% of the carers). Other information sources included varied groups, such as social workers or libraries (11% of the carers), local councils (7% of carers), nursing homes (6% of the carers), carers' associations (4% of the carers) and friends or relatives (4% of the carers).

7.2 Availability

A high proportion of carers (39%) did not know if respite care was available or reported that the service was not available. Carers with a higher CAI were statistically significantly more likely to report that the service was available (77%) compared to carers with a middle (56%) or lower (47%) CAI.

The percentage of carers who reported that respite care was not available or did not know if it was (dark grey) compared to the percentage of carers who reported that the service was available (light grey and thatched areas) are presented in Figure 6 for each CAI. Of those carers who reported the service was available, the thatched area indicates the percentage of carers who used the service.

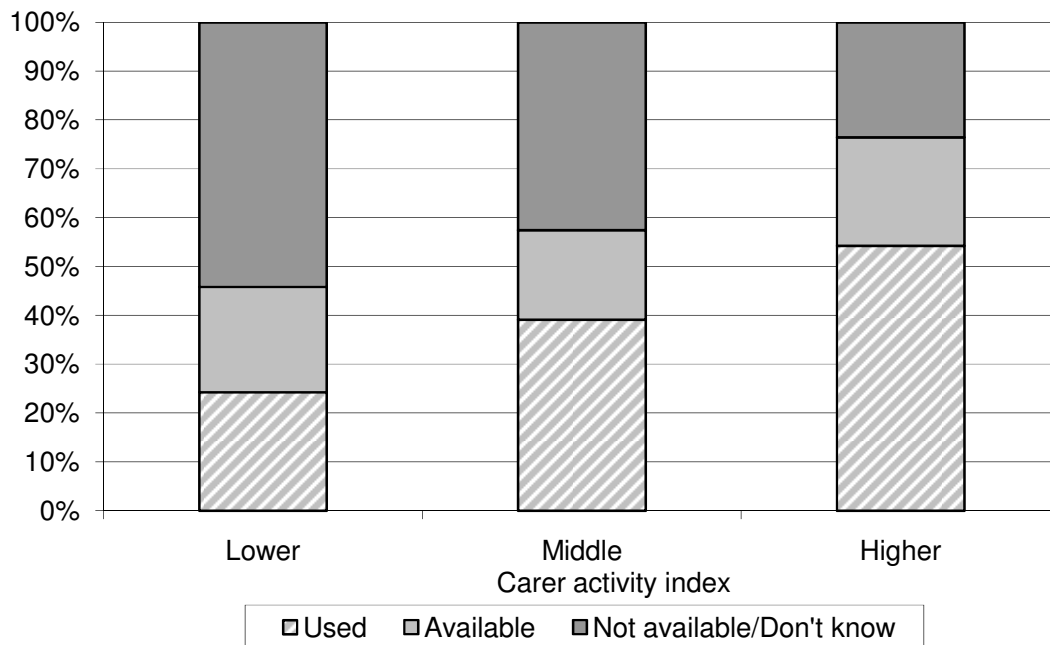


Figure 6 Availability and use of respite care for each CAI group

7.3 Use

Those carers who reported that the service was available indicated whether they had used the service. Of those carers who answered the question 'have you used respite care?' approximately two-thirds (67%) reported that they had used the service. As expected, more carers with a higher CAI (70%) used the service than did carers with a lower (56%) or middle (66%) CAI.

Carers who reported that they did not use the service were asked to write an explanation for why they chose not to use the service. Forty-five carers provided 52 responses. Five themes emerged from the written comments. In order of frequency in the responses, they were:

1. *care recipient preference* (51% of the carers);
2. *carer being able to provide help* (20% of the carers)
3. *aspects of the service* (20% of the carers);
4. *carer preference* (18% of the carers); and
5. *assistance by family or friends* (7% of the carers).

The choice not to use respite care was strongly driven by care recipient preference. The care recipients preferred to stay at home where they were happy and comfortable. There was a general reluctance or refusal to have strangers 'entertaining' the care recipients within their home or to leave the house for respite care: '*Person I care for won't go for respite care[,] won't leave home, does not want to go to Hospital where respite is available [and] is worried he won't come home where he is happy.*' Some care recipients refused to use respite care, even to the possible detriment of the carer: '*He knows all about respite[,] but until he actually faces that I can use a break[,] things will just go on until urgent.*'

Carers also indicated that they preferred to continue caring for their recipients as long as they were able. For some, family or friends were able to provide a respite for the

carer. Therefore, these carers did not use respite care because they had other available resources.

Several 'aspects of the service' prevented carers from using respite care. The timing of respite care may have been prohibitive with the service not being available on weekends or the waiting lists were long. Some carers indicated that they did not use 'respite care' per se because they received respite while their care recipients were under palliative care or using disability services. On the other hand, some carers noted that respite was not an option for them because their care recipients needed more specific or palliative services that could not be addressed in their respite care. One carer commented that cultural differences prohibited her from using respite care: *'Because of our cultural needs and limited English skills[,] to be placed in an 'Anglo Saxon' environment causes great anxiety, disorientation and depression.'*

7.4 Accessibility, duration of wait to receive service, frequency and quality

Those carers who reported that they used respite care then reported on ease of access, how long it took the service to start after requesting it, how often they used the service, how often they would like to have used the service and the quality of the service. These results are presented by CAI group in Table 8.

- Most carers (74%) found that respite care was easy to access. Carers with a higher CAI were more likely to report that it was difficult to access this service compared to carers with a lower or middle CAI.
- There were no apparent differences between the CAI groups and how long the carer waited to receive respite care after requesting it. Most carers waited less than 2 weeks (45%) for respite care or between 2 and 4 weeks (29%).
- More carers, regardless of their CAI, reported that they received respite care, and preferred to receive it, once a week or less often rather than more than once a week.
- When comparing the amount of respite care received and wanted, 91% of the carers reported that they received the service as often as they wanted. However, 7% of the carers reported they received the service less frequently than they wanted and one carer (2%) reported that she received the service more than wanted. The pattern was similar across the CAI groups.
- Most of the carers (79%) reported that when they used respite care, it was of a good quality. All three CAI groups rated the quality highly with no apparent differences between them.

In the final question in the series, the carers were asked to write whether they had any comments or complaints about the respite care service. Carers (n=47) provided 74 responses. Half of the carers (51%) responded favourably about respite care, reporting that it was excellent, reliable and *'above reproach.'* Carers commented that respite care gave them a break and provided companionship for their care recipient. However, 19% of the carers provided unfavourable comments. Several comments suggested how the service could be improved including improving general availability and availability with last minute notice and providing regular workers to maintain consistency.

It was evident in the written comments that the choice not to use respite care was strongly driven by care recipient preference. Providing more options, such as in-home, weekend or night respite care, would likely increase the use of the service. In addition, respite care that is more flexible to the needs of the recipient would also give carers who are providing intense help (palliative, severe disability), a break.

Table 8 Percentages of responses to each quantitative question for those carers who used respite care

	All carers (%)	Lower CAI (%)	Middle CAI (%)	Higher CAI (%)
How easy was it to get the service?				
Easy	74	80	86	65
Difficult	26	20	14	35
After requesting it, how long did it take to receive the service?				
Less than 2 weeks	45	50	44	44
2-4 weeks	29	25	33	28
More than 4 weeks	20	25	17	20
Don't know	6	0	6	8
How often do you receive the service?				
Every day	4	12	0	4
Several days per week	13	0	23	11
Once a week or less often	83	88	77	85
How often would you like to receive the service?				
Every day	4	0	7	4
Several days per week	19	22	21	16
Once a week or less often	77	78	72	80
How would you rate the quality of the service?				
Good quality	79	75	82	79
Poor quality	21	25	18	21

Chapter 8 Other health, government and community services

Carers were also asked about the ease of access to health services and whether other services have helped them. Quantitative results and themes from written comments are presented here for the following services:

- Health services for the care recipient (Question 19)
- Government or community services for the care recipient (Question 24)
- Groups of significant support to the carer (Question 43)
- Significant government services for the carer (Question 44)

8.1 Health services for the care recipient

The care recipients' ease of access to health services was varied. Generally, 75% or more of the carers reported that it was easy to access all the listed services, except house calls by the doctor (Table 9). Of all the services, house calls by the doctor were the most difficult to obtain. There were no apparent relationships between access to services and CAI group, except for hospital admissions: statistically significantly more carers with a higher CAI reported that it was difficult to access hospital admissions than carers with a lower or middle CAI.

Carers (n=135) wrote 161 complaints or comments on health services. Carers most often wrote that they did not have any complaints about health services or praised them (60% of the carers). Of note, 14 carers (10%) indicated they received health services through the Department of Veterans' Affairs. All but one of them complimented the services. For instance, *'My husband is a T.P.I. Veteran and as such has wonderful care provided by Dept. Vet. Affairs we can't speak highly enough.'* The remaining carer commented on hospital services.

Carers expressed difficulty with the availability of, and wait time for, services (16% of the carers) or commented on the distance needed to travel to services (10% of the carers) which sometimes proved prohibitive. At times these difficulties were combined as one carer noted:

'My Husband has been having appointments for podiatry at the local Hospital medical centre at no cost, but we often have the appointments cancelled and when we get another one it is almost 3 months later. We have to have transport, the Medical Centre is just a short journey, now we will have a much longer journey.'

Similar to the quantitative data, carers also indicated that in home or after hours doctor calls were difficult to receive for checkups or for emergencies (6% of the carers). This was distressing to the carers and often resulted in calling an ambulance to go to the hospital: *'House calls if required usually mean the patient is required to go to the local hospital. Since living here that has been by ambulance which seems to be the ideal way.'*

It is apparent in the carers' comments that there is a sense of relief when the health services are supportive and the carers feel that they have options:

'The care of Dialysis patients in West Australia is excellent. We are able to contact [the] Nephrology Unit at all hours and receive suitable advice and

treatment. We have a feeling we are never alone and this a great help to the carers.'

Table 9 Ease of access to health services for the care recipient

	All carers (n=280*) (%)	Lower (n=93*) (%)	CAI Middle (n=93*) (%)	Higher (n=93*) (%)
House calls by the doctor				
Easy	55	57	50	60
Difficult	45	43	50	40
The doctor of their choice				
Easy	85	88	83	84
Difficult	15	12	17	16
A specialist doctor				
Easy	76	78	78	70
Difficult	24	22	22	30
A hospital doctor				
Easy	81	85	85	73
Difficult	19	15	15	27
Admission to a hospital				
Easy	82	92	83	73
Difficult	18	8	17	27
A dentist				
Easy	75	75	78	70
Difficult	25	25	22	30
Allied health services				
Easy	80	84	80	75
Difficult	20	16	20	25

*Actual sample sizes vary for each variable due to missing data.

8.2 Government or community services for the care recipient

Carers were also given the opportunity to write a list of any other government or community services received by the care recipient. The carers who responded to this question (n=93) provided 141 responses. Care recipients used various medical services (31% of the carers), such as allied health visits or hearing help, to name a few examples. Over one-quarter of the carers (28%) indicated that the recipients' services were provided in part or fully by the Department of Veterans' Affairs.

Two other main service themes were the use of home management (23%) and transportation services (17% of the carers). Home management included services that have previously been discussed (cleaning, gardening). However, in this question the carers provided more specific information on the types of home modifications or repairs that were made to their houses including, rails, ramps or security systems. For transportation, carers discussed discounted taxi or public transportation fares as well as driver services that take the recipients to and from appointments. More carers (28%) provided positive comments than negative comments (10%).

8.3 Groups of significant support to the carer

Carers were asked to write their answers to 'Are there any groups who have provided significant support to you in your role as a carer? (eg. a stroke support group)' The carers (n=182) provided 224 responses. Nearly half of the carers (48%) indicated that no group had provided them with significant help and 8% of the carers said that no support group was needed.

Some carers (20%) described service providers or medical professionals that had previously been described, such as '*The DVA with their Gardening and Wood Chopping. My daughter vacuums my floors and shops for us.*' For most of these responses it is unclear if the carers simply reported the services that helped them, or if these services actually provided significant support to the women in their roles as carers.

However, other carers did specifically indicate the support they received from their community or families and friends (8% of the carers), condition-specific groups (8% of the carers) and carer support groups (7% of the carers). One carer wrote that she received significant support from her community: '*A network of friends and tradesmen and people in the bank and the shops etc. who we have known for years because we have lived in a country town for so long - our community.*' Some of the support groups mentioned included those for dementia, stroke, Parkinson's disease and posttraumatic stress disorder.

8.4 Government services of significant support to the carer

The carers wrote responses to the question 'Are there any government services, such as Centrelink, who have provided significant support to you in your role as a carer?' Three-quarters of the carers (n=211) responded to this question and wrote 265 responses. Approximately two of every five carers (43% of the carers) indicated that no government services provided significant support.

For those who responded affirmatively, most received a carer or pensioner allowance through Centrelink (35% of the carers) and a further 6% reported that the Department of Veterans' Affairs provided significant support to the carers. Feelings were mixed about Centrelink ranging from satisfactory, prompt service, to the allowance amount being '*insulting,*' to one carer writing that she '*found them unhelpful, unfriendly and at times hostile and quite insensitive.*'

Chapter 9 Discussion and conclusions

This chapter discusses and summarises the results in terms of the areas of requirement for which this research was commissioned, which were:

1. Carer needs:
 - a. What is the broad impact of caring on women's lives?
 - b. What needs, unmet or under met, can be identified for carers?
2. Intervention/services:
 - a. What types of interventions/services do carers use?
 - b. What patterns of health or community service use are demonstrated?
 - c. What information can be provided on access, information and perception of services that carers use?
 - d. What interventions/services lessen the impact of caring?
 - e. What carer support strategies and interventions assist or could assist employed carers?
 - f. What type/dose/timing of respite interventions are effective in maintaining a caring relationship for the different carer types and settings?

9.1 Carer needs

9.1.1 What is the broad impact of caring on women's lives?

In general, carers' lives were worse from caring. This was particularly evident for the carers with a middle or higher CAI. The written comments indicated that the carers' lives were worse from caring because of the practicalities of their situations, such as restrictions on everyday life or coping with continual demands and greater responsibility.

The carers' mental and physical health scores (as measured by the Medical Outcomes Study Short Form 26) did not differ between the CAI groups. However, the substudy's carers had statistically significantly poorer mental and physical health compared to the entire 1921-1926 cohort of the ALSWH. Conversely, carer strain and developmental burden were related to CAI. Carers with a higher or middle CAI had statistically significantly more developmental burden and strain than did carers with a lower CAI.

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

9.1.2 What needs, unmet or under met, can be identified for carers?

The results indicate that the needs of carers and their recipients were mainly being met. Nearly all of the carers had major medical conditions or disabilities and the 23% who needed help were generally satisfied with the help they received. The carers mainly received help with domestic home care and the help was mostly provided by service providers and family.

Nearly all of the care recipients' needs for the nine activities of daily living were met by the combination of the carers who completed the survey, other unpaid carers and paid services. The carer who completed the survey provided, by far, the most help of the three.

However, the carers did report that needs were not being met for some care recipients. In particular, care recipients needed the most help with washing, dressing and grooming, so understandably, it was most frequently reported that help was needed, but not provided for this activity in comparison to the other activities. The carers also indicated in their written comments that they would like to receive household management services, such as garden maintenance and cleaning, which they were currently not receiving.

9.2 Interventions / services

9.2.1 What types of interventions/services do carers use?

The overall percentage of health insurance coverage was similar between carers and their care recipients except that carers more frequently had private hospital cover while recipients more frequently had health services cover from the Department of Veterans' Affairs.

The carers used paid services to varying degrees for all activities of daily living. Paid services were employed most for washing, dressing, and grooming and least for eating or drinking. Similarly, all four of the highlighted services (Meals on Wheels, personal home care, domestic home care and respite care) were used, but the numbers of carers using each service were generally quite low (see Appendix 11.5 for sample sizes). Carers used domestic home care services the most followed by personal home care, respite care and Meals on Wheels in descending order of frequency.

Carers' written comments also indicated that they used home management services to make repairs and modifications to their houses (rails, ramps, security systems) and utilized discounted taxi and transportation fares.

'Care recipient preference' and 'being able to manage' were the two main responses for why the four services were not used. When possible, the carers and their care recipients preferred to manage on their own. The care recipients dictated the use of services as they preferred to have food prepared to their liking, preferred not to have strangers handle their more personal or household needs and preferred not to alter the routine of living at home with family. Care recipient preference was more prevalent in respite care responses and was least prevalent for the Meals on Wheels service, for which dietary needs were more fundamental.

Nearly half of the carers wrote that no groups or government services had provided significant support to them as carers. Carers mainly received support from their communities and family and friends as well as support groups for carers or specific conditions. By far, Centrelink was discussed most often for providing significant monetary support to the carers.

9.2.2 What patterns of health or community service use are demonstrated?

Carers typically received Meals on Wheels and personal home care several days a week while they received domestic home care and respite care once a week or less often. Generally, most carers received the four highlighted services as often as they wanted. Personal home care had the highest proportion of carers reporting that they received the service less often than they wanted, followed by domestic home care and respite care in descending order. No carers reported that they received Meals on Wheels less often than wanted. Conversely, out of the four services, Meals on Wheels stood out as the service that had the most carers reporting they received it more frequently than wanted.

9.2.3 What information can be provided on access, information and perception of services that carers use?

Approximately one-half to two-thirds of the carers had not received enough information for the four highlighted services (Meals on Wheels, personal home care, domestic home care and respite care). If they did receive information, it was typically from medical professionals, service providers and local councils. Despite this lack of information, about two-thirds of the carers knew these services were available.

When the carers or recipients used the services, they generally rated them as easy to access. Meals on Wheels was most frequently reported as easy to access, followed by personal home care, domestic home and respite care. In addition, most services started within two weeks of requesting them. Meals on Wheels was the most prompt and respite care took the longest to start. This was also evidenced in the written comments: carers commended the Meals on Wheels service delivery and lamented the availability of respite care.

Personal home care was most frequently rated as being of a good quality (95% of the carers) while approximately three-quarters of the carers rated the other three services as being of good quality.

Carers also typically reported that it was easy for the care recipients to access health services. House calls by the doctor were the most difficult to access and carers with a higher CAI had more difficulty with hospital admissions than did carers with a lower or middle CAI.

There was a high proportion of carers and care recipients with health services coverage provided by the Department of Veterans' Affairs. There was no consistent statistical link between this and satisfaction of support or ratings of service quality due to sample sizes across the variables. However, written comments showed that these carers liked the Department of Veterans' Affairs. This may be an area for further investigation.

9.2.4 What interventions/services lessen the impact of caring?

This question can be informed by the survey data, but a causal relationship cannot be determined due to the cross-sectional nature of the substudy. To determine if the use of any of the four highlighted services (Meals on Wheels, personal home care, domestic home care or respite care) was related to carer strain, developmental burden, or physical or mental health, carers who used the service were compared to carers who chose not to use the service.

Several results were found:

- Carers who used Meals on Wheels were statistically significantly more strained, but had statistically significantly better physical health, than carers who chose not to use the service.
- There were no apparent relationships between use of personal home care and any of the impact variables.
- Carers who used domestic home care had statistically significantly poorer physical health than carers who chose not use to the service.
- Carers who used respite care were statistically significantly less burdened than carers who chose not to use the service.

It may be that carers who were more heavily impacted by caring were more likely to use Meals on Wheels and domestic home care services or that carers who are less burdened use respite care. However, further investigation is required to determine the causality of these associations.

9.2.5 What carer support strategies and interventions assist or could assist employed carers?

Due to the carers' ages, the carers were not likely to be in the labour force and questions about employment were not asked in the current substudy or the main ALSWH Survey 3. However, Survey 3 did ask about volunteer work for any community or social organisations. Approximately half of the carers volunteered for a community or social organisation.

9.2.6 What type/dose/timing of respite interventions are effective in maintaining a caring relationship for the different carer types and settings?

Only 66 carers reported that they had used respite care, which is approximately one-quarter of the carers who completed the survey. As a carer's CAI level increased, the more likely she was to use respite care. However, it was evident in the written comments that the choice not to use respite care was strongly driven by care recipient preference. Providing more options, such as in-home, weekend or night respite care, would possibly increase the use of the service. In addition more flexible respite care would also give carers who are providing intense help (palliative, severe disability), a break. For those who were using the service, receiving respite care once a week or less often was as much as they wanted to receive.

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Chapter 11 Appendices

Appendix 11.1 Lucke et al. (2008) published paper

Lucke, J, Russell, A, Tooth, L, Lee, C, Watson, M, Byrne, G, Wilson, A & Dobson, A 2008, 'Few urban-rural differences in older carers' access to community services', *Australian Health Review*, vol. 32, no. 4, pp. 684-90.

Few urban-rural differences in older carers' access to community services

Jayne Lucke, Anne Russell, Leigh Tooth, Christina Lee, Melanie Watson, Gerard Byrne, Andrew Wilson and Annette Dobson

Abstract

To examine perceived adequacy of access to information and services, and perceived quality of health and community services, among older female carers across rural and urban areas primary data were collected as part of the ongoing Australian Longitudinal Study on Women's Health (ALSWH). In all, 306 women in their 70s who had family caregiving roles responded to a nested substudy of the ALSWH. There were few reported differences between urban and rural older carers in their access to health and community services for the people they cared for. In fact, those in rural areas fared slightly better than those in urban areas in awareness of service availability and perceived quality of service. Many older carers in both rural and urban areas do not access health and community services even when appropriate services are available. A better understanding is needed of how support can be delivered to complement older carers' existing arrangements.

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Jayne Lucke, PhD, Senior Research Fellow, School of Population Health

Anne Russell, Research Manager, School of Nursing and Midwifery

Leigh Tooth, PhD, Senior Research Fellow, School of Population Health

Christina Lee, PhD, Head, School of Psychology

Melanie Watson, BEc, BMath(Hons), Research Assistant, School of Population Health

Gerard Byrne, MBBS, PhD, Head, Discipline of Psychiatry, School of Medicine

Andrew Wilson, MBBS, PhD, Professor of Public Health, Faculty of Health Sciences

Annette Dobson, PhD, Professor of Biostatistics, School of Population Health

The University of Queensland, Brisbane, QLD.

Correspondence: Dr Jayne Lucke, Public Health Building, Herston Road, Herston, QLD 4006. j.lucke@uq.edu.au

What is known about the topic?

Older carers have difficulty accessing health and community services.

What does this paper add?

This study provides new insights into the way in which older caregivers perceive their access to community services, suggesting that those in rural areas have slightly better access to some services than their urban counterparts.

What are the implications for practitioners?

Boundaries between caregiving and normal family life are blurred for many older women carers and a better understanding is needed of what women want and how support could be delivered in a manner caregivers find acceptable and complements their existing support arrangements.

MANY PEOPLE WITH long-term disability, illness or frailty are cared for by family members. While there are many positive outcomes from caregiving, such as personal growth¹ or feelings of gratification, pride and resiliency,² there is also evidence that the task of providing care can become an overwhelming burden which results in significant negative consequences for the carer's physical and mental health and for the community in general.³ Appropriate services have the potential to reduce the stress and burden felt by carers.⁴

A number of studies have identified high levels of unmet need for services among carers but it is not clear whether it is lack of services or reluctance to use them which causes the problem.³ Reasons for low use of existing services are varied and may include the belief that caring is part of the role of spouse or family member, the care recipient not wishing to accept services, the service not being suitable for some reason, carers not being aware of service availability, or problems

with access to services.⁵ Particularly low service use has been reported among carers of people with neurological impairments⁵⁻⁷ and by carers belonging to minority groups⁸ or living in rural areas.⁹

Older carers may have particular problems in accessing services. These may relate to their attitudes towards their own roles as carers, for example, the expectation that they should provide for all the care recipient's needs, or constraints on their interaction with service providers, such as a lack of trust, or an expectation that services will not be available.¹⁰ They may have insufficient access to respite services and more problems with transport and communication than younger carers. Financial hardship and diminishing social networks compound these problems for many older carers.¹⁰

Understanding how carers use health services is necessary in order to tailor services to their needs. This study examined use of health and community services by a group of older participants in the Australian Longitudinal Study on Women's Health (ALSWH) who identified themselves as family caregivers. In particular, we compared older women carers in urban and rural areas on their reported access to medical and allied health and community services, focusing on information about services, perceived access to and use of services, and their assessment of the quality of community services they received.

Methods

The project was a nested cross-sectional substudy of ALSWH which recruited over 40 000 women in three age cohorts (younger, mid-aged, older) from all parts of Australia. Women were randomly selected from the Australian Medicare database in 1996, with intentional over-sampling in rural and remote areas.¹¹ The Medicare database includes all citizens and permanent residents. Participants in this study were selected on the basis of their responses to the third survey of the older cohort conducted in 2002. All women who were identified as providing care for someone living with them ($n = 674$; 78–83 years),

either from their response to a specific survey item or from free text responses, and who had not been selected for other related substudies at the same time, were invited to participate. These women were sent a written invitation and a special survey. Those not responding were contacted by phone and encouraged to complete the survey if they were eligible. Those unwilling to complete the postal survey were offered the option of completing it over the phone.

The survey consisted of 55 closed-response items (some with open-ended components) and four open-ended questions. It was constructed in 14-point font and was written at a grade seven to eight reading level, consistent with the educational levels of Australian women now in their 70s and 80s. The survey content was informed by focus groups held in Newcastle and Brisbane. There were two Newcastle focus groups: a group of women in their 70s and 80s who were caring for their husbands, and a group of women in their 50s and 60s who were caring for parents or disabled adult children. Following these focus groups, substantive changes were made to the draft survey, and two more focus groups were held in Brisbane with carers of patients diagnosed with Alzheimer's disease and neurological conditions who were attending a hospital outpatient clinic. The draft survey was then pilot tested on 30 older women (aged 70–75 years) who were members of the ALSWH pilot sample. These women did not participate in the main ALSWH survey, but were selected in a similar manner to the main survey sample and are involved in ongoing pilot testing for the ALSWH surveys. The study was approved by both University of Queensland and University of Newcastle Ethics Committees.

The survey was divided into two sections. The first concerned the care recipient, with questions about the nature of the disabilities; whether the recipient lived with the caregiver; health insurance; and whether they needed help with a number of personal and instrumental activities of daily living. Ten specific activities were listed including: washing, dressing and grooming; preparing meals; eating or drinking; getting on or off the bed, toilet, chair, etc; managing the toilet or

I Demographic, health and care characteristics of care recipients, by area of residence (n = 282 women whose care recipient does not live in a nursing home or care facility)

Characteristics of care recipients	Urban no. (%)	Rural no. (%)	Rural-Urban* (95% CI)
Total	113 (40)	169 (60)	-
Relationship to caregiver	111	169	-
Spouse	102 (92)	153 (91)	-1 (-8 to 5)
Child	6 (5)	11 (7)	1 (-4 to 7)
Sibling/other	3 (3)	5 (3)	0 (-4 to 4)
Living status	112	169	
Live with caregiver	109 (97)	168 (99)	2 (-1 to 5)
Other	3 (3)	1 (1)	-2 (-5 to 1)
Medical conditions†			
Heart disease	48 (43)	77 (47)	4 (-8 to 16)
Arthritis/rheumatism	47 (42)	74 (44)	2 (-10 to 14)
Lung/breathing problems	33 (30)	45 (28)	-2 (-13 to 9)
Stroke	35 (32)	36 (22)	-10 (-20 to 1)
Alzheimer's disease/dementia	25 (23)	27 (16)	-6 (-16 to 3)
Parkinson's disease	11 (10)	11 (7)	-3 (-10 to 3)
Multiple sclerosis	1 (1)	0 (0)	-1 (-3 to 1)
Other disease/condition	66 (60)	100 (61)	1 (-10 to 13)

* Difference between percentages. † Percentages do not sum to 100 as respondents could choose more than one medical condition; the denominator for each row may differ slightly due to missing data on these items.

incontinence; mobility (walking or wheelchair, stairs, etc.); household management (eg, shopping, cleaning); recreation or hobbies; transportation; management of finances, insurance etc. For each activity respondents were asked to circle a response indicating whether the person they cared for needed help with the activity, how often help was provided by the carer, another unpaid carer or a paid service, and how often the help was needed but not provided.

The second section assessed access to services. Access to medical and allied health services was assessed by asking how easy it was for the care recipient to obtain: house calls by a doctor; a doctor of their choice; a specialist doctor; admission to a hospital; a dentist; and allied health services. Access to community services was assessed by asking specific questions about Meals on Wheels, personal home care, domestic home care and respite care services. Carers were asked whether they had received adequate information (response options were "no information", "some information but not enough", and "enough information"), whether these services were available ("yes", "no", "don't know"), whether the care recipient had used the service ("don't need it", "choose not to", "yes", "don't know"), how easy it was to obtain the service ("very difficult", "somewhat difficult", "easy", "very easy", "don't know"), and how they would rate the quality of the service ("excellent", "very good", "average", "poor", "very poor"). Respondents were asked to circle the option that applied to them.

Care recipients' place of residence was defined as urban or rural (including large rural centres, small rural centres and remote areas). Differences in response patterns, for demographic factors and service use, according to place of residence, were examined using chi-square analysis and calculating percentage difference and 95% confidence intervals.

Results

Survey response and participant demographic characteristics

A total of 674 women were invited to participate, and 306 (45.4%) returned completed surveys. Of the remainder, 201 were ineligible (ie, they did not provide, or no longer provided, care), 86 did not want to participate, and three had died. Another 58 did not specify reasons for non-response, while 20 surveys were returned unopened.

There were 24 women who were identified as caring for someone who lived in a nursing home

2 Care recipients' needs for help with activities of daily living, by area of residence (n = 282 women whose care recipient does not live in a nursing home or care facility)

	Urban (n/N [%])	Rural (n/N [%])	Rural - Urban* (95% CI)
Help needed			
Washing or dressing	76/109 (70)	101/157 (64)	-5 (-17 to 6)
Preparing meals	86/108 (80)	109/153 (71)	-8 (-19 to 2)
Eating and drinking	18/105 (17)	30/157 (19)	2 (-8 to 11)
Transfers	47/108 (44)	62/156 (40)	-4 (-16 to 8)
Toileting	45/108 (42)	50/160 (31)	-10 (-22 to 1)
Mobility	76/111 (68)	90/157 (57)	-11 (-23 to 0)
Household management	85/110 (77)	109/161 (68)	-10 (-20 to 1)
Recreation	46/108 (43)	60/157 (38)	-4 (-16 to 8)
Transport	95/109 (87)	131/161 (81)	-6 (-14 to 3)
Finances	74/108 (69)	110/161 (68)	0 (-12 to 11)
Ever paid for help†			
Washing or dressing	32/70 (46)	45/91 (49)	4 (-12 to 19)
Preparing meals	13/78 (17)	20/100 (20)	3 (-8 to 15)
Eating and drinking	6/18 (33)	5/27 (19)	-15 (-41 to 11)
Transfers	17/46 (37)	20/56 (36)	-1 (-20 to 18)
Toileting	15/42 (36)	10/45 (22)	-13 (-32 to 5)
Mobility	15/68 (22)	29/82 (35)	13 (-1 to 28)
Household management	24/73 (33)	34/101 (34)	1 (-13 to 15)
Recreation	9/40 (23)	14/51 (27)	5 (-13 to 23)
Transport	38/88 (43)	44/116 (38)	-5 (-19 to 8)
Finances	7/73 (10)	8/103 (8)	-2 (-10 to 7)
Needed help but not received†			
Washing or dressing	25/58 (43)	29/82 (35)	-8 (-24 to 9)
Preparing meals	17/72 (24)	26/94 (28)	4 (-9 to 17)
Eating and drinking	2/15 (13)	6/25 (24)	11 (-13 to 35)
Transfers	12/42 (29)	15/54 (28)	-1 (-19 to 17)
Toileting	9/37 (24)	11/42 (26)	2 (-17 to 21)
Mobility	14/62 (23)	18/73 (25)	2 (-12 to 16)
Household management	12/67 (18)	24/94 (26)	8 (-5 to 20)
Recreation	12/39 (31)	12/48 (25)	-6 (-25 to 13)
Transport	26/82 (32)	25/110 (23)	-9 (-22 to 4)
Finances	2/71 (3)	4/102 (4)	1 (-4 to 6)

* Difference between percentages. † Only includes those who responded "yes" to needing help. Denominators vary due to missing data on some items.

or care facility. These women were excluded from the analysis because access to health and community services is not relevant to nursing

home participants in the same way as for those living in the community, leaving 282 participants for analysis. Box 1 shows demographic and health

3 Care recipients' access to medical and allied health services, by area of residence ($n = 282$ women whose care recipient does not live in a nursing home or care facility)

Service [†]	Difficult to access		
	Urban (<i>n</i> / <i>N</i> [%])	Rural (<i>n</i> / <i>N</i> [%])	Rural – Urban* (95% CI)
House calls by a doctor	30/81 (37)	56/112 (50)	13 (-1 to 27)
Doctor of choice	16/95 (17)	20/149 (13)	-3 (-13 to 6)
Specialist doctor	16/85 (19)	38/136 (28)	9 (-2 to 20)
Hospital doctor	15/70 (21)	19/111 (17)	-4 (-16 to 8)
Admission to hospital	16/91 (18)	25/143 (17)	0 (-10 to 10)
Dentist	17/81 (21)	34/122 (28)	7 (-5 to 19)
Allied health	13/68 (19)	26/125 (21)	2 (-10 to 13)

* Difference between percentages. † The denominator for each row may differ slightly due to missing data on these items.

characteristics of the care recipients according to area of residence. The caregivers' mean age was 78.0 years (SD, 1.45), the mean age of the care recipients was 81.1 years (SD, 9.73), and over 90% cared for, and lived with, their husbands. The median time for which the caregivers had provided care was 5 years. There were no statistically significant differences in these characteristics between urban and rural care recipients.

Help required with activities of daily living

Participants were asked whether the people they cared for needed help with ten different personal and instrumental activities of daily living. For those endorsed, participants stated whether they had ever paid for help, and whether they had ever needed help but not received it from either a paid or unpaid helper.

Box 2 shows that there were no differences between rural and urban participants in relation

to help required or received with activities of daily living. Activities which most commonly required help were transport (83.7% overall), preparation of meals (74.7%), household management (71.6%), finances (68.4%), washing and dressing (66.5%) and mobility (61.9%). Of those who needed help, at least 18% had paid for help for each activity except financial management. Similarly, except for help with finances, over 20% had needed help for each activity but not received it. Most notably, almost 40% reported that the care recipient had needed help at some time with washing or dressing but that they had not received assistance from either a paid or unpaid helper.

Access to medical and allied health services

Box 3 shows that there were no differences in access to medical and allied health services for care recipients living in urban or rural locations.

Community service information, availability, access and quality

Box 4 shows the number and proportion of participants who had reported receiving enough information about community services, who said that the service was available, who had used the service and who had found the service easy to access and of good quality. At a significance level of 0.05, five of 20 analyses indicated a statistically significant difference between urban and rural carers, suggesting that any overall effect is weak. All of the significant effects indicated that rural participants gave higher ratings with respect to these services.

Discussion

This study provides new insights into the way in which older caregivers perceive their access to community services, suggesting that those in rural areas fare slightly better in some areas than their urban counterparts. Overall levels of community service use was low, as found in previous studies.^{3,10,12-14} However, there were very slight trends for rural women to be more likely than urban women to report receiving enough infor-

4 Care recipients' access to community services, by area of residence (n = 282 women whose care recipient does not live in a nursing home or care facility)

	Urban n/N (%)	Rural n/N (%)	Rural – Urban* (95% CI)
Meals on Wheels			
Have received enough information	40/89 (45)	76/142 (54)	9 (-5 to 22)
Service is available	43/89 (48)	100/142 (70)	22 (9 to 35)
Have used the service [†]	9/15 (60)	25/29 (86)	26 (-2 to 54)
Easy to access the service [‡]	8/9 (89)	24/24 (100)	11 (-9 to 32)
Service of good quality [‡]	6/8 (75)	16/21 (76)	1 (-34 to 36)
Personal home care			
Have received enough information	51/92 (55)	101/146 (69)	14 (1 to 26)
Service is available	55/88 (63)	107/149 (72)	9 (-3 to 22)
Have used the service	35/40 (88)	50/54 (93)	5 (-7 to 17)
Easy to access the service	31/34 (91)	46/47 (98)	7 (-4 to 17)
Service of good quality	31/31 (100)	45/47 (96)	-4 (-10 to 2)
Domestic home care			
Have received enough information	53/97 (55)	106/154 (69)	14 (2 to 27)
Service is available	52/92 (57)	110/151 (73)	16 (4 to 29)
Have used the service	29/37 (78)	63/73 (86)	8 (-8 to 23)
Easy to access the service	24/29 (83)	51/60 (85)	2 (-14 to 19)
Service of good quality	17/27 (63)	46/55 (84)	21 (0 to 41)
Respite care			
Have received enough information	51/103 (50)	86/153 (56)	7 (-6 to 19)
Service is available	54/89 (61)	90/149 (60)	0 (-13 to 13)
Have used the service	26/36 (72)	37/49 (76)	3 (-16 to 22)
Easy to access the service	17/24 (71)	26/34 (76)	6 (-17 to 29)
Service of good quality	11/20 (55)	31/31 (100)	45 (23 to 67)

* Difference between percentages. † "Have used the service" only includes those who answered the service was available. ‡ "Easy to access the service" and "Service of good quality" only includes those who used the service. Denominators vary due to missing data on some items

mation about some community services, being aware of service availability, and rating the service as being of high quality. The consistent pattern, however, is one of no difference between urban and rural caregivers — this challenges assumptions that rural residents have inferior access to health care services, at least in the case of self-reports from older carers in Australia in the early 2000s. The issue of service access differences according to area of residence is complicated. While there may be fewer services in rural areas, where services are available, it is possible that

access may be facilitated in rural areas by factors such as closer community networks and smaller local populations.

Use of community services by carers and care recipients was found to be low, with between 43% and 49% of carers either not knowing whether services were available or choosing not to answer the question; between 24% and 57% of carers for whom the services were available reported having used them. Our findings are consistent with previous research which found that service access is low for those caring for

spouses, even though they rated the quality of information on respite services as good.^{4,7-9,15}

Australian research on this topic has generally been conducted with non-representative samples and has tended to focus on restricted populations, such as carers of people with dementia, while research from other countries is of limited use because of the substantial differences in health care systems. The low response rate and levels of missing data are causes for caution in interpretation of the findings of this study. However, the randomly selected sample is a considerable strength.

Further, probably qualitative, research is needed to develop a more complete picture of the resources drawn on by caregivers who have no access to appropriate services or choose not to use those which are available. Particularly for older women, the boundaries between caregiving and normal family life are blurred, and a better understanding is needed of what these women want, and how support could be delivered in a manner that caregivers find acceptable and complements their existing support arrangements.

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Competing interests

The authors declare that they have no competing interests.

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Appendix 11.2 Tooth et al. (2008) published paper

Tooth, L, Russell, A, Lucke, J, Byrne, G, Lee, C, Wilson, A & Dobson, A 2008, 'Impact of cognitive and physical impairment on carer burden and quality of life', *Quality of Life Research*, vol. 17, no. 2, pp. 267-73.

Impact of cognitive and physical impairment on carer burden and quality of life

Leigh Tooth · Anne Russell · Jayne Lucke · Gerard Byrne · Christina Lee · Andrew Wilson · Annette Dobson

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Abstract

Background and purpose How the cognitive and/or physical impairment experienced by care recipients impacts on their carers is not well understood. This study investigated the effect of type of impairment of care recipients on the level of burden and quality of life (QOL) of elderly Australian carers.

Methods This article describes a nested cross-sectional substudy of 276 older women (aged 78–83 years) enrolled in the Australian Longitudinal Study on Women's Health who indicated they were providing care for someone living with them.

Results In this nationally representative sample of elderly women carers, 60% were looking after people (predominantly their husbands) who had both cognitive and physical impairments. Carers of people with both types of impairments had higher scores for objective burden of caring than those caring for people with either type of impairment

alone. In contrast, scores for limitations on their own lives were higher among women caring for people with cognitive impairments (with or without physical impairments). **Conclusions** The majority of elderly women caring for someone else are likely to suffer multifaceted burdens of caring.

Keywords Caregivers · Cognition · Impairment · Physical impairment · Carer burden · Quality of life

Introduction

The ageing of the population, combined with a systemic shift away from institutionalised care and towards early hospital discharge into the community, has resulted in increased reliance on family members to provide care to the frail, sick, or disabled. Carers are typically the spouses or children of the person with a disability or illness, and the majority of them are women, many of whom are themselves elderly [1, 2]. Carers have to manage functional, sensory, and cognitive impairment, and often deal with behavioural problems and personality changes in the people they care for [3]. As a result, carers may experience poorer mental and physical health and reduced quality of life (QOL), as well as higher morbidity and mortality than others [4–7].

The burden on carers has been linked to many factors, related to both care recipients and to carers. It has been found that cognitive impairment and personality changes in patients with conditions such as dementia, head injury, stroke, and other neurological disorders are linked with higher burden and poorer mental health in carers, compared to those caring for family members with physical deficits only [8, 9]. Carers find cognitive changes to be more

L. Tooth · J. Lucke (✉) · A. Dobson
School of Population Health, The University of Queensland,
Brisbane, QLD 4072, Australia
e-mail: j.lucke@uq.edu.au

A. Russell
School of Nursing and Midwifery, University of Queensland,
Brisbane, QLD, Australia

G. Byrne
School of Medicine, University of Queensland, Brisbane, QLD,
Australia

C. Lee
School of Psychology, University of Queensland, Brisbane,
QLD, Australia

A. Wilson
Queensland Health, Brisbane, QLD, Australia

threatening and stressful than physical changes, which are appraised as more readily manageable [3, 10] in part because of differences in the time demands on the carer [11]. Physical care needs can generally be met in planned and discrete time periods and many health and community services, such as meals on wheels, home nursing care, domestic home care, and respite, can help to alleviate some major practical aspects of caring [11] and thus decrease the physical and emotional strain on carers. In contrast, care for the cognitively impaired may require constant supervision and may be complicated by uncooperative or oppositional behaviour. For example, care recipients who lack insight into, or deny, their dependencies may refuse to accept or cooperate with services, further contributing to increased strain and poorer QOL in carers [12].

In practice, impairment, especially among the elderly, is often not only physical or only cognitive. Rather, physical and cognitive impairment occur together imposing multiple burdens on carers that are not well understood. The aim of this paper is to investigate the effect of type of impairment of care recipients on the level of burden and QOL of elderly Australian carers.

Methods

This project was a nested cross-sectional substudy of the Australian Longitudinal Study on Women's Health (ALSWH). Participants were members of the older cohort of the ALSWH, which initially recruited over 40,000 women in three age cohorts (younger, mid-aged, older) from all parts of Australia. Women were randomly selected from the Medicare database in 1996 with purposive oversampling in rural and remote areas [13]. The Medicare database includes all citizens and permanent residents. Participants in this study were selected on the basis of their responses to survey 3 of the older cohort (2002). All women ($n = 674$, aged 78–83 years) who indicated that they were providing care for someone living with them, either from a specific survey item or in-text responses, and who had not been selected for other ALSWH substudies, were invited to participate. These women were sent a written invitation and the survey. Those not responding were contacted by phone and encouraged to complete the survey if they were eligible. Those unwilling to complete the postal survey were offered the option of completing it over the phone. This only occurred for 1.8% (5 of 276) of the women.

The survey consisted of 55 closed-response items (some with open-ended components) and four open-ended questions. It was constructed in 14-point font and was written at a grade seven to eight reading level, consistent with the educational levels of Australian women now in their 70s

and 80s. The survey content was informed by focus groups and pilot tested.

Care recipient characteristics

We obtained the age of the care recipient, their relationship with their carer, and whether they live with their carer, other family, or in a care facility. Carers were asked 'Does the person you care for have difficulty managing their daily lives because of: cognitive problems (remembering things, making decisions or planning, or organising) and physical problems (moving around, using their arms and legs, weakness)'. Responses of 'a little' and 'a lot' were used to identify care recipients with cognitive (or physical) impairment, and 'not at all' to identify those without. The type of impairment was defined as primarily physical impairment, primarily cognitive impairment, and both cognitive and physical impairment.

Closed-response items allowed the carers to indicate if the person they provided care for had a stroke, Parkinson's disease, Alzheimer's disease/dementia, arthritis/rheumatism, lung or breathing problems, or heart disease. An open ended item allowed them to indicate other major medical conditions or disabilities. They also indicated the physical function of the person they cared for (yes or no) according to the Katz Index of Activities of Daily Living [14].

Cognitive change in the care recipient was assessed with the 16-item Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) [15]. This instrument is designed to be completed by a carer or family member who has known the person for 10 years and asks how the person's memory or intelligence has changed over a 10 year period. Higher scores indicate worse cognitive decline. The IQCODE has been shown to have good validity [15], and we have used Jorm's recommended cut-point for dementia screening (3.31/3.38).

Carer items

The physical- and mental-health-related QOL of the carers was assessed by the 36-item Short Form Health Survey (SF-36) [16]. Physical functioning, physical role limitations, bodily pain, and general health comprise the 'physical health' subscales, and vitality, social functioning, emotional role limitations, and mental health comprise the 'mental health' subscales. Higher scores represent better health.

A 10-item version of the Duke Social Support Index (DSSI) [17] measured carers' perceived social support. The scale consists of two dimensions: satisfaction with social support (score range 6–18) and social interaction (score

range 4–12), with higher scores indicating better social support. Satisfaction scores are highly skewed, and were dichotomised as “dissatisfied” (≤ 15) and “satisfied” (≥ 16). The scale has been shown to be an acceptable, reliable, and valid brief instrument to include in mailed surveys to community-dwelling older women [18].

Carer burden was measured using the 13-item Caregiver Strain Index (CSI) [19] and the developmental burden subscale of the Caregiver Burden Inventory (CBI) [20]. Items on the CSI have ‘yes’ or ‘no’ responses which are scored as 1 and 0, respectively; the index is the sum of item scores, with higher values indicating greater burden. The CSI principally measures objective burden. The developmental burden subscale of the CBI consists of five items, scored from 0 to 4. This subscale reflects carers’ perceptions of how caring is affecting them in comparison with their peers (e.g., “I feel that I am missing out on life” and “I expected things would be different at this point in my life”). Higher scores indicate greater burden.

Carers were also asked their perception of the overall effect on their lives of providing care and responses were categorised as ‘better’, ‘neither better nor worse’, and ‘worse’. They were also asked whether they regularly needed help with daily tasks because of long-term illness, disability, or frailty.

Data analysis

Differences in means and percentages for carers of people with predominantly physical, predominantly cognitive, or both physical and cognitive impairments were assessed using analysis of variance (ANOVA) and chi-square tests. Where there was a statistically significant difference in crude means, regression analysis was used to adjust for potential confounding factors. The potentially confounding factor of age was not taken into account because of the narrow range (5 years) of ages. All analyses were conducted using SAS (version 9.1; SAS Institute Inc., Cary, NC, USA).

Results

Overall, 201 (29.8%) of the women invited to participate reported being ineligible (i.e. they did not or no longer provided care), 86 (12.8%) did not want to participate, no response was received from 78 (11.6%), three had died, and 306 (45.4%) returned completed surveys. Among the 306 who returned surveys, 15 (4.9%) reported that the person they cared for had no difficulty managing their daily lives because of either cognitive or physical problems; a further 15 (4.9%) respondents gave insufficient data for the care

recipient to be classified. Data concerning the remaining 276 carers and care recipients were thus used in these analyses. This represented a participation rate of 276 out of 470 (58.7%) women who were eligible to participate.

The IQCODE was used to corroborate the carers’ assessment of cognitive impairment in the care recipient. Mean IQCODE score was 2.9 for those reported to have no cognitive impairment, 3.5 for those with ‘a little’ cognitive impairment and 4.3 for those with ‘a lot’ ($P < 0.01$), while the proportions exceeding the cut-off recommended for dementia screening were 18%, 69%, and 85%, respectively ($P < 0.01$). In contrast, there were small and nonsignificant differences in mean IQCODE score by reported level of physical impairment (means of 3.3, 3.7, and 3.6, for ‘no impairment’, ‘a little’, or ‘a lot’, respectively, $P = 0.06$).

Characteristics of carers and care recipients

Almost one-third of care recipients were classified as having primarily physical impairment (31%), with few having primarily cognitive impairment (9%) and the majority having both physical and cognitive impairment (58%) (see Table 1). The mean age of carers was not significantly different ($P = 0.16$) when care recipients were primarily physically impaired (78.1 years), primarily cognitively impaired (77.6 years), or both (78.8 years), while care recipients with primarily cognitive impairment were younger (66.3 years) and had been provided with care for longer (20.3 years) than those with primarily physically impaired (83.6 years of age; care provided for 12.0 years), or both (83.2 years of age; care provided for 13.8 years). The differences in care recipient ages were statistically significant ($P < 0.01$), but the differences in duration of care were not ($P = 0.26$).

Care recipients with physical impairments (with or without cognitive impairment) were most likely to be the husbands of the carers, while those with cognitive impairment were only about equally likely to be their husbands or children ($P < 0.01$). As expected, people with cognitive impairment (with or without physical impairment) were more likely to have Alzheimer’s disease or dementia. Those with physical impairment (with or without cognitive impairment) were more likely to require help with eating and drinking, transfers, grooming, toileting, and mobility; while those with cognitive impairment (with or without physical impairment) were more likely to need help with finances.

Carers’ burden and QOL

Characteristics of the carer’s which were included as confounding factors in the analysis of carer burden and

Table 1 Demographic, health, and care characteristics of care recipients classified according to their types of impairment ($n = 276$)^a

Characteristic	Type of impairment			<i>P</i> value
	Primarily physical ($n = 85$)	Primarily cognitive ($n = 26$)	Both physical and cognitive ($n = 165$)	
Percent of total	30.8	9.4	59.8	
Relationship with caregiver				<0.01 ^b
Husband	94.1	53.9	97.6	
Sibling	2.4	0.0	0.6	
Child	0.0	46.2	1.2	
Other	3.6	0.0	0.6	
Living arrangements				0.16 ^c
Lives with carer	94.1	96.2	87.9	
Lives with own family	1.2	0.0	0.0	
Lives in nursing home/care facility	3.5	3.9	11.5	
Other	1.2	0.0	0.6	
Medical conditions/disabilities				
Heart disease	41.0	26.9	52.4	0.03
Arthritis/rheumatism	54.2	30.8	46.7	0.11
Lung or breathing problems	33.3	19.2	31.1	0.39
Stroke	23.2	11.5	33.5	0.03
Alzheimer's disease/dementia	1.2	30.8	33.3	<0.01
Parkinson's disease	4.8	7.7	10.3	0.34
Medical conditions/disabilities reported in an open ended question				
	Number with condition			
Cancer	8	3	15	
Deafness/hearing loss	4	1	8	
Depression	0	0	8	
Hypertension	3	1	4	
Post traumatic stress disorder/war neurosis	2	0	5	
Requires assistance with activities of daily living	Percent of impairment group			
Preparing meals	74.0	87.5	80.0	0.32
Eating/drinking	18.2	0.0	27.6	<0.01
Transfers	44.2	7.7	55.1	<0.01
Grooming	70.5	28.0	79.9	<0.01
Toileting	35.4	16.0	47.4	<0.01
Mobility	73.8	12.0	72.6	<0.01
Household management	70.4	76.0	73.3	0.83
Recreation	33.3	44.0	45.4	0.21
Transport	86.8	87.5	85.9	0.97
Finances	49.4	87.5	80.3	<0.01

^a Missing data: 1 for relationship, 2–5 for diseases, 12–20 for activities of daily living

^b Chi-square for comparison of husband with all other relationships

^c Chi-square for comparison of 'lives with carer' with all other living arrangements

QOL are shown in Table 2. There were no significant differences in these factors in relation to the type of impairment of care recipients.

Carers' level of burden (mean CSI, CBI scores) and overall QOL (mean SF-36 scores) according to the category of impairment of the care recipient are shown in

Table 3. There were no statistically significant differences in means between the groups for physical functioning, bodily pain, mental health, emotional role limitations, and vitality. Differences which were statistically significant ($P < 0.05$) in unadjusted analysis remained after multivariate adjustment for both measures of carer burden and

Table 2 Confounding factors included in the analysis of carer burden and quality of life according to the type of impairment of the care recipient ($n = 276$)^a

Characteristic	Type of impairment			P value
	Primarily physical ($n = 85$)	Primarily cognitive ($n = 26$)	Both physical and cognitive ($n = 165$)	
	Mean (95% CI)			
Social interaction (DSSI)	9.2 (8.9–9.5)	9.0 (8.3–9.6)	8.8 (8.5–9.0)	0.08
	Percent			
Satisfied with social support (DSSI)	85.4	80.8	80.7	0.65
Carer needs help with daily tasks	21.4	38.5	20.1	0.11

^a Missing data: 43 for DSSI social interaction, 13 for DSSD satisfaction with social support, and 2 for carer's need for help with daily tasks

Table 3 Crude and adjusted means for carer burden scores, social support, and quality of life scores for groups of carers defined by the nature of care recipients' impairment

Outcome variable	Difficulty managing their lives due to impairment which is:			P value
	Primarily physical	Primarily cognitive	Both physical and cognitive	
Carer burden				
Caregiver Strain Index (CSI)				
Crude mean (95% CI)	3.7 (3.0–4.3)	3.8 (2.7–4.9)	5.5 (5.0–6.0)	<0.01
Adjusted mean (95% CI) ^a	3.6 (2.9–4.3)	3.6 (2.4–4.8)	5.4 (4.9–5.8)	<0.01
Caregiver Burden Inventory developmental subscale (CBI)				
Crude mean (95% CI)	4.3 (3.3–5.2)	6.1 (4.5–7.8)	6.4 (5.8–7.2)	<0.01
Adjusted mean (95% CI) ^a	4.1 (3.2–5.1)	6.0 (4.2–7.9)	6.4 (5.7–7.1)	<0.01
SF-36 Physical subscales				
Physical role limitations				
Crude mean (95% CI)	43.6 (35.1–52.0)	31.3 (16.0–46.5)	27.0 (21.0–32.9)	<0.01
Adjusted mean (95% CI) ^b	45.3 (36.3–54.4)	34.4 (17.1–51.7)	28.4 (22.0–34.7)	0.01
General health				
Crude mean (95% CI)	66.2 (62.1–70.3)	57.3 (49.9–64.7)	60.7 (57.7–63.6)	0.04
Adjusted mean (95% CI) ^b	66.0 (61.8–70.3)	58.1 (50.0–66.1)	61.6 (58.6–64.7)	0.13
Physical functioning				
Crude mean (95% CI)	56.4 (51.0–61.9)	47.6 (37.7–57.5)	52.2 (48.2–56.2)	0.24
Bodily pain				
Crude mean (95% CI)	59.8 (54.2–65.4)	59.3 (49.4–69.3)	55.7 (51.7–59.7)	0.45
SF-36 mental subscales				
Social functioning				
Crude mean (95% CI)	75.8 (69.7–81.8)	72.6 (61.9–83.3)	63.6 (59.2–67.9)	<0.01
Adjusted mean (95% CI) ^a	73.7 (67.4–80.0)	73.7 (62.0–85.4)	65.2 (60.8–69.7)	0.07
Mental health				
Crude mean (95% CI)	76.7 (73.1–80.3)	74.7 (68.2–81.3)	71.6 (69.0–74.2)	0.07
Emotional role limitations				
Crude mean (95% CI)	61.8 (52.2–71.4)	47.8 (30.5–65.2)	51.8 (45.0–58.5)	0.18
Vitality				
Crude mean (95% CI)	53.4 (49.3–57.4)	57.4 (50.1–64.7)	50.8 (47.8–53.7)	0.20

^a Adjusted for DSSI satisfaction with social support, DSSI social interaction, and carer's need for help with daily tasks

^b Adjusted for DSSI satisfaction with social support, DSSI social interaction

for the physical role limitations subscale of the SF-36. After adjustment for confounding, both measures of burden were higher for carers of people with both physical and cognitive impairment than impairment by either factor alone. Mean CSI for carers of those with both physical and cognitive impairment was 5.4 (95% CI 4.9–5.8) compared with means of 3.6 (95% CI 2.9–4.3, post hoc $P < 0.01$) for those with primarily physical impairment and 3.6 (95% CI 2.4–4.8, post hoc $P = 0.01$) for those with primarily cognitive impairment. Post hoc differences in the CBI developmental subscale were between carers of recipients with both cognitive and physical impairments (mean 6.4, 95% CI 5.7–7.1) and those with primarily physical impairment (mean 4.2, 95% CI 3.2–5.2, $P < 0.01$). Women caring for someone with a physical impairment alone reported better health in relation to limitation to their physical role (mean 45.3, 95% CI 36.3–54.4, post hoc $P < 0.01$) than women caring for someone with both impairments (mean 28.4, 95% CI 22.0–34.7).

When asked to judge the overall effect on their life of providing care, 12% of carers replied that it was ‘better’, 41% replied ‘neither better nor worse’, and 48% replied that it was ‘worse’. There was no significant association between the carer’s perception of the overall effect on their life of providing care and type of impairment (data not shown).

Discussion

This paper has described a study of older Australian women who care for persons with cognitive and/or physical impairment, with the principal focus being whether the type of impairment was associated with carer burden and QOL.

Like Silliman and Sternberg [11] we found that it was not useful to categorise care recipients as having only “cognitive” or “physical” impairments as the majority of care recipients were described as having both. This has implications for the types of support likely to be needed by carers.

We found substantially higher (worse) scores on the CSI, which measures objective aspects of caring, and lower (worse) scores for physical role limitations (using SF-36) for carers of people with both cognitive and physical impairment than for either type of impairment alone. In contrast, scores on the developmental subscale of the CBI, which is more of a measure of emotional strain, were significantly higher (worse) among women caring for people with cognitive impairment (with or without physical impairment). This may reflect the more emotional and time-consuming impact of cognitive impairment on carers [21].

There were some limitations in how type of impairment was measured leaving scope for misclassification which may have impacted upon the results. It would have been useful to have separated out the effects of cognitive impairment and behavioural or personality changes, as the latter have been identified as influencing burden and QOL [8, 9]. Accurate identification of cognitive or physical impairment may have been affected by using a postal survey, although we did find acceptable corroboration with the scores on the IQCODE.

These carers were recruited from a national longitudinal study on women’s health, which ensured a representative sample of women, caring for people with a wide range of health conditions. This selection method has advantages over research that focuses on members of lobby groups or support groups which may be susceptible to particular biases.

These results illustrate the substantially greater burden suffered by carers of people with both cognitive and physical impairment. They have to cope with providing higher levels of instrumental support, while incurring greater role limitations and the impact on their own lives and aspirations, compared with carers of people with only physical impairments. Our data show that the majority of elderly women carers, who are looking after their husbands, are likely to be in this most vulnerable group, while smaller proportions look after husbands with only physical impairments or children with only cognitive impairments.

The implications of our results are that support for elderly women who are carers needs to be informed by the type of impairment suffered by the people they are caring for. Instrumental support in the form of social services such as meals on wheels or personal home care (if acceptable to the carer and the care recipient) may relieve some of the burden. However, more extensive support, such as respite care or easier access to residential care or nursing homes, is likely to be needed to provide relief for the substantial burden carried by many elderly carers. To ensure the success of support programs, the carers and care recipients most in need must firstly be identified and secondly encouraged to accept such programs [21]. Identification of these carers during hospital discharge planning and at general practitioner visits would assist in the timely referral to services or carer support groups. As well as referring carers to services, primary care health practitioners could also play a greater role in providing educational materials on the benefits, range, availability, and cost of services [21, 22] and in destigmatising service use [12]. Additionally, carer support groups and organisations such as Carers Australia can play a significant role in educating carers about, linking carers with, and supporting carers to use services which may alleviate burden and improve QOL.

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Appendix 11.3 Older carers substudy survey



Caregiving Survey

Thank you for agreeing to participate in this survey of women who care for or have cared for an adult with long-term illness, disability or frailty.

Your participation is very important to us.

Please answer Question 1 over the page and follow the instructions there about the rest of the survey.

Some of the remaining questions are ABOUT YOU and some are ABOUT THE PERSON YOU CARE FOR.

When you have finished the survey please return it, including the signed consent form inside the back page, in the enclosed reply-paid envelope.

All responses are confidential. As part of the Australian Longitudinal Study on Women's Health, no people outside of this group will have access to these surveys.

How To Complete This Survey

To answer each question, circle the number corresponding to the most appropriate answer for you. For example:

Do you smoke cigarettes?
(Circle one number only)

Yes
No

①
2

You would circle '1' if you smoke cigarettes.

Please answer every question you can. If you are unsure about how to answer a question, circle the response for the closest answer to how you feel.

If you need help, please ring FREECALL 1800 068 081.

1 Thinking about providing care to an ADULT needing assistance because of ill health, disability or frailty: which of the following statements best describes your situation?

I CURRENTLY care for an adult who requires assistance (they may be living with you or have moved to a nursing home or care facility such as a hostel)

1 → *Please complete all of this survey.*

I WAS providing care for an adult who required assistance who has passed away in **the last 12 months**

2 → *We understand this may be difficult for you. Please answer the questions on the following pages as well as you can, recalling the last few months before their passing.*

I WAS providing care for an adult who required assistance, however they passed **away more than 12 months ago**

3 → *Thank you. That is all the questions, please sign the consent form on the inside of the back page and return the survey in the enclosed envelope.*

I HAVE NOT cared for an adult who requires assistance

4 → *Thank you. That is all the questions, please sign the consent form on the inside of the back page and return the survey in the enclosed envelope.*

If you are providing care for MORE THAN ONE PERSON, please select the PERSON YOU HAVE CARED FOR THE LONGEST and answer the questions in relation to that person.

These questions are about the PERSON YOU PROVIDE CARE FOR NOW or PROVIDED CARE FOR RECENTLY, BEFORE THEY PASSED AWAY

- 2 What is the relationship to you of the PERSON YOU CARE FOR?** (Circle one number only)
- | | | |
|--|-----------------------|---|
| | Husband or partner | 1 |
| | Brother | 2 |
| | Sister | 3 |
| | Daughter | 4 |
| | Son | 5 |
| | Other, please specify | 6 |
-

3 How old is the PERSON YOU CARE FOR? _____ Age in years

4 How long have you been caring for this person?
 _____ Years **OR** _____ Months

5 Does the PERSON YOU CARE FOR? (Circle one number only)

Live with you	1		
Live alone	2		
Live with their family	3		
Live with their friends	4		
Live in a nursing home or care facility	5	➔	How long have they lived there? _____ Years
Other	6	➔	<i>Please describe</i>

6 Does the PERSON YOU CARE FOR have difficulty managing their daily lives because of:

(Circle one number on each line)

Not at all A little A lot

a Cognitive problems , that is, remembering things, making decisions or planning or organising	1	2	3
b Physical problems , for example, moving around, using their arms and legs, weakness	1	2	3

7 Does the PERSON YOU CARE FOR have any of the following major medical conditions or disabilities?

(Circle one number on each line)

		Yes	No
a	Stroke	1	2
b	Parkinson's disease	1	2
c	Alzheimer's disease/Dementia	1	2
d	Multiple sclerosis	1	2
e	Arthritis/rheumatism	1	2
f	Lung or breathing problems	1	2
g	Heart disease	1	2
h	Other, <i>please describe below</i>	1	2

If there are any more conditions, please continue this list on Page 31

8 Does the PERSON YOU CARE FOR have:

(Circle one number on each line)

		Yes	No
a	Veterans' Affairs coverage for health services?	1	2
b	Private health insurance for Hospital services?	1	2
c	Private health insurance for Ancillary services? (eg. physiotherapy or dental services)	1	2

The next set of questions is about the types of help that the PERSON YOU CARE FOR needs. (“Help” refers to assistance or supervision which is needed because the person cannot do the task safely by themselves)

9 Does the PERSON YOU CARE FOR need help with washing, dressing or grooming? (Circle one number only)

Yes 1 → Please answer parts a, b, c & d
 No 2 → Go to Question 10

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

10 Does the PERSON YOU CARE FOR need help with preparing meals? (Circle one number only)

Yes 1 → Please answer parts a, b, c & d
 No 2 → Go to Question 11

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

11 Does the PERSON YOU CARE FOR need help with eating or drinking?
(Circle one number only)

- Yes 1 → *Please answer parts a, b, c & d*
 No 2 → *Go to Question 12*

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

12 Does the PERSON YOU CARE FOR need help with getting on or off the bed, toilet, chair etc?
(Circle one number only)

- Yes 1 → *Please answer parts a, b, c & d*
 No 2 → *Go to Question 13*

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

13 Does the PERSON YOU CARE FOR need help with managing the toilet or continence? *(Circle one number only)*

Yes 1 → *Please answer parts a, b, c & d*
 No 2 → *Go to Question 14*

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

14 Does the PERSON YOU CARE FOR need help with mobility (walking or wheelchair, stairs, etc)? *(Circle one number only)*

Yes 1 → *Please answer parts a, b, c & d*
 No 2 → *Go to Question 15*

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

15 Does the PERSON YOU CARE FOR need help with household management (eg. shopping, cleaning)? *(Circle one number only)*

- Yes 1 → *Please answer parts a, b, c & d*
 No 2 → *Go to Question 16*

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

16 Does the PERSON YOU CARE FOR need help with recreation or hobbies? *(Circle one number only)*

- Yes 1 → *Please answer parts a, b, c & d*
 No 2 → *Go to Question 17*

(Circle one number on each line)

	Every day	A few times a week	A few times a month	Hardly ever	Never
a How often do YOU provide this help?	1	2	3	4	5
b How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d How often is this help needed but NOT provided?	1	2	3	4	5

17 Does the PERSON YOU CARE FOR need help with transportation?

(Circle one number only)

Yes 1 → *Please answer parts a, b, c & d*

No 2 → *Go to Question 18*

(Circle one number on each line)

		Every day	A few times a week	A few times a month	Hardly ever	Never
a	How often do YOU provide this help?	1	2	3	4	5
b	How often does a different unpaid caregiver (eg another relative) provide this help?	1	2	3	4	5
c	How often do paid services (eg community, government or private) provide this help?	1	2	3	4	5
d	How often is this help needed but NOT provided?	1	2	3	4	5

18 Does the PERSON YOU CARE FOR need help with management of finances, insurance etc? *(Circle one number only)*

Yes 1 → *Please answer parts a, b, c & d*

No 2 → *Go to Question 19*

(Circle one number on each line)

		Yes	No
a	Do YOU provide this help?	1	2
b	Does a different unpaid caregiver (eg. another relative) provide this help?	1	2
c	Do paid services (eg. community, government or private) provide this help?	1	2
d	Is this help needed but NOT provided?	1	2

Questions 19 to 23 are about particular government or community services that the PERSON YOU CARE for may receive. After these questions you will have a chance to comment on other services as well.

19 How easy is it for the PERSON YOU CARE FOR to get the following health services? (Circle one number on each line)

		Very difficult	Somewhat difficult	Easy	Very easy	Don't know
a	House calls by the doctor	1	2	3	4	5
b	The doctor of their choice	1	2	3	4	5
c	A specialist doctor	1	2	3	4	5
d	A hospital doctor	1	2	3	4	5
e	Admission to a hospital	1	2	3	4	5
f	A dentist	1	2	3	4	5
g	Allied health services (eg. physiotherapy)	1	2	3	4	5

h Do YOU have any complaints or comments about health services?
Please tell us about them. There is more space on Page 31 if needed.

20 These questions are about Meals on Wheels or other services delivering meals to your home.

a How much information about **MEALS ON WHEELS** has you or the **PERSON YOU CARE FOR** received? *(Circle one number only)*

- No information 1 → Go to c
- Some information, but not enough 2 → Go to b
- Enough information 3 → Go to b

b Where did **YOU** or the **PERSON YOU CARE FOR** get the information?

c Is **MEALS ON WHEELS** available to the **PERSON YOU CARE** for? *(Circle one number only)*

- Service is available 1 → Go to d
- Service is NOT available 2 → Go to Question 21
- Don't know 3 → Go to Question 21

d Has the **PERSON YOU CARE** for used **MEALS ON WHEELS**? *(Circle one number only)*

- Don't need this service 1 → Go to Question 21
- No, either I or the **PERSON I CARE FOR** choose not to use it 2 → Go to e
- Have used it 3 → Go to f
- Don't know 4 → Go to Question 21

e Can you explain why you chose **NOT** to use this service? *(eg. You don't like the people who come, the service provided is poor)*

Go to Question 21

These questions are about Meals on Wheels or other services delivering meals to your home.

- f How easy was it to get this service?** *(Circle one number only)*
- | | | | | |
|----------------|--------------------|------|-----------|------------|
| Very difficult | Somewhat difficult | Easy | Very easy | Don't know |
| 1 | 2 | 3 | 4 | 5 |
- g After requesting MEALS ON WHEELS, how long did the PERSON YOU CARE FOR have to wait before the service started?** *(Circle one number only)*
- | | |
|-----------------------------|---|
| Less than 2 weeks | 1 |
| Between 2 weeks and 1 month | 2 |
| More than 1 month | 3 |
| Don't know | 4 |
- h How often does the PERSON YOU CARE FOR receive MEALS ON WHEELS?** *(Circle one number only)*
- | | |
|------------------------|---|
| Every day | 1 |
| Several days a week | 2 |
| One day a week or less | 3 |
- i How often would the PERSON YOU CARE FOR like to receive MEALS ON WHEELS?** *(Circle one number only)*
- | | |
|------------------------|---|
| Every day | 1 |
| Several days a week | 2 |
| One day a week or less | 3 |
- j How would YOU rate the quality of the MEALS ON WHEELS service received by the PERSON YOU CARE FOR?** *(Circle one number only)*
- | | |
|-----------|---|
| Excellent | 1 |
| Very good | 2 |
| Average | 3 |
| Poor | 4 |
| Very poor | 5 |
- k Do YOU have any complaints or comments about the MEALS ON WHEELS service?** *(Please describe)*

21 These questions are about **PERSONAL HOME CARE** eg assistance with self care (bathing, dressing) and nursing care (wound care, continence) by someone paid to do this.

a How much information about **PERSONAL HOME CARE** has you or the **PERSON YOU CARE FOR** received? (*Circle one number only*)

- No information 1 → *Go to c*
- Some information, but not enough 2 → *Go to b*
- Enough information 3 → *Go to b*

b Where did **YOU** or the **PERSON YOU CARE FOR** get the information?

c Is **PERSONAL HOME CARE** available to the **PERSON YOU CARE for**? (*Circle one number only*)

- Service is available 1 → *Go to d*
- Service is NOT available 2 → *Go to Question 22*
- Don't know 3 → *Go to Question 22*

d Has the **PERSON YOU CARE for** used **PERSONAL HOME CARE**? (*Circle one number only*)

- Don't need this service 1 → *Go to Question 22*
- No, either I or the **PERSON I CARE FOR** choose not to use it 2 → *Go to e*
- Have used it 3 → *Go to f*
- Don't know 4 → *Go to Question 22*

e Can you explain why you chose **NOT** to use this service? (*eg. You don't like the people who come, the service provided is poor*)

Go to Question 22

These questions are about **PERSONAL HOME CARE** eg assistance with self care (bathing, dressing) and nursing care (wound care, continence) by someone paid to do this.

- f How easy was it to get this service?** *(Circle one number only)*
- | | | | | |
|----------------|--------------------|------|-----------|------------|
| Very difficult | Somewhat difficult | Easy | Very easy | Don't know |
| 1 | 2 | 3 | 4 | 5 |
- g After requesting PERSONAL HOME CARE, how long did the PERSON YOU CARE FOR have to wait before the service started?** *(Circle one number only)*
- | | |
|-----------------------------|---|
| Less than 2 weeks | 1 |
| Between 2 weeks and 1 month | 2 |
| More than 1 month | 3 |
| Don't know | 4 |
- h How often does the PERSON YOU CARE FOR receive PERSONAL HOME CARE?** *(Circle one number only)*
- | | |
|------------------------|---|
| Every day | 1 |
| Several days a week | 2 |
| One day a week or less | 3 |
- i How often would the PERSON YOU CARE FOR like to receive PERSONAL HOME CARE?** *(Circle one number only)*
- | | |
|------------------------|---|
| Every day | 1 |
| Several days a week | 2 |
| One day a week or less | 3 |
- j How would YOU rate the quality of the PERSONAL HOME CARE service received by the PERSON YOU CARE FOR?** *(Circle one number only)*
- | | |
|-----------|---|
| Excellent | 1 |
| Very good | 2 |
| Average | 3 |
| Poor | 4 |
| Very poor | 5 |
- k Do YOU have any complaints or comments about the PERSONAL HOME CARE service?** *(Please describe)*

22 These questions are about Domestic Home Care such as cleaning, ironing, shopping or gardening by someone paid to do this (that is, home help NOT INCLUDING NURSING CARE).

a How much information about DOMESTIC HOME CARE has you or the PERSON YOU CARE FOR received? *(Circle one number only)*

- No information 1 → Go to c
- Some information, but not enough 2 → Go to b
- Enough information 3 → Go to b

b Where did YOU or the PERSON YOU CARE FOR get the information?

c Is DOMESTIC HOME CARE available to the PERSON YOU CARE for? *(Circle one number only)*

- Service is available 1 → Go to d
- Service is NOT available 2 → Go to Question 23
- Don't know 3 → Go to Question 23

d Has the PERSON YOU CARE for used DOMESTIC HOME CARE? *(Circle one number only)*

- Don't need this service 1 → Go to Question 23
- No, either I or the PERSON I CARE FOR choose not to use it 2 → Go to e
- Have used it 3 → Go to f
- Don't know 4 → Go to Question 23

e Can you explain why you chose NOT to use this service? *(eg. You don't like the people who come, the service provided is poor)*

Go to Question 23

These questions are about Domestic Home Care such as cleaning, ironing, shopping or gardening by someone paid to do this (that is, home help NOT INCLUDING NURSING CARE).

f How easy was it to get this service? *(Circle one number only)*

Very difficult	Somewhat difficult	Easy	Very easy	Don't know
1	2	3	4	5

g After requesting DOMESTIC HOME CARE, how long did the PERSON YOU CARE FOR have to wait before the service started? *(Circle one number only)*

Less than 2 weeks	1
Between 2 weeks and 1 month	2
More than 1 month	3
Don't know	4

h How often does the PERSON YOU CARE FOR receive DOMESTIC HOME CARE? *(Circle one number only)*

Every day	1
Several days a week	2
One day a week or less	3

i How often would the PERSON YOU CARE FOR like to receive DOMESTIC HOME CARE? *(Circle one number only)*

Every day	1
Several days a week	2
One day a week or less	3

j How would YOU rate the quality of the DOMESTIC HOME CARE service received by the PERSON YOU CARE FOR? *(Circle one number only)*

Excellent	1
Very good	2
Average	3
Poor	4
Very poor	5

k Do YOU have any complaints or comments about the DOMESTIC HOME CARE service? *(Please describe)*

23 These questions are about **RESPITE CARE**, that is, any service provided to give **YOU** a break from caring, This service may be provided in your home or in a place where the **PERSON YOU CARE FOR** can go.

a How much information about **RESPITE CARE** have you received?
(Circle one number only)

- No information 1 → Go to c
- Some information, but not enough 2 → Go to b
- Enough information 3 → Go to b

b Where did **YOU** get the information?

c Is **RESPITE CARE** available to you? (Circle one number only)

- Service is available 1 → Go to d
- Service is NOT available 2 → Go to Question 24
- Don't know 3 → Go to Question 24

d Have you used **RESPITE CARE**? (Circle one number only)

- Don't need this service 1 → Go to Question 24
- No, I choose not to use it 2 → Go to e
- Have used it 3 → Go to f
- Don't know 4 → Go to Question 24

e Can you explain why you chose **NOT** to use this service?
(eg. You don't like the people who come, the service provided is poor)

Go to Question 24

These questions are about RESPITE CARE, that is, any service provided to give YOU a break from caring, This service may be provided in your home or in a place where the PERSON YOU CARE FOR can go.

f How easy was it to get this service? *(Circle one number only)*

Very difficult	Somewhat difficult	Easy	Very easy	Don't know
1	2	3	4	5

g After requesting RESPITE CARE, how long did you have to wait before the service started? *(Circle one number only)*

	Less than 2 weeks	1
	Between 2 weeks and 1 month	2
	More than 1 month	3
	Don't know	4

h How often DO you receive RESPITE CARE? *(Circle one number only)*

	Every day	1
	Several days a week	2
	One day a week or less	3

i How often would you LIKE to receive RESPITE CARE? *(Circle one number only)*

	Every day	1
	Several days a week	2
	One day a week or less	3

j How would YOU rate the quality of the RESPITE CARE service received? *(Circle one number only)*

	Excellent	1
	Very good	2
	Average	3
	Poor	4
	Very poor	5

k Do YOU have any complaints or comments about the RESPITE CARE service? *(Please describe)*

24 Please list ANY OTHER government or community services that the PERSON YOU CARE FOR receives. Include any comments or complaints you have about them.

25 Are there any services you or PERSON YOU CARE FOR want but are not getting? (please describe)

26 Did you know the PERSON YOU CARE FOR 10 years ago?

(Circle one number only)

Yes 1 → Go to Question 27

No 2 → Go to Question 28

27 We want you to remember what the PERSON YOU CARE FOR was like 10 years ago and to compare it with what he/she is like now. Ten years ago was 1994. Below are situations where they have had to use their memory or intelligence and we want you to indicate whether this has improved, stayed the same or got worse over the past 10 years. So, if 10 years ago this person always forgot where she/he had left things, and he/she still does, then this would be considered “not much change”. Please indicate the changes you have observed by *circling one number on each line.*

**Compared with 10 years ago
how well does the person
you care for:**

		Much improved	A bit improved	Not much change	A bit worse	Much worse
a	Remember things about family and friends eg occupations, birthdays, addresses	1	2	3	4	5
b	Remember things that have happened recently	1	2	3	4	5
c	Recall conversations a few days later	1	2	3	4	5
d	Remember his/her address and telephone number	1	2	3	4	5
e	Remember what day and month it is	1	2	3	4	5
f	Remember where things are usually kept	1	2	3	4	5
g	Remember where to find things which have been put in a different place from usual	1	2	3	4	5
h	Know how to work familiar machines around the house	1	2	3	4	5
i	Learn how to use a new gadget or machine around the house	1	2	3	4	5
j	Learn new things in general	1	2	3	4	5

Continued over the page

Compared with 10 years ago how well does the person you care for:		Much improved	A bit improved	Not much change	A bit worse	Much worse
k	Follow a story in a book or on TV	1	2	3	4	5
l	Make decisions on everyday matters	1	2	3	4	5
m	Handle money for shopping	1	2	3	4	5
n	Handle financial matters e.g. the pension, dealing with the bank	1	2	3	4	5
o	Handle other everyday arithmetic problems eg. knowing how much food to buy, knowing how long between visits from family or friends	1	2	3	4	5
p	Use his/her intelligence to understand what's going on and to reason things through	1	2	3	4	5



Why not have a cup of tea and a short break before doing the rest of the survey!

31 During THE PAST 4 WEEKS, have you had any of the following problems with your work (including your work outside the home and housework) or other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?

(Circle one number on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	1	2
b	Accomplished less than you would like	1	2
c	Were limited in the kind of work or other activities	1	2
d	Had difficulty performing the work or other activities (for example it took extra effort)	1	2

32 During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

(Circle one number on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	1	2
b	Accomplished less than you would like	1	2
c	Didn't do work or other activities as carefully as usual	1	2

33 During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

(Circle one number only)

Not at all Slightly Moderately Quite a bit Extremely
 1 2 3 4 5

34 How much BODILY pain have you had during the PAST 4 WEEKS?

(Circle one number only)

No bodily pain Very mild Mild Moderate Severe Very severe
 1 2 3 4 5 6

35 During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

(Circle one number only)

Not at all A little bit Moderately Quite a bit Extremely
 1 2 3 4 5

36 For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS:

(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a	Did you feel full of life?	1	2	3	4	5	6
b	Have you been a very nervous person?	1	2	3	4	5	6
c	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d	Have you felt calm and peaceful?	1	2	3	4	5	6
e	Did you have a lot of energy?	1	2	3	4	5	6
f	Have you felt down?	1	2	3	4	5	6
g	Did you feel worn out?	1	2	3	4	5	6
h	Have you been a happy person?	1	2	3	4	5	6
i	Did you feel tired?	1	2	3	4	5	6

37 During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting friends, relatives, etc)? *(Circle one number only)*

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

38 How TRUE or FALSE is EACH of the following statements for you? *(Circle one number on each line)*

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	I seem to get sick a little easier than other people	1	2	3	4	5
b	I am as healthy as anybody I know	1	2	3	4	5
c	I expect my health to get worse	1	2	3	4	5
d	My health is excellent	1	2	3	4	5

41 Do YOU regularly NEED help with daily tasks because of long-term illness, disability or frailty? (eg. personal care, getting around, preparing meals etc)

(Circle one number only)

Yes 1 → *Please describe*

No 2 → *Go to Question 43*

Please describe the type of help you receive and who provides this help

42 How satisfied are YOU with the help you receive?

(Circle one number only)

Very
Satisfied
1

Satisfied
2

Dissatisfied
3

Very
Dissatisfied
4

43 Are there any groups who have provided significant support to YOU in your role as carer? (eg. a stroke support group) *(please describe)*

44 Are there any government services, such as CentreLink, who have provided significant support to YOU in your role as carer? *(please describe)*

The next set of questions asks about whether YOU have people to talk to and support you. (Circle one number on each line for Questions 45 to 54 below)

		None	1	2	3	4	5	6	7 or more
45	How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?	0	1	2	3	4	5	6	7
46	How many times did you talk to someone (friends, relatives or others) on the telephone in the past week (either they called you, or you called them)?	0	1	2	3	4	5	6	7
47	About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?	0	1	2	3	4	5	6	7

		Hardly ever	Some of the time	Most of the time
48	Does it seem that your family and friends (people who are important to you) understand you?	1	2	3
49	Do you feel useful to your family and friends (people important to you)?	1	2	3
50	Do you know what is going on with your family and friends?	1	2	3
51	When you are talking with your family and friends, do you feel you are being listened to?	1	2	3
52	Do you feel you have a definite role (place) in your family and among your friends?	1	2	3
53	Can you talk about your deepest problems with at least some of your family and friends?	1	2	3
54	How many people in your local area do you feel you can depend on or feel very close to (other than members of your family)? <i>(Circle one only)</i>		None	1
			1 - 2 people	2
			More than 2 people	3

55 Here is a list of things that carers sometimes find to be issues when caring for somebody. Please read each statement and circle one response for each statement as it applies to how YOU feel in caring for the PERSON YOU CARE FOR.

		Yes	No
a	Your sleep is disturbed (eg. because they wake or need help at night)	1	2
b	It is inconvenient to care for them (eg. because it takes so much time)	1	2
c	It is a physical strain (eg. because of lifting, helping)	1	2
d	It is confining (eg. because it stops you doing other things)	1	2
e	There have been family adjustments (eg. disrupted routines, no privacy)	1	2
f	There have been changes in personal plans (eg. changes to holidays, work)	1	2
g	There have been other demands on your time (eg. from other family members, friends)	1	2
h	There have been emotional adjustments (eg. arguments or conflict)	1	2
i	Some behaviour is upsetting (eg. wetting clothes or bedding, or memory problems, or impulsiveness)	1	2
j	It is upsetting that the person you care for has changed and is not the same person as he/she used to be	1	2
k	There have been work adjustments (eg. because of having to take time off or leave work)	1	2
l	It is a financial strain	1	2
m	Feeling completely overwhelmed (for eg. because of worry about them or concerns for how you will manage)	1	2

56 Overall, what is the effect on YOUR life of providing care?
(Circle one number only)

- My life is a LOT better for it 1
- My life is a LITTLE better for it 2
- My life is a neither better or worse 3
- My life is a LITTLE worse for it 4
- My life is a LOT worse for it 5



Family caregivers: do health and community services meet their needs?

CONSENT FORM

I understand that this research is a substudy of the Women's Health Australia project, and I have read and understood the *Information for Participants* statement which was sent to me.

I understand that completing and returning the survey is voluntary.

I understand that I may be phoned by one of the researchers to clarify survey responses.

I understand that my responses to the survey will be entered into a database and that no personal details, such as name and address, will be included in this database. I understand that the surveys will be stored in a secure area at the School of Population Health, University of Queensland.

I understand that all information will be confidential, subject to legal requirements, and only anonymous summary data will be reported.

I realise that I can withdraw from the study at any time and do not have to give my reasons for withdrawing.

I have had all my questions relating to the study answered satisfactorily.

Name _____

Signed_____ **Date**_____

If you have any concerns about this project, and would prefer to discuss these with an independent person, you should feel free to contact the University of Newcastle's Human Research Ethics Officer, Ms Sue O'Connor, on 02 4921 6333 or write to her at Research Branch, The University of Newcastle, University Drive, Callaghan NSW 2308 or the Ethics Officer, Office of Research and Postgraduate Studies at the University of Queensland, Qld 4072 on 07 3365 3924.

***Thank you for taking the time
to complete this survey.***



*Australian Longitudinal Study on Women's
Health*

The University of Newcastle, Callaghan NSW 2308.

Phone: 02 4923 6872 Fax: 02 4923 6888 Email: whasec@newcastle.edu.au

Web: <http://www.newcastle.edu.au/centre/wha>

Appendix 11.4 Profile of the ALSWH 1921-1926 cohort

Table 10 Demographic profile of carers who responded to the older carer substudy and the 1921-1926 cohort of women who responded to Survey 3 (2002) of the ALSWH

	Older carers substudy women (n=280*)	1921-1926 ALSWH cohort (n=8418*)
Age (years) [mean (SD)]	78.0 (1.5)	78.3 (1.5)
Marital status (%)		
Married	92	44
De facto	1	1
Divorced	1	5
Widowed	5	47
Never married	1	3
Residence** (%)		
Major city	40	44
Inner regional	41	37
Outer regional	18	17
Remote	1	2
Very remote	0	0
Language† (%)		
English	97	90
Other	3	10
Education† (%)		
No formal qualifications	20	34
School or intermediate certificate	46	37
Higher school or leaving certificate	13	13
Trade / apprenticeship	5	4
Certificate / diploma	12	8
University degree	3	3
University higher degree	1	1
Volunteer work (%)		
Every day	2	2
Every week	17	20
Every month	19	15
Less than once a month	7	7
Not at all	55	56
Manage on available income (%)		
It is impossible	0	1
It is difficult all the time	5	6
It is difficult some of the time	15	18
It is not too bad	55	51
It is easy	25	24
Insurance cover‡ (%)		
Veterans' Affairs cover	18	19
Private hospital insurance	50	50
Private ancillary insurance	34	35

* Actual sample sizes vary for each variable due to missing data. SD=standard deviation.

** Areas of residence were based on the ARIA+ system, which is determined by remoteness based on the distance to the nearest service centre.

† These data for all ALSWH participants were obtained from Survey 1 (1996)

‡ Percentages do not add up to 100 as care recipients could have selected more than one response.

Appendix 11.5 Sample sizes and frequency of responses

Table 11 Sample sizes and frequency of responses to each survey question for the four services

	Meals on Wheels n/N (%)	Personal home care n/N (%)	Domestic home care n/N (%)	Respite care n/N (%)
Have received enough information				
Enough	116/231 (50)	152/238 (64)	159/251 (63)	137/256 (54)
Not enough	115/231 (50)	86/238 (36)	92/251 (37)	119/256 (46)
Service is available				
Available	143/231 (62)	162/237 (68)	162/243 (67)	144/238 (61)
Not available / don't know	88/231 (38)	75/237 (32)	81/243 (33)	94/238 (39)
Have used the service				
Used	34/48 (71)	89/104 (86)	100/132 (76)	66/99 (67)
Not used	14/48 (29)	15/104 (14)	32/132 (24)	33/99 (33)
Easy to access the service				
Easy	36/37 (97)	85/90 (94)	88/107 (82)	53/72 (74)
Difficult	1/37 (3)	5/90 (6)	19/107 (18)	19/72 (26)
Wait time for start of service				
Less than 2 weeks	31/36 (86)	71/93 (76)	56/104 (54)	29/65 (45)
2 to 4 weeks	1/36 (3)	11/93 (12)	35/104 (34)	19/65 (29)
More than 4 weeks	0/36 (0)	1/93 (1)	6/104 (6)	13/65 (20)
Don't know	4/36 (11)	10/93 (11)	7/104 (6)	4/65 (6)
Frequency of service use				
Every day	4/21 (19)	11/78 (14)	2/95 (2)	2/47 (4)
Several days per week	12/21 (57)	45/78 (58)	3/95 (3)	6/47 (13)
Once a week or less often	5/21 (24)	22/78 (28)	90/95 (95)	39/47 (83)
Frequency would like to use service				
Every day	3/20 (15)	13/67 (19)	3/87 (3)	2/48 (4)
Several days per week	9/20 (45)	39/67 (58)	11/87 (13)	9/48 (19)
Once a week or less often	8/20 (40)	15/67 (22)	73/87 (84)	37/48 (77)
Service of good quality				
Good quality	23/30 (77)	82/86 (95)	74/98 (76)	46/58 (79)
Poor quality	7/30 (23)	4/86 (5)	24/98 (24)	12/58 (21)

Denominators vary due to missing data on some items. The denominator (N) represents the number of carers that responded to that question. The numerator (n) represents the number of carers that responded to the response option.



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