

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

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## 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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## 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 growth<sup>1</sup> or feelings of gratification, pride and resiliency,<sup>2</sup> 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.<sup>3</sup> Appropriate services have the potential to reduce the stress and burden felt by carers.<sup>4</sup>

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.<sup>3</sup> 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.<sup>5</sup> Particularly low service use has been reported among carers of people with neurological impairments<sup>5-7</sup> and by carers belonging to minority groups<sup>8</sup> or living in rural areas.<sup>9</sup>

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.<sup>10</sup> 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.<sup>10</sup>

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.<sup>11</sup> 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) |
|------------------------------------|-----------------|-----------------|-----------------------|
| <b>Total</b>                       | <b>113 (40)</b> | <b>169 (60)</b> | –                     |
| <b>Relationship to caregiver</b>   | <b>111</b>      | <b>169</b>      | –                     |
| 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)           |
| <b>Living status</b>               | <b>112</b>      | <b>169</b>      |                       |
| Live with caregiver                | 109 (97)        | 168 (99)        | 2 (–1 to 5)           |
| Other                              | 3 (3)           | 1 (1)           | –2 (–5 to 1)          |
| <b>Medical conditions†</b>         |                 |                 |                       |
| 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) |
|--------------------------------------|-----------------|-----------------|-------------------------|
| <b>Help needed</b>                   |                 |                 |                         |
| 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)           |
| <b>Ever paid for help†</b>           |                 |                 |                         |
| 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)           |
| <b>Needed help but not received†</b> |                 |                 |                         |
| 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 <sup>†</sup>    | Difficult to access                 |                                     | Rural – Urban*<br>(95% CI) |
|-------------------------|-------------------------------------|-------------------------------------|----------------------------|
|                         | Urban<br>( <i>n</i> / <i>N</i> [%]) | Rural<br>( <i>n</i> / <i>N</i> [%]) |                            |
| House calls by a doctor | 30/81<br>(37)                       | 56/112<br>(50)                      | 13<br>(–1 to 27)           |
| Doctor of choice        | 16/95<br>(17)                       | 20/149<br>(13)                      | –3<br>(–13 to 6)           |
| Specialist doctor       | 16/85<br>(19)                       | 38/136<br>(28)                      | 9<br>(–2 to 20)            |
| Hospital doctor         | 15/70<br>(21)                       | 19/111<br>(17)                      | –4<br>(–16 to 8)           |
| Admission to hospital   | 16/91<br>(18)                       | 25/143<br>(17)                      | 0<br>(–10 to 10)           |
| Dentist                 | 17/81<br>(21)                       | 34/122<br>(28)                      | 7<br>(–5 to 19)            |
| Allied health           | 13/68<br>(19)                       | 26/125<br>(21)                      | 2<br>(–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.<sup>3,10,12-14</sup> 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) |
|---|---------------|---------------|-------------------------|
| <b>Meals on Wheels</b>                  |               |               |                         |
| 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 <sup>†</sup>      | 9/15 (60)     | 25/29 (86)    | 26 (–2 to 54)           |
| Easy to access the service <sup>‡</sup> | 8/9 (89)      | 24/24 (100)   | 11 (–9 to 32)           |
| Service of good quality <sup>‡</sup>    | 6/8 (75)      | 16/21 (76)    | 1 (–34 to 36)           |
| <b>Personal home care</b>               |               |               |                         |
| 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)           |
| <b>Domestic home care</b>               |               |               |                         |
| 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)            |
| <b>Respite care</b>                     |               |               |                         |
| 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.<sup>4,7-9,15</sup>

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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