

Understanding the use of respite services among informal carers

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Abstract

Objective: To examine the use of respite services among carers of non-institutionalised individuals aged 15 and over with either profound or severe disabilities.

Methods: Based on data collected from the Australian Survey of Disability, Ageing and Carers in 2003, the investigation evaluated the statistical significance of a number of carer and recipient characteristics on the likelihood of the use of respite services. Further analysis assisted in identifying the support most desired by the majority of carers (88.6%, $n=243\ 690$) who have never used respite.

Results: The results revealed that social and cultural factors played a critical role in the receipt of respite services. Family relationships were important. Just under one-fifth of all primary carers most preferred more financial assistance in their role as caregiver. After controlling for confounding variables it was found that, compared with other forms of assistance, the desire for an improvement in the primary carers' own health was more likely among non-respite users. This may reflect the carers' preference to improve their own capacity to service the recipient rather than rely on others outside the household.

Conclusions: Since the recipients under investigation typically possess core communication restrictions and highly individualised needs, it is speculated that carers perceive family members as better able to interpret and meet the sporadic and individualised care demands of recipients.

Implications: Given the low usage of respite services among primary informal carers, policy makers and health organisations need to dispel the "one size fits all" approach to support services for households.

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What is known about the topic?

The de-institutionalisation of the Australian health care system, coupled with an ageing Australian population, has placed greater care burdens on family members of individuals with disabilities. Community support services, such as respite, assist in maintaining high quality care at home, yet a relatively large proportion of Australian carers of recipients with disabilities do not use respite services.

What does this paper add?

This study used data from the 2003 Australian Survey of Disability, Ageing and Carers and examined the use of respite services among carers of individuals aged 15 and over with either profound or severe disabilities residing at home.

What are the implications for practitioners?

Primary caregivers prefer financial assistance. Non-respite users would rather improve their own health compared with other forms of assistance. This implies that practitioners need to give greater attention to strategies that will improve the capacity of caregivers to manage their duties.

AUSTRALIA'S POPULATION continues to age at an unprecedented rate, accompanied by an increase in disability rates and a dramatic rise in the proportion of Australians with either profound or severe restrictions.¹ Of particular concern to policy makers are the continuing constraints on the health care system and the anticipated increase in costs associated with the care and support of a rapidly ageing population. This has led to community care programs receiving increased attention as a cost-effective way of providing services for people in their own homes rather than in institutions.^{2,3}

The Australian Government's emphasis on home-based care has led to informal carers becoming the linchpin of the community care programs.⁴⁻⁷ Informal carers are usually family members who provide unpaid care and support

to individuals who have a disability or frailty. For many of these carers, formal support services, such as respite, are central to maintaining high quality care at home. Respite services offer family members regular breaks from caring. Many organisations and individuals provide these services either in the home or elsewhere for a few hours, a day, or longer. Services may be partly or fully subsidised by the government while others are set at the market price.⁸

In Australia a relatively large proportion of primary carers do not use respite services.⁹ This may reflect the highly individualised and sporadic needs of this group that often require flexibility in the management of care. This study examines the use of respite services among carers of individuals aged 15 years and over with either profound or severe disabilities residing at home. Analysis is based on data collected from the Survey of Disability, Ageing and Carers (SDAC).¹⁰ This study evaluates the statistical significance of socio-economic variables on the likelihood of using respite services. Factors analysed include family composition, care and recipient characteristics and environmental factors. Further analysis identifies the types of support most desired by a primary carer. Understanding the factors that influence the use of respite services will assist policy makers in implementing effective and efficient community care programs that meet the needs of an ageing population.

A substantial amount of literature has been generated on the influences of informal care. The consensus among researchers is that the characteristics of carers and their recipients predict informal care.¹¹⁻¹³ The amount of assistance required that allows an individual to reside at home is also determined by the severity of the disability,¹³⁻¹⁷ the perception of unmet needs and opportunity costs.¹⁸

Several qualitative studies examined respite usage among Australians. Factors influencing the non-utilisation of respite care services among older carers of Sydney residents with a mental illness included the carer's lack of understanding of respite care, passivity towards respite care, negativity towards mental health services and the

recipient's attitude towards respite care.¹⁹ Other issues identified in the study included the health staff's lack of understanding of respite services, attitudes towards carers' need for respite, lack of flexibility and focus particularly in the area of mental health, and inadequate respite care and related services. A further study of interviews of 144 caregivers in Canberra revealed that a dysfunctional relationship between the carer and care recipient increased the likelihood of using respite care. Other factors included being female and dealing with high task demands.²⁰ A review of the literature by Jeon and colleagues²¹ reported a significant unmet need in the provision of respite services for the mentally ill. They identified a need for greater quality, quantity, variety and flexibility in respite provision.

The majority of studies that investigate respite care are qualitative and use a relatively small sample of individuals.^{19,20,22-24} Since data are often sourced from local rather than national surveys the conclusions of these studies may not be suitable for policy purposes. Research tends to focus on the impact of respite care on specific groups, such as individuals with dementia and family members of recipients.²⁴ There is consensus within this literature that respite programs do provide benefits to clients, their carers and families.

More recently, the research has moved to the issue of service allocation. A healthy debate now exists with critics of traditional community-based services arguing that decisions on service allocation tend to be based more on the interest of the agency than in response to recipient needs. Consumer-directed approaches that are believed to empower recipients and their carers by shifting the choices and responsibilities of care to the recipient and their family have gathered momentum.²⁵⁻²⁸ Outcomes include greater flexibility and choice that often involve non-medical and low technological support rather than skilled staff and extensive external monitoring.

Informal carers play a pivotal role in the health and maintenance of the frail and disabled residing in the community. This study poses two questions:

1. Who are the likely users of respite services?
2. What type of support is most desired by carers?

Several terms used throughout this paper are clarified in Box 1.

Methods

The Survey of Disability, Ageing and Carers (SDAC), conducted by the Australian Bureau of Statistics throughout Australia in the months of June to November 2003, covered people in both urban and rural areas in all states and territories. Trained interviewers collected the household component of the survey. Where possible, a personal interview was conducted with people identified as either disabled, and/or aged 60 years and over, and those providing care to them.¹⁰

Based on the SDAC, the analysis was confined to primary carers of non-institutionalised people aged 15 and over who possessed either a pro-

found or severe disability. After excluding individuals who did not fit this study's criteria, 526 observations remained. Using the person-level weights applied by the Australian Bureau of Statistics (ABS) this represented an estimated population of 268 000 that met the study's criteria.

Who uses respite?

Initially, a binary logistic regression was performed to address the question "Who are the likely users of respite services?" The model consisted of "respite use" as the dichotomous dependent variable (0 if used respite care; 1 if never used respite care). Certain carer and recipient characteristics identified in previous studies^{11-13,16-18,20} as important in the investigation of informal care were included in the model. The explanatory variables included age (ordinal age group from 15 years in 5-year intervals up to 85 and over) and gender (male as the referent) of

I Definitions

Disability	A limitation, restriction or impairment that lasts at least 6 months and restricts everyday activities. ¹⁰
Profound disability	An inability to do, or always needing help with a core activity task in communication, mobility and self-care. ¹⁰
Severe disability	Sometimes needs help with a core activity task, has difficulty understanding or being understood by family or friends, can communicate more easily using sign language or non-spoken forms of communication. ¹⁰
Care recipient	A non-institutionalised person with a profound or severe disability. ¹⁰ This definition has been used in similar studies of informal care. ^{6,32-34}
Primary carer	A person aged 15 or over who provides the most informal assistance to the care recipient. The assistance is ongoing for at least 6 months and includes communication, mobility and self-care. ¹⁰ In this study only probable primary carers were included in the modelling. This is consistent with other studies of this nature. ^{6,32}
Informal care	Unpaid care and support provided by family and friends.
Formal assistance	Assistance provided to persons with disabilities by organisations (either for-profit or not-for-profit, government or private) and other persons (excluding informal care by family and friends) who provide assistance on a regular, paid basis and who are not associated with any organisation. ¹⁰
Fall-back carer	A person identified by the primary carer as taking responsibility for care should the primary carer become unavailable. ¹⁰ A fall-back carer is not a formal provider.
Mental disability	Mental and behavioural disorders including psychoses and mood affective disorders (dementia, Alzheimer's disease, depression and mood affective disorders), neurotic, stress-related and somatoform disorders (nervous tension, stress), intellectual and developmental disorders (Down syndrome) and other mental and behavioural disorders. ¹⁰

2 Respite use by demographic characteristics, Australia, 2003

Characteristic	Respite		P
	Used	Never	
Total number of respondents	31 296	243 690	
Recipient's gender			<0.001
Male	12.9%	87.1%	
Female	10.0%	90.0%	
Recipient's disability status			<0.001
Profound restriction	15.2%	84.8%	
Severe restriction	5.5%	94.5%	
Country of birth			<0.001
Australia	11.8%	88.2%	
Main English-speaking countries	12.6%	87.4%	
Others	9.2%	90.8%	
Remoteness			<0.001
Major cities	11.6%	88.4%	
Inner regional	9.5%	90.5%	
Other areas	13.7%	86.3%	
Duration of care (mean years)	12%	7%	<0.001
Relationship of carer to recipient			<0.001
Spouse/partner	6.3%	93.7%	
Father/mother	32.4%	67.6%	
Son/daughter	15.4%	84.6%	
Other	9.3%	90.7%	
Carer's labour-force status			<0.001
Employed full-time	14.4%	85.6%	
Employed part-time	17.2%	82.8%	
Not in the labour force	9.7%	90.3%	
All parents with children under 15 years of age			<0.001
Yes	8.2%	91.8%	
No	11.9%	88.1%	
Gender of carer			<0.001
Male	8.0%	92.0%	
Female	13.3%	86.7%	
Availability of fall-back informal carer			<0.001
Yes	10.0%	89.9%	
No	12.7%	87.3%	
Main source of cash income			<0.001
Government pension/allowance	13.8%	86.2%	
Other	10.0%	90.0%	
Main disabling condition			<0.001
Mental	22.5%	77.5%	
Physical	9.5%	90.5%	

Data derived from the Australian Bureau of Statistics Survey of Ageing, Disability and Carers, 2003.¹⁰

both the carer and the recipient. Other independent variables included country of birth, relationship to recipient, labour force status (reference groups: non-English speaking country, spouse, not in the labour force, respectively) and the dichotomous variables major source of income (government pension or allowance as the referent) and children under fifteen (1 if yes, 2 if no).

The model also adjusted for the recipient's disability status (0 if profound, 1 if severe) and their main disabling condition as defined by the ABS¹⁰ (0 if mental, 1 if physical). It is acknowledged that recipients of care may possess both a physical and mental disability. For practical reasons the model included the main disabling condition rather than all the conditions of the recipient.

The use of the national dataset in this study allowed the inclusion of additional variables in the model unavailable to previous research. For instance, recognising possible differences in the level of availability of support services between urban and rural areas the model included remoteness status (categories: remote, regional and major city as the referent). Duration of care (ordinal from less than 1 year in 5 year intervals until 35 and over) was also included in the model because years of care may impact on the demand for respite assistance. Information about the assistance received from other family members and friends by the primary carer was captured by including the dichotomous variable that identified a fall-back carer (1 if yes, 2 if no).

What type of support is most desired by primary carers?

A second regression model added the independent variable, "type of support most desired by a primary carer". The variable consisted of five categories: "does not need improvement or more support"; "more

3 Respite use by type of support most desired by primary carers to assist in their carer role, Australia, 2003

	Used respite	Never	Total
More respite care	7 049 (23.8%)	16 651 (7.4%)	23 700 (9.3%)
More financial assistance	4 917 (16.6%)	40 918 (18.1%)	45 835 (18%)
More physical assistance	945 (3.2%)	3 775 (1.7%)	4 720 (1.8%)
More emotional support	1 424 (4.8%)	11 075 (4.9%)	12 499 (4.9%)
Improvement in own health	891 (3%)	8 845 (3.9%)	9 736 (3.8%)
Other support or improvement	1 170 (4%)	4 664 (2.1%)	5 834 (2.3%)
Does not need improvement or more support	13 166 (44.5%)	139 802 (61.9%)	152 968 (59.9%)
Total	31 297 (100.0%)	243 690 (100.0%)	274 987 (100.0%)

Data derived from the Australian Bureau of Statistics Survey of Ageing, Disability and Carers, 2003.¹⁰ All values no. (%).

financial assistance”; “more respite care”; “more physical, emotional and other support”; “improvement in own health”. The category “does not need an improvement or more support” was the reference category to which the other four categories were compared. The control variables included gender, age, disability status, country of birth, remoteness, duration of care, relationship, labour-force status, children under fifteen, fall-back carer, income and main disabling condition.

Results

Descriptive statistics

A statistical summary of the weighted population is presented in Box 2. The characteristics of the carers and their recipients are segregated by respite service use — those that have used respite ($n = 31\,296$) and those that have not ($n = 243\,690$). A greater proportion (88.6%) of informal carers had never used respite services.

Non-users of respite tended to be carers of recipients with a severe rather than profound disability and possessed a physical rather than mental condition. These carers were either a spouse or partner of the recipient, they were not in the labour force, and tended to be male. Respite use increased with the duration of care.

Referring to Box 3, just over half of the informal carers (59.9%; $n = 152\,968$) reported that they

did not need more support in their role as carer. A substantial proportion of carers (18%; $n = 45\,835$) desired “more financial assistance”. This compared with 9.3% ($n = 23\,700$) requiring “more respite”, 9% ($n = 23\,053$) “more physical/emotional/other support”, and 3.8% ($n = 9\,736$) “improvement in own health”. Among the non-users of respite a substantial proportion (18%) desired financial support. In contrast, those that received respite were likely to require more of this service (23.8%).

Identifying the users of respite

The results of the binary logistic regression, including the odds ratios and 95% confidence intervals, are presented in Box 4.

The increasing age of carers was associated with a greater use of respite services. That is, the odds of non-respite use decreased (OR, 0.773; CI, 0.766–0.780) with each successively older 5-year age group starting at 15–19 years. Compared with households residing in cities, there was a decrease in the odds of those in remote areas being non-users of respite (OR, 0.856; CI, 0.824–0.890). Carers from non-English speaking countries were 1.2 times (CI, 1.194–1.287) more likely to be non-users of respite than those born in Australia. Those carers who received a government pension or allowance as their main source of income were 75% (CI, 0.721–0.779) as likely as others to be non-users. The odds of never

4 Odds ratios for the use of respite care,* Australia, 2003

	Odds ratio	95% CIs
Age of carer (5-year intervals until 85 and over)	0.773 [†]	0.766–0.780
Remoteness — inner city is referent		
Regional	1.064 [†]	1.029–1.100
Remote	0.856 [†]	0.824–0.890
Country of birth — Australia is referent		
English speaking	0.597 [†]	0.573–0.621
Non-English speaking	1.240 [†]	1.194–1.287
Income (0 otherwise; 1 if government pension)	0.750 [†]	0.721–0.779
Disability status (0 if profound; 1 if severe)	2.490 [†]	2.409–2.574
Age of recipient (5-year intervals until 85 and over)	1.094 [†]	1.087–1.102
Duration of care (from less than 1 year in 5-year intervals until 35 and over)	0.893 [†]	0.887–0.900
Relationship of carer to recipient — spouse is referent		
Parent	0.245 [†]	0.231–0.260
Adult children	0.110 [†]	0.104–0.116
Other	0.537 [†]	0.507–0.570
Labour force status — not in the labour force is referent		
Full-time	0.333 [†]	0.316–0.350
Part-time	0.336 [†]	0.321–0.351
Children under 15 (1 if yes; 2 if no)	0.703 [†]	0.671–0.735
Gender of carer (male)	0.752 [†]	0.726–0.779
Fall-back carer (1 if yes; 2 if no)	0.519 [†]	0.505–0.535
Gender of recipient (male)	0.422 [†]	0.407–0.438
Main disabling condition (physical)	1.449 [†]	1.398–1.502
Constant	103.408 [†]	
R²	0.23	

*0 if used respite; 1 if never used respite. † Significant at 0.01 level (two tailed). Data derived from the Australian Bureau of Statistics Survey of Ageing, Disability and Carers, 2003.¹⁰

5 Odds ratios for the support most desired by the primary carer, Australia, 2003

Categories of support most desired*	Odds ratio	95% CIs
More respite care	0.343 [†]	0.330–0.357
More financial assistance	0.911 [†]	0.875–0.947
More physical/emotional/ other assistance	0.620 [†]	0.592–0.648
Improvement in own health	1.529 [†]	1.413–1.654

*Reference category of the dependent variable is "Does not need an improvement or more support". † Significant at 0.01 level (two tailed). Data derived from the Australian Bureau of Statistics Survey of Ageing, Disability and Carers, 2003.¹⁰

using respite were 2.5 times (CI, 2.409–2.574) more likely for carers of recipients with severe rather than profound disabilities. Referring to the recipient of care, the odds ratio for non-respite use increased, on average, by 9% (CI, 1.087–1.102) with each successively older 5-year age group starting at 15–19 years. The odds of non-respite use decreased (CI, 0.887–0.900) with each successive five-year interval rise in the duration of care.

Of all the carer relationships, spouses were the most likely to be non-users of respite services compared with parents, adult children or friends (25%, 11% and 54%, respectively, as likely as). Carers working either full-time or part-time were more likely to use respite services than those not in the labour force. Male carers and recipients were, respectively, about 75% (CI, 0.726–0.779) and 42% (CI, 0.407–0.438) as likely to be non-users of respite as females. Although the findings relating to the odds ratio for gender of carer contradicted the findings of the descriptive statistics (Box 2), it was as expected and indicates that female carers were more likely to be non-users of respite services once controlling for other variables. Carers with no children under fifteen were 70% (CI, 0.671–0.735) as likely to be non-respite users as those with children under fifteen years. A fall-back carer increased the odds of non-respite use compared with carers without a fall-

back carer (OR, 0.519; CI, 0.505–0.535). Recipients with a physical disability were 1.5 times (CI, 1.398–1.502) more likely to be non-respite users compared with those with a mental disability.

Identifying the type of support most desired by primary carers

Why is it that only 11.4% of informal carers under investigation have used respite? Due to data limitations of the national dataset this could not be answered directly. Instead the analysis reported here focuses on the type of support that is most desired by primary carers.

Box 5 presents the results from the regression analysis that added the independent variable “support most desired by the carers” to the model. Box 5 reports only the odds ratio for the categories of desired support.

Compared with the reference category, “does not need an improvement or more support”, the odds of desiring “more respite”, “more physical/emotional/other assistance” or “more financial assistance” among non-users of respite were 34% (CI, 0.330–0.357), 62% (CI, 0.592–0.648), 91% (CI, 0.875–0.947), respectively, as likely. In contrast, there was a 53% (CI, 1.413–1.654) increase in the odds of non-respite carers reporting a desire to improve their own health compared with the reference category.

Discussion and conclusion

The de-institutionalisation of the Australian health care system, coupled with an ageing Australian population has placed greater care burdens on family members of individuals with disabilities. Community support services such as respite are central to maintaining high quality care at home. This study examined the use of respite services among carers of non-institutionalised individuals aged 15 and over with either profound or severe disabilities. Based on the data collected from the Australian Survey of Disability, Ageing and Carers,¹⁰ the statistical significance of a number of socio-economic variables was evaluated on the likelihood of the use

of respite services. Further analysis assisted in identifying the support most desired by the majority of the selected carers who have never used respite services.

Economic forces influenced who were the likely users of respite. For instance, carers participating in the labour force were more likely to use such support services. Those who received a government pension also tended to use more respite services, possibly reflecting their eligibility for subsidised care. Laporte’s²⁹ study confirmed a higher use of publicly funded home care services among low income households.

While economic forces were important, social and cultural factors, such as family relationships and responsibilities towards household members, played a critical role in the decision to use respite services. After controlling for recipient characteristics, the analysis revealed a strong association between respite use and the carer/recipient relationship. Spouses of recipients tended to be non-users of respite services. This is consistent with the findings of Wang et al that investigated the use of community support services by older Sydney residents.¹⁷ Robinson and colleagues also reported that being a spouse decreased the odds that the caregiver would use community resources.³⁰

Carers from non-English speaking countries were associated with non-respite use compared with those from Australia and other English-speaking countries. Further analysis of the ABS data¹⁰ revealed that carers from non-English speaking backgrounds received the greatest amount of informal support (38%, compared with those from Australia, 30.1%, and main-English speaking countries, 12.7%) and this may explain the finding. Also the limited availability of family and friends to share the burden of care may explain the greater use of respite services among remote households compared with those residing in regional towns and major cities. Of carers residing in remote areas of Australia, only 18.3% received support from family and friends compared with 33.1% and 27.7%, respectively, from those residing in major cities and regional areas.¹⁰

Other carer characteristics associated with non-respite use included being female, younger in age, experiencing less duration of care, having children under 15 years and the presence of a fall-back carer. Lobb's investigation also found that for caregivers, factors such as being a wife and younger in age were associated with non-respite use.³¹ In contrast, Braithwaite reported that the odds of non-respite use were greater for male caregivers.²⁰ The exclusion of certain key variables — labour-force participation, income and children — from Braithwaite's logistic model may explain the difference in the findings reported here.

Female recipients were associated with non-respite use. Tennstedt and colleagues confirm a higher non-usage rate of formal services and personal care services among older female recipients.¹³ Other recipient characteristics associated with non-respite use included being older in age, possessing a physical rather than a mental main disabling condition, and a severe rather than profound disability. This is consistent with several studies^{20,30,31} that found a greater likelihood of respite services among carers with high task demands and activities of daily living.

Limitations of this study included data restrictions that did not allow the inclusion of some relevant independent variables into the model. In particular, a variable that recorded the proportion of income contributed by other family members could not be constructed. The disability variables used in the model were based on the main disabling condition rather than all the diagnosed conditions of the recipient. Also, for the selected sample the available data did not provide adequate information on family members or carers other than primary carers. Furthermore, misunderstanding by respondents regarding the term "respite service" may have led to an underreporting of its use.

Of the carers under investigation, 88.6% reported never having used respite services. Furthermore, only a minority of the non-users of respite desired such a service. Thus the shortfall in respite services applied to a small minority. Since the recipients under investiga-

tion were likely to possess core communication limitations coupled with sporadic and highly individualised needs, it is speculated that carers perceived themselves and family members as better able to interpret and meet the needs of the recipients. In terms of the support most desired in the role of primary caregiver the analysis of the national data revealed a greater preference for more financial assistance. After controlling for confounding variables it was found that, compared with other forms of assistance, the desire for an improvement in the primary carers' own health was more likely among non-respite users. This may reflect the carers' preference to improve their own capacity to service the recipient rather than rely on individuals outside the household.

Previous research shows that direct payments better service the diverse needs of carers and their recipients by enabling them to purchase a much wider range of flexible help, and to obtain better continuity, greater control and an enhanced quality of life compared with conventional services.²⁶⁻²⁸ Given the low usage rate of respite services among primary informal carers, it is recommended that future research investigates the effectiveness of programs that support households in managing care in a flexible and timely manner. Policy makers and health organisations may need to dispel the "one-size-fits-all" approach to support services for households.

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Competing interests

The author declares that she has no competing interests.

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