

Respite service use among caregivers of older people: comparative analysis of family dementia caregivers with musculoskeletal and circulatory system disorder caregivers

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Published

2018

Journal Title

Aging and Mental Health

Version

Accepted Manuscript (AM)

DOI

[10.1080/13607863.2016.1232368](https://doi.org/10.1080/13607863.2016.1232368)

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1 **Respite service use among caregivers of older people:**
2 **Comparative analysis of family dementia caregivers with**
3 **musculoskeletal and circulatory system disorder caregivers**

4

5 **Aging & Mental Health**

6

7 **Abstract**

8 **Objectives:** To identify the main drivers of the use of respite services and the need for respite
9 services among caregivers of people experiencing dementia relative to family caregivers of
10 people with other health conditions. **Method:** Based on nationally representative secondary
11 data regression analysis was used to test the association between selected health conditions and
12 the utilisation of and need for respite services.

13 **Results:** For a person living with dementia the odds of using respite care are higher than for a
14 person with either a musculoskeletal or circulatory condition. Family caregivers of people
15 living with dementia report the odds of the need for more respite as 5.3 times higher than for
16 family caregivers of people with musculoskeletal conditions and 7.7 times higher than for
17 family caregivers of people with circulatory conditions. The main reason for never using respite
18 services is largely driven by the type of health condition, age of care recipient, existence of a
19 spouse, and level of disability.

20 **Conclusions:** Respite services that cater to the specific needs of families experiencing
21 dementia at home should become a higher priority within the aged care sector. Alternative
22 models of respite care that focus on prevention and early intervention would be cost effective.

1

2 **Key words:** home care, dementia, unmet need, primary carer, respite

3

4

1 **Introduction**

2 Australia's aging population, people living longer with disabling health conditions (Woolf
3 et al., 2010, Bosanquet and Sikora, 2004), and a national policy emphasis towards home-
4 based care, has placed greater financial, and emotional stress on family members and
5 caregivers. Not surprisingly there is a growing demand for day respite services (NSW
6 Government, 2011) that offer family members a break from caregiving responsibilities by
7 providing planned short-term, time-limited breaks while also providing a break for the
8 individual with a disability (Australian Institute of Health and Welfare, 2012). Day respite
9 provides the care recipient with opportunities to attend/participate in group activities in a day
10 centre setting (Australian Institute of Health and Welfare, 2012). However the use and impact
11 of respite services is an under-researched area in Australia.

12
13 Older people make up the vast majority of individuals requiring home-based care, including
14 respite care at home, and in the community (Australian Government Department of Health and
15 Ageing, 2012). They are also most likely to report their main disabling condition as either
16 arthritis and related disorders (21%) or disease of the circulatory system such as heart disease,
17 stroke or high blood pressure (13%) (Australian Bureau of Statistics, 2012a). While a smaller
18 percentage of older people currently report dementia or Alzheimer's disease (2.7%) as the main
19 condition relating to mental or behavioural disorder (Australian Bureau of Statistics, 2012a),
20 as the population continues to age we can expect a rising proportion of older people reporting
21 living with a diagnosis of dementia. This is because an individual aged 80 years or over is
22 seven times more likely to identify dementia or Alzheimer's disease as their main long-term
23 health condition in comparison to someone aged 65-79 years (7.9% compared with 1.0%). In

1 contrast, the proportion of those reporting arthritis as their main condition are similar across
2 these age groups (17.3% compared with 15.9%) (Australian Bureau of Statistics, 2012a).

3 In addition, by the year 2050, approximately one million people are expected to be living
4 with a dementia-related illness in Australia (Deloitte Access Economics, 2011). This represents
5 an increase of 375% from 267,000 people in 2011. Moreover, because dementia is one of the
6 major reasons why older people enter residential aged care or seek assistance from community
7 care programs within Australia (Australian Bureau of Statistics, 2012b, Department of Health
8 and Ageing, 2011), it becomes even more important to examine the support services provided
9 to the older population and their caregivers.

10 The investigation of the use of services by primary caregivers is also important because
11 primary caregivers of people living with dementia are more likely than other caregivers to
12 report needing support or an improvement in their role as a caregiver (Australian Institute of
13 Health and Welfare, 2012). Yet it is acknowledged that the greatest area of unmet demand
14 reported by caregivers is respite care (Australian Institute of Health and Welfare, 2012). In fact,
15 investigations by the Australian Institute of Health and Welfare (2012) found that 48% of co-
16 resident primary caregivers of people living with dementia, who require additional support,
17 reported respite care as their main area of need. In contrast only 15% of all co-resident primary
18 caregivers of people without dementia indicated respite as the main area in which they need
19 assistance (Australian Institute of Health and Welfare, 2012).

20 In recent years a number of changes have been implemented across the aged care sector in
21 Australia with greater importance given to consumer-directed care. Part of these reforms
22 include the government's continued emphasis on home based care with the aim of home
23 support and home care packages providing greater choice and flexibility for people residing at

1 home. Other initiatives include the development and implementation of My Aged Care which
2 is a national contact centre through which all referrals for government subsidised services must
3 be made, centralising client records, the establishment of Australian Aged Care Quality
4 Agency, and the launch of the Aged Care Pricing Commission. Changes to funding
5 arrangements for both community and residential care services occurred in 2015 resulting in a
6 greater emphasis on a self-funded approach. The 2015-16 changes build on those already
7 achieved, such as the national voluntary quality indicators for aged care and the national fee
8 framework for the Commonwealth Home Support Programme (Government, 2015).

9 The Australian government's continued commitment towards reforms in the aged care
10 sector highlight the importance of national level investigations in this area of research. A better
11 understanding of the use of respite care will assist in developing aged-care strategies to reduce
12 the vulnerability of older people prematurely entering residential aged care facilities. If respite
13 services fail to meet the needs of caregivers, and caregivers are unable to cope, recipients of
14 care will require accommodation support options at approximately five times the cost per client
15 (ACT Government, 2011).

16

17 **Literature Review**

18 Over the years increased attention has been devoted to understanding the support services used
19 by people living with dementia and their families. A review of the literature by Phillipson,
20 Jones and Magee (Phillipson et al., 2013a) reinforces the importance of the assessment and
21 matching of services to the needs of individual caregivers and care recipients at the local level.
22 Their review identified an association of service use behaviours of caregivers with
23 demographic variables, factors representing social structure, and health beliefs about dementia.

1 Also caregivers' attitudes towards respite services were important in predicting respite use.
2 Additionally, a review of 76 international studies by Neville et al. (2014) identified the lack of
3 knowledge by caregivers of the availability of respite services and misinformation surrounding
4 respite services as significant barriers to the use of respite care. The recognition for the need
5 for respite by caregivers, their willingness to accept respite, and the availability of social
6 support resources also influenced the use of respite services. Other factors identified as
7 influential in the use of respite services included satisfaction with respite services, the
8 characteristics of respite services, and the role of health workers in providing appropriate
9 respite care.

10 Using a large sample of secondary data collected across Queensland, Australia, researchers
11 (Vecchio et al., 2016) found that users of home-care services aged 65 and over with cognitive
12 impairment used more day centre care and respite care compared to other users of these
13 services. The Australian Institute of Health and Welfare (AIHW) also identified the use of
14 respite services by primary caregivers of people living with dementia as higher than other co-
15 resident primary caregivers (Australian Institute of Health and Welfare, 2012).

16 Further evidence from an Australian investigation showed that the use of respite services
17 for family caregivers of people living with dementia was often low. Despite reporting unmet
18 need for respite services, 44.2% of those surveyed were not utilizing day respite and 60.2%
19 were not utilizing residential respite programmes. Beliefs that service use would result in
20 negative outcomes for the care recipient were strongly associated with non-use of both day care
21 and residential respite care and were more strongly associated with service non-use than other
22 predisposing, impeding, and need variables (Phillipson et al., 2013b).

23

1 ***Objectives of the Study***

2 The objectives of this study are to identify characteristics associated with the need for respite
3 services and the use of respite services among family caregivers of people experiencing
4 dementia. Given the competing interests and priorities within the community care sector, this
5 is better understood when examined in the context of other major disabling health conditions.
6 Although it is clear that there is a greater need for respite services among caregivers of people
7 experiencing dementia, what is of value to policy makers is a demonstration of the main drivers
8 of this need and use of services and the extent of this need and use relative to family caregivers
9 of people with other health conditions. For instance, is the need for respite services driven by
10 demographic factors, comorbidity, or does the dementia condition itself lead to greater need?
11 If, after controlling for confounding variables, the analysis shows that caregiving of people
12 experiencing dementia is associated with inadequate respite services, then a case is made for
13 the development of respite models specific to people with cognitive decline and their
14 caregivers.

15 Understanding the use of respite services by caregivers of people living with dementia is
16 important to plan for future service needs and ensuring effective and sustainable aged care
17 services. The findings of this study will provide a case for the development of suitable models
18 of respite for caregivers of people living with dementia. This study extends the current research
19 in this area by conducting a quantitative study of the relationship between selected health
20 conditions and the use of and need for community respite. The use of a nation-wide database
21 from the Australian Bureau of Statistics improves the accuracy of information and allows
22 results to be generalizable to people 65 and over living with dementia, musculoskeletal, and
23 circulatory system conditions and living in the community.

1

2 **Method**

3 *Data source*

4 The cross sectional data for analysis were sourced from the Survey of Disability, Ageing and
5 Carers 2012 (SDAC), Confidential Unit Record Files, collected throughout Australia from 5
6 August 2012 to 2 March 2013 (Australian Bureau of Statistics, 2012a). The collection of the
7 information was on the basis of informed consent prior to data collection. The SDAC included
8 people in urban and rural areas of all Australian States and Territories, living in both private
9 and non-private dwellings (including persons in cared-accommodation). The survey collected
10 information from three target populations: people with disability, older people and people who
11 care for individuals with disability, long-term health conditions or older people. Multi-stage
12 sampling techniques were used to select the sample for the survey. Trained interviewers from
13 the Australian Bureau of Statistics collected the household component of the data survey. After
14 exclusions due to scope and coverage, the final combined sample was 79,164 individuals,
15 comprising of 68,802 individuals from the household component and 10,362 individuals from
16 the cared-accommodation component.

17 The analysis was confined to information about non-institutionalized main recipients of care
18 aged 65 and over with selected health conditions (either dementia, musculoskeletal or
19 circulatory system) and their caregivers. Reasons for these confinements are as follows: 1.
20 Older people make up the majority of individuals who use respite care (Australian Government
21 Department of Health and Ageing, 2012); 2. Older people are most likely to report dementia,
22 musculoskeletal or circulatory system as their main disabling condition (Australian Bureau of
23 Statistics, 2012a); 3. Non-institutionalised care is preferred by the recipient of care, their family

1 (Healy, 2002) and the government (Hamilton and Menezes, 2011) and this trend towards
2 deinstitutionalisation is expected to continue. An individual may have two or more health
3 conditions. The assigned condition is based on their main disabling condition. Since we are
4 interested in the use of respite care the analysis was also confined to recipients of care living
5 with their caregivers. In the 2012 survey, primary carers of an individual with a disability
6 reported their attitudes to, and experience of, their caring role (Australian Bureau of Statistics,
7 2012a).

8 After excluding those who did not fit this study's criteria, 444 observations remained for
9 analysis, resulting in an estimated weighted population of 154694. Since the data is de-
10 identified and collected by the Australian Bureau of Statistics, ethical approval was not
11 required for the data.

12

13 *Statistical Analysis*

14 Analyses were conducted using Stata version 11.2 (StataCorp, Texas, USA) and followed the
15 statistical methods recommended by the Australian Bureau of Statistics (Australian Bureau of
16 Statistics, 2006). All the results were calculated using the person weights provided in the
17 SDAC. These weights indicate how many individuals in the population are represented in the
18 survey, and take into account the individual's probability of being selected into the sample.
19 Standard errors of population estimates were calculated as recommended using the jackknife
20 method (UCLA, 2016).

21

1 *Model*

2 The current health care system delivers a broad range of respite services in three main settings:
3 home-based; community-based; and centre-based. Costs can vary depending on the type of
4 service (Australian Government, 2015). While individuals generally contribute to the cost of
5 care if they can afford to do so, the Australian Government pays for the bulk of aged care in
6 Australia and subsidises those unable to pay (Australian Government, 2015). An analysis of
7 the sample under investigation indicates that overall 86% of respite care recipients receive a
8 pension. It is therefore assumed that the majority of the sample under investigation receives a
9 government subsidy for respite services.

10 Empirical studies of health utilization usually consider as regression variables those that
11 measure: need/morbidity (indicators of chronic conditions and limited activity); age
12 (accounting for imperfect health status measurement but also for individual preferences); sex
13 (accounting for gender-specific health care requirements and also for preferences); ability to
14 pay (income); and other socio-demographic factors such as marital status (Jones et al., 2007).
15 Based on these studies and the Andersen ‘Behavioural Model of Service Use’ that suggests
16 access to health and social services is determined by predisposing, enabling and need
17 characteristics (Andersen and Newman, 1973b), we test the association between respite care
18 and type of disabling health condition. The Anderson model is used in the health care service
19 literature to explain service usage, particularly in relation to respite use by carers of people
20 with dementia (see review by Phillipson et al (Phillipson et al., 2014))(Vecchio et al., 2016).

21

22 Using regression analysis, estimates are obtained regarding the effect that a care recipient’s
23 health condition has on a caregiver’s probability of: (a) use of respite services; (b) perception

1 of inadequate respite services; and (c) reason for non-use of respite services. These aspects of
2 respite service use are based on the perspective of the family caregiver. The decision to seek
3 care support services is taken by the family caregiver. We do not consider the amount of respite
4 care since this often depends on supply factors such as agency resources (Vecchio and Stevens,
5 2011).

6 A binary logistic regression is initially run to estimate the relationship between respite use
7 and type of health condition. The second model estimates the relationship between perceived
8 inadequate respite and type of health condition. The dependent variable in model 1, *Respite*
9 *Use*, represents caregivers that have used respite services against caregivers that have never
10 used respite services. *Respite Need* in model 2, indicates caregivers that report the need for
11 more respite when asked ‘what is the main source of support’, 0 otherwise. The independent
12 variables for both models include predisposing, enabling and need characteristics.

13 The *Predisposing* vector of categorical variables relating to care recipient characteristics
14 include age, gender, language spoken and relationship to caregiver. Applying these
15 demographic characteristics allows the control, for as much as possible, of the unobserved
16 individual fixed effects. The supply side of family care provision relates to family caregivers,
17 specifically whether or not they are the spouse of a care recipient. Given that the investigation
18 is confined to older people, supply considerations are mostly captured in the ‘spouse’ variable.
19 The majority of caregivers under investigation are spouses (66%), over the age of 60 years and
20 therefore assumed to be retired from the paid labour market.

21 The *Enabling* vector represents receipt of a government pension and “urbanicity”. The
22 “urbanicity” variable (major city, inner region, outer/remote region) is based on the ABS
23 Accessibility Remoteness Index of Australia. The classification relates to the distance to large

1 towns and cities, and the distance to other people. There is the assumption that: (a) people tend
2 to obtain goods and services from the nearest urban center; (b) large urban centers offer a wider
3 range of goods and services compared to smaller urban centers; and (c) frequency of access to
4 goods and services is relative to remoteness.

5 In a home setting need characteristics are reflected in the capacity of the recipient of care to
6 meet tasks relating to daily living. This is represented in the *Need* vector that includes: (a) level
7 of disability; (b) number of health conditions; and (c) type of main disabling health condition.
8 Disability level reflects the capacity of the recipient of care to meet tasks relating to domestic
9 activity, self-care, cognitive, and behavioural function. The level of disability is used to
10 determine the quantity and intensity of care that is required. The greater the level of disability
11 of an ill family member, the more care demands are placed on the caregiver (Sherwood et al.,
12 2008, AIHW, 2011). The number of health conditions, from 1 to 9, captures the number of pre-
13 existing health conditions. As the number of health conditions experienced by an individual
14 increases one would expect a greater strain on the individual and increased care demands.

15 An individual is considered to have a disabling condition if he or she reports a health
16 condition and possesses a limitation (either profound¹, severe², moderate, or mild) or restriction
17 (either schooling or employment) that lasts at least six months and restricts everyday activities

¹ An inability to do, or always needing help with a core activity task in communication, mobility and self-care.

² 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.

1 (Australian Bureau of Statistics, 2010). Type of main disabling health condition is represented
2 as a categorical variable that includes dementia, circulatory system, and musculoskeletal
3 conditions. Dementia becomes the referent. These categories were chosen because of the higher
4 prevalence of these conditions among older people (Australian Bureau of Statistics, 2012a).
5 Health conditions determine what type of care (residential/institutionalized or non-residential)
6 individuals use. Individuals with more severe health conditions are more likely to use
7 residential care. To minimise the possibility of bias associated with the health condition
8 variables we include disability status and number of health conditions as control variables.

9 Lastly, a multinomial logistic regression is used to estimate the caregiver's relative risk ratio
10 for each main reason a primary caregiver has never used respite care. The main reasons under
11 investigation include: "Does not need respite", "Recipient does not want respite" and
12 "Caregiver does not want respite". The base case used for comparison is the category "Has
13 used respite".

14

15 **Results**

16 *Descriptive statistics*

17 Table 1, presents the demographics of descriptive statistics of the recipients of care and their
18 caregivers under investigation. Most recipients are cared for by their spouse. A large
19 proportion (63%) of care recipients report a profound disability and have a mean of 2.4 health
20 conditions. The stratification of demographics by selected health conditions indicate that a
21 greater proportion of older people living with dementia report a profound disability (82%),
22 followed by circulatory system conditions (65%), and those experiencing musculoskeletal
23 conditions (59%). The greatest amount of care per week is provided by family caregivers of

1 people living with dementia. Forty or more hours of care are provided by 68% of dementia
2 caregivers, 56% circulatory system caregivers, and 38% musculoskeletal caregivers. While
3 only 11% of all caregivers use respite, 30.9% of caregivers of people with dementia use
4 respite compared to only 7.5% and 10.6% respectively, of caregivers of people with either
5 musculoskeletal or circulatory system conditions.

6 The chi square in the table represents the ‘uncorrected’ chi square with weighted cell
7 proportions. The test indicates significance of difference of socio-demographic variables
8 among the three health groups. Differences are found for the *use* of respite and *need* for more
9 respite. Specifically, carers of people with dementia not only use a greater amount of respite
10 care (30.9%), but also need more respite care (31.9%) compared to those caring for people with
11 either musculoskeletal (7.5% and 6.9%, respectively) or circulatory (10.6% and 4.5%,
12 respectively) conditions. Also gender, age, level of disability, and hours of care differences are
13 observed among the groups of health conditions.

14

15 INSERT TABLE ONE HERE

16

17 Table 2, presents the findings relating to the main unmet source of support for primary
18 caregivers and the primary caregiver’s unmet need for respite care. The results are stratified by
19 health condition. Among those caring for people with dementia, “More respite” is the most
20 reported (31.9%) unmet source of support. “More financial assistance” is the most reported
21 among the musculoskeletal (18.7%) and among the circulatory system (9.7%) caregivers.
22 Caregivers of people living with dementia report the greatest need for respite care at short
23 notice or on an irregular basis (21.2%), compared to other caregivers (musculoskeletal 12.9%

1 and circulatory 11.0%). This group also reports that, compared to others, there is a greater need
2 for ‘this type of respite’ during weekdays (24.72%), and a greater need for respite but ‘not this
3 type of respite’ during week nights and weekends (refer Table 3).

4

5 INSERT TABLE TWO AND THREE HERE

6

7 ***Regression***

8 *Factors associated with the use/non-use of respite*

9 The results of two logistic regressions - the odds ratios associated with the use of respite (model
10 (1)) and the odds ratios associated with the need for more respite (model (2)) – are presented
11 in Table 4. Referring to the use of respite, the direction of the signs appears as expected.
12 Generally increasing age is associated with higher odds of respite use. The odds of using respite
13 for those with a profound disability are 2.1 times higher than for those with a milder disability.
14 The odds of caregivers of individuals with musculoskeletal or circulatory conditions using
15 respite are 0.24 and 0.33 times, respectively, as great as those of caregivers of individuals living
16 with dementia. To aid interpretation, for odds ratios less than one, we invert these (one divided
17 by the value). In other words, for an individual with a dementia condition, the odds of using
18 respite care are 4.12 times higher (CI 10, 1.689) than for an individual with a musculoskeletal
19 condition and three times higher (CI 8, 1.126) than an individual with a circulatory condition.

20

21 *Factors associated with the need for more respite services*

22 In regard to the need for more respite, a greater number of health conditions decrease the odds
23 for needing more respite services. Given the complexity arising from acquiring more health

1 conditions, it is possible that specialised services such as nursing and allied health are used
2 instead of respite services. Relative to other caregivers, the need for more respite is greater for
3 caregivers of people living with dementia. That is, the odds of caregivers of individuals with
4 musculoskeletal or circulatory conditions reporting the need for more respite services are 0.19
5 and 0.13 times, respectively, as great as those of caregivers of individuals living with dementia.
6 In other words, caregivers of people living with dementia report the odds of the need for more
7 respite as 5.3 times higher (CI 17.241, 1.563) than for caregivers of people with
8 musculoskeletal conditions and 7.7 times higher (CI 31.25, 1.98) than for caregivers of people
9 with circulatory conditions.

10 INSERT TABLE FOUR HERE

11

12 *Factors associated with non-use of respite services*

13 The relative risk ratios computed from the multinomial logistic regression are presented in
14 Table 5. The estimates show the caregiver's relative possibility of reporting a particular reason
15 why respite care has never been used compared to the base case, "Has used respite". Individuals
16 with a greater chance of reporting that they do not need respite tend to possess a non-profound
17 disability, are cared for by their spouse, and experience either a musculoskeletal or circulatory
18 system health condition. Those with a greater chance of reporting that the recipient of care
19 does not want respite tend to have a carer other than a spouse and possess a non-profound
20 disability. Individuals from non-English speaking backgrounds, reside in a major city, and have
21 a non-profound disability tend to report that the family caregiver does not want respite.

22

23 INSERT TABLE FIVE HERE

1

2 **Discussion**

3 To provide sustainable community services for older people living with dementia it is important
4 to look at service usage in the context of other health conditions. This study investigated the
5 use of, and need for, more respite services and the link between these services and selected
6 main disabling conditions. The investigation was confined to caregivers of older people
7 residing in their own homes experiencing either dementia, musculoskeletal, or circulatory
8 health conditions. The analysis was based on a nationally representative data set sourced from
9 residents across Australia – making this the largest Australian study of this nature.

10 Family caregivers play a vital role in supporting individuals living with dementia to reside
11 in the community and delay entering residential aged care facilities (Gaugler et al., 2000). The
12 descriptive statistics revealed that among care recipients aged 65 and over, most were cared for
13 by their spouse. The older age of caregivers means that greater community support is required
14 to delay institutionalization of care recipients as their health, and the health of their caregivers,
15 deteriorate. The descriptive statistics also showed that the hours of care provided by caregivers
16 to individuals with a dementia condition was higher than other caregivers. These findings are
17 consistent with research by Kim and Schulz (2008) and the AIHW (2012).

18 A greater proportion of carers of people with dementia who used respite care during the
19 weekdays, reported more need for the same type of care. The same primary carers reported
20 that they required more respite on weeknights and weekends, stating that the type of respite
21 care offered was unsuitable. Possibly services are inadequate for short notice or irregular
22 respite care (as indicated in Table 2) or do not suit the needs of families.

1 Further analysis that controlled for confounding variables revealed that more respite
2 services were being used by those living with dementia than those with other health conditions.
3 This suggests that a significant increase in these services will be required in the future, as
4 individuals with a cognitive impairment are projected to increase significantly. Indeed, for an
5 individual living with dementia the odds of using respite care were found to be 4.12 times
6 higher than for an individual with a musculoskeletal condition and three times higher than an
7 individual with a circulatory condition. Furthermore, caregivers of people living with dementia
8 reported the odds of the need for more respite as 5.3 times higher than for caregivers of people
9 with musculoskeletal conditions and 7.7 times higher than for caregivers of people with
10 circulatory conditions. The main reason for never using respite services was largely driven by
11 the type of health condition, age of care recipient, existence of a spouse, and level of disability.

12

13 ***Limitations***

14 Due to data limitations, our study was unable to capture information relating to the care
15 recipient's diagnostic category or the stage of the condition. Higher need individuals are
16 expected to be either residing in residential aged care facilities or use specialist dementia care.
17 In our analysis the inclusion of several indicators relating to functional status, i.e. disability
18 level and main disabling health condition, acted as proxies for care recipient need. It would be
19 beneficial to expand the models to include psychosocial factors such as attitudes, knowledge,
20 and social norms (Bradley et al., 2002). We expect, however, that the predisposing factors of
21 the model (gender, age, language, and relationship to caregiver) capture to some extent these
22 types of influences. Whilst this study has used a large quantitative sample, this limits our
23 understanding of carers' non-use of respite. The categories of "does not need respite,"

1 “recipient does not want respite,” and “caregiver does not want respite,” are very broad, and
2 exploring such reasons are better addressed through qualitative methods.

3 For people experiencing a dementia condition, the survey responses may have been reported
4 by the caregiver. This is not expected to bias the findings since the family caregiver is likely to
5 be well informed about the circumstances of the care recipient.

6

7 **Conclusions**

8 This study showed that relative to other health conditions, caregivers of people living with
9 dementia report an imbalance in service whereby they use more respite and need more respite.

10 The expected rising diagnosis of dementia cases accompanied by an aging population means
11 the provision of viable and reliable respite support to long term family caregivers requires
12 urgent attention. Inadequate support services may force family caregivers to prematurely
13 transfer cognitively impaired individuals to institutionalized care such as hospitals and
14 residential aged care facilities..

15 Care at home offers people with long-term care needs a higher quality of life and better
16 outcomes at lower cost than care in a nursing home (Konetzka, 2014). The use of respite
17 services by caregivers has been shown to extend the length of time people living with dementia
18 can remain living in the community with family support (Phillipson et al., 2013a).

19 The extent of respite use among those experiencing dementia, as evidenced in this study,
20 combined with changing economic, demographic and social pressures highlights the need for
21 quality and cost effective formal care arrangements in Australia (Baxter, 2002; MacDonald,
22 2000). Addressing this need must acknowledge the shift towards viewing respite as a service

1 that provides a positive experience to improve the quality of life for participants and to support
2 their relationships.

3 Currently in Australia there is a range of government subsidised home care packages for
4 people who need extra help to remain living at home. These services include respite care,
5 personal care, nursing care, allied health care, help with household tasks, transport and home
6 maintenance. Some home care service providers also use an additional dementia supplement.
7 However, these services are “more of the same” and do not provide specialised services that
8 cater to the needs of people experiencing a dementia condition. Instead government subsidised
9 services and staff that specifically cater to the needs of people with dementia are primarily
10 available in aged care homes. (Australian Government, 2015) Furthermore, to our knowledge
11 no home care service employs purposeful therapy or programs to assist in the slowing of
12 cognitive decline. Rather education and support is aimed at health professionals, carers and the
13 community in general. Organisations such as Alzheimer’s Australia provide programs for
14 people with dementia with most focusing on social outings and activities (Australia, 2016).

15 Of importance is the exploration of models of care that strengthen relationships within the
16 community. There is a need for community-based respite care packages which go beyond the
17 existing models to explore new, more innovative models of care that cater to the needs of
18 people living with dementia and their caregivers. In doing so, this may result in a greater
19 supply of suitable respite care packages and a higher uptake by caregivers of people living
20 with dementia. It is acknowledged, however, that increasing availability of services does not
21 guarantee uptake. Even so, clever future planning of community respite care is an essential
22 component in improving the quality of life for families dealing with dementia.

1 To date there is no research undertaken to explore caregiver or care recipient preferences
2 for alternative models of respite community care (rather than residential aged care facilities)
3 that cater to the specific needs of individuals with cognitive decline. It is simply assumed that
4 individuals prefer the current models. Future studies that identify viable alternative models of
5 respite care must test this assumption.

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