

# BEHAVIOUR OF OLDER PEOPLE ADMITTED FOR RESIDENTIAL RESPITE CARE

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## ABSTRACT

The aim of this pilot study was to determine whether residential respite care is used because of disruptive behaviour displayed by older people. The specific objectives were to 1) characterise older people being admitted for residential respite care, 2) obtain a preliminary estimate of the proportion of older people in residential respite care because of disruptive behaviour, and, 3) examine the relationship between residential respite care and disruptive behaviour. A quantitative approach using a cross-sectional survey was employed. The respite recipients were 35 older people with a mean age of 81.5 years (range 67-96 years). The respite recipients had been admitted for residential respite care to aged care hostels and nursing homes in a provincial city and its surrounding rural area. Nurses rated disruptive behaviour using the Dementia Behavior Disturbance Scale (DBDS). Additional reliability data for the DBDS are provided. The study found that the largest specific group of residential respite care users were widows (31.4%) who lived alone in their own home. The reason for over half (51.4%) of the residential respite admissions was to give a carer a 'break' from the older person. Although a large proportion (80%) of respite recipients were rated as having disruptive behaviour, the proportion of admissions because of disruptive behaviour was much less (28.6%). People with dementia (37.1%) scored significantly higher than people without dementia on the DBDS [ $F(1,33)=15.57, p<0.001$ ]. Older people with dementia were prescribed a greater number of psychotropic medications. It is concluded that despite residential respite care being offered primarily to assist with carer burden it is not being used mainly for older people whose behaviour is problematic for the carers.

## INTRODUCTION

In Australia, the tightening of access to permanent nursing home care has created a huge demand for respite care (Gibson 1998). Respite services can be provided at a day centre, nursing home, hostel, hospital or in-home. They can be provided on a planned or an emergency basis. The duration of respite care can vary from hours to days to months. The spectrum of respite care ranges from impersonal 'sitting' services to structured, small group activities geared to individual needs and abilities. This paper will only focus on residential respite care.

The Australian Institute of Health and Welfare (1999, p.86) defines a respite admission as: 'a short-term admission to a residential aged care facility for respite purpose' and respite care as 'an alternative care arrangement with the primary purpose of giving the carer or care recipient a short-term break from their usual care arrangement'.

There were very large increases in approved respite bed-days for Australian nursing homes (143%) and hostels (34%) between 1991 and 1995, albeit from a low base (2%) (Choi and Liu 1998). Respite care accounted for some 47% of 39,652 admissions to residential aged care facilities during the first six months of 1998 (Australian Institute of Health and Welfare [AIHW] 1999).

Characteristics of permanent and respite residents differ. In 1998, the average length of stay for permanent residents was 128 weeks and for respite residents it was 3.5 weeks (AIHW 1999).

On discharge from the residential care facility, 5% of permanent residents returned to the community whereas 74% of respite recipients returned to the community. Respite recipients were more likely than permanent nursing home or hostel residents to be married and prior to admission be living in a house or flat either alone or with a spouse or/and children (AIHW 1999). The number of respite admissions and level of dependency is likely to rise as the population ages.

Associated with the trend toward population ageing, there has been an increase in the number of people

suffering from age-related, neurodegenerative disorders such as dementia (Finkel and Cooler 1996). The Department of Community Services and Health (1990) estimated that dementia affects 5% of persons over the age of 65 years and approximately 20% of persons over the age of 80 years. It is anticipated that age-specific prevalence rates will remain stable. However, the overall prevalence rate will greatly increase due to the ageing of the population (Jorm and Korten 1988). The clinical syndrome of dementia is characterised by cognitive impairment, psychiatric symptoms, neurological symptoms, problems with activities of daily living and disruptive behaviour (American Psychiatric Association 1994). These may all be a burden to carers.

Disruptive behaviour includes aggression, wandering, general psychomotor overactivity, vocalisations, abnormal sleep/wake cycle and inappropriate sexual behaviours (Cohen-Mansfield and Billig 1986). Disruptive behaviour has been identified as the strongest predictor of carer burden (Coen et al 1997) and will often precipitate admission to a residential care facility (Swearer 1994). Several Australian studies (Brodsky et al 2001; Rosewarne et al 1997; Miller et al 1995; Gray et al 1992) have reported the prevalence of disruptive behaviour in the nursing home population as between 29% and 90%.

In an attempt to reduce the frequency and severity of disruptive behaviour in people with dementia, treatment with psychotropic medications is common practice in Australia (Rosewarne et al 1997). However, empirical studies supporting the usefulness of psychotropic medication in treating disruptive behaviour are limited, with problematic medication side effects compounding the dilemma (Borson and Raskind 1997). There is also a paucity of well-structured studies supporting the efficacy of non-pharmacological strategies for disruptive behaviour (Opie et al 1999).

To date, very little research has investigated the prevalence of disruptive behaviour in older people who have been admitted for residential respite care and no Australian studies could be identified. In Homer and Gilleard's (1994) English study, 58 carers and their elderly dependants with a medical diagnosis of stroke or dementia were studied during a hospital respite admission. Using the Clifton Assessment Procedures for the Elderly Behaviour Rating Scale (CAPE-BRS; Pattie and Gilleard 1979), nursing staff recorded a mean score of 15.2 ( $SD=7.0$ ) from a possible range of 0 to 36 with higher scores indicating more disability. A similar finding was reported in a United States study conducted by Hirsch et al (1993) who rated the behaviour of 39 residential respite care recipients using the Functional and Behavioral Scale for Advanced Dementia (FABSAD; Hirsch et al 1993). Nursing staff recorded a mean score of 24.4 ( $SD=6.8$ ) from a possible range of 10 to 50 with higher scores indicating worse behavioural problems. The findings from these two studies indicate a moderate level of behavioural disturbance in English and United States patients admitted for residential respite care.

Although disruptive behaviour is both common and a major contributor to carer burden it remains unclear whether it is an important reason for older people being admitted for residential respite care. To help address this question a pilot study was undertaken of older people admitted for residential respite care in a provincial Australian city.

## METHODS

The research ethics committee of the University of Southern Queensland approved the study protocol. The nurses and the respite recipients (or their substitute decision makers for the cognitively impaired) gave informed consent.

Directors of 18 aged care facilities (two nursing homes and 16 hostels) that offered residential respite care in the provincial city of Toowoomba and the surrounding rural districts were asked to participate. Logistical considerations meant that only those facilities within a one-hour drive of Toowoomba could be included and that the study was conducted over a three-month period. One nursing home and one hostel did not participate because the study coincided with an accreditation process and the directors of nursing felt it would be too difficult to do both. The total number of beds in the one participating nursing home was 78, with one bed designated for respite care. The total number of beds in the 15 participating hostels was 690, with 24 beds designated for respite care. A consecutive series of 43 people aged 65 years and over admitted for residential respite care was approached and 35 (81.4%) agreed to participate. Sixteen nurses participated in the study.

The following socio-demographic and medical data were obtained for each respite recipient: gender, age, usual person they reside with, residence prior to admission, medical problems including dementia, current medications, and, reason for admission. The respite recipient's nurse indicated whether or not the admission was related to the person's behaviour. Data were obtained by the nurses from the respite recipients' clinical records. Data was not obtained from the respite recipients themselves because of the potential for recall bias. Information was not obtained from relatives because not all respite recipients had relatives, whereas a nurse was available for all respite recipients.

Respite recipients were rated for the frequency of disruptive behaviour by the nurses using the Dementia Behavior Disturbance Scale (DBDS; Baumgarten et al 1990). The DBDS was selected after a review of available disruptive behaviour rating scales for older people (Neville and Byrne 2001a). The reference period for the DBDS is the preceding week, which makes it ideal for respite care studies, because the average length of stay is 3.5 weeks (AIHW 1999). This rating scale was developed to measure the behavioural dimension of the dementia syndrome. The 28 items reflect specific observable

behaviours likely to cause stress to the caregiver. A nurse familiar with the respite recipient completed the DBDS. Each item was rated on a 5-point frequency scale ranging from 0 (never) to 4 (all the time). Scores may range from 0 to 112, with higher scores indicating greater behavioural disturbance. High scores on the DBDS were significantly associated with increased duration and severity of dementia. Using two samples ( $n=96$ ) of community dwelling dementia patients, the scale was found to have a high internal consistency of 0.84, a moderate test-retest reliability of 0.71 and a validity rating of 0.73 (Baumgarten et al 1990).

In an unpublished study conducted by Neville and Byrne (2001b), 10 home caregivers and 10 nurses were recruited to assess the inter-rater and test-retest reliability of the DBDS for 10 older people admitted for residential respite care. Each home caregiver and nurse completed the

DBDS during the respite admission. A parallel questionnaire, containing the same items but arranged in a different order, was completed one week later. Using the intraclass correlation coefficient, the inter-rater reliability for the total score was 0.93;  $F(9,198) = 13.71$ ,  $p = 0.0001$ . This suggests that the DBDS can be used reliably across observers. The test-retest reliability was good for nurses 0.942,  $p = 0.000$  and moderately good for home caregivers 0.778,  $p = 0.0024$ .

After checking and editing, data were stored on a purpose-designed computer database prior to analysis using SPSS for Windows 10.0 (Statistical Package for the Social Sciences Inc. 1999). After the means and standard deviations were determined, differences between respite recipients with and without dementia were evaluated by analysis of variance (ANOVA).

**Table 1: Number and percentage of respite recipients who exhibited behavioural symptoms.**

<b>Dementia Behavior Disturbance Scale items</b>	<b>Dementia (n=13) No. (%)</b>	<b>Non-dementia (n=22) No. (%)</b>	<b>Both samples (n=35) No. (%)</b>
Lack of interest in daily activities	10 (77)	9 (41)	19 (54)
Wakes up at night for no obvious reason	8 (62)	8 (36)	16 (46)
Asks same question repeatedly	6 (46)	4 (18)	10 (28)
Is incontinent of urine	7 (54)	4 (18)	11 (31)
Makes unwarranted accusations	5 (39)	3 (14)	8 (23)
Is incontinent of stool	5 (39)	2 (9)	7 (20)
Gets lost outside	5 (39)	2 (9)	7 (20)
Sleeps excessively during the day	6 (46)	3 (14)	9 (26)
Wanders in the house at night	5 (39)	0 (0)	5 (14)
Loses, misplaces or hides things	5 (39)	4 (18)	9 (26)
Wanders aimlessly during the day	5 (39)	0 (0)	5 (14)
Repeats the same action over and over	6 (46)	4 (18)	10 (28)
Is verbally abusive, curses	4 (31)	0 (0)	4 (11)
Refuses to be helped with personal care	2 (15)	3 (14)	5 (14)
Dresses inappropriately	2 (15)	1 (5)	3 (9)
Moves arms or legs in a restless or agitated way	2 (15)	1 (5)	3 (9)
Refuses to eat	1 (8)	2 (9)	3 (9)
Cries or laughs inappropriately	1 (8)	0 (0)	1 (3)
Empties drawers or closets	1 (8)	0 (0)	1 (3)
Hoards things for no obvious reason	2 (15)	0 (0)	2 (6)
Overeats	2 (15)	0 (0)	2 (6)
Makes inappropriate sexual advances	1 (8)	0 (0)	1 (3)
Screams for no reason	1 (8)	0 (0)	1 (3)
Makes physical attacks (hits, bites, scratches, kicks, spits)	1 (8)	0 (0)	1 (3)
Paces up and down	0 (0)	1 (5)	1 (3)
Throws food	1 (8)	0 (0)	1 (3)
Destroys property or clothing	1 (8)	0 (0)	1 (3)
Exposes private body parts	0 (0)	0 (0)	0 (0)

## RESULTS

Of the 35 respite recipients, 24 (68.6%) were female and 11 (31.4%) were male. The mean age of the respite recipients was 81.5 years ( $SD=7.11$ , range=67-96). One male was divorced, eight males were married and two males were single. Of the 24 females, 17 were widowed, one was divorced, four were married and two were single. Three males lived alone and eight lived with their spouses, whereas 12 of the females (11 widows, one single) lived alone, four with their spouses and eight with other family members. Of the total sample, 12 (34%) were married. Prior to admission for residential respite care, 21 (60%) lived in their own home, eight (22.8%) were in hospital, four (11.4%) were in someone else's home and one (2.8%) was residing in a nursing home. Of the total sample 13 (37.1%) had a diagnosis of dementia.

In each case, the nurse was asked an open-ended question about their understanding of why the person was admitted for residential respite care. A break from caring for the respite recipient was the reason stated for 18 (51.4%) of the 35 respite recipients. Thirteen (72.2%) of these people had a diagnosis of dementia. Other reasons included the respite recipient being unable to cope on their own (8; 22.9%), followed by post-hospitalisation (physical problems) (4; 11.4%), familiarisation to residential care (3; 8.6%) and awaiting permanent residential care placement (2; 5.7%).

Of the 18 respite recipients whose reason for respite care was to give the carer a break, eight (22.9%) were reported as having behavioural problems. One of the post hospitalisation respite recipients and one person unable to cope on their own also had behavioural problems. In addition to the open-ended question about the reason for admission, nurses were asked specifically if the admission related to the respite recipient's behaviour. Nurses indicated that 10 of 35 (28.6%) admissions were related to the respite recipient's behaviour.

The mean nurse-rated DBDS score was 8.6 ( $SD=12.21$ , range 0-51). Respite recipients whose respite admission was reported to have been related to their behaviour obtained higher DBDS mean scores than respite recipients whose respite admission was reported not to have been related to their behaviour [23.70 vs 2.56;  $F(1,33)=56.204$ ,  $p<0.001$ ]. The 22 (62.9%) respite recipients without dementia recorded a mean DBDS score of 3.36 ( $SD=4.64$ , range=0-19) whereas the 13 (37.1%) respite recipients with dementia recorded a mean score of 17.46 ( $SD=15.78$ , range=1-51), a significant difference [ $F(1,33)=15.57$ ,  $p<0.001$ ]. Only seven (20%) respite recipients of the total sample showed no DBDS behaviours whereas 28 (80%) showed one or more DBDS behaviours even though these were not necessarily displayed all of the time. The number and proportion of respite recipients who exhibited disruptive behaviour as rated by the nurses can be found in Table 1.

Of the 13 respite recipients with a diagnosis of dementia, nine (69.2%) were prescribed psychotropic

medications. Of the 22 respite recipients who did not have dementia, 13 (59%) were prescribed psychotropic medications. However, seven (70%) of the 10 respite recipients who were admitted to respite care because of behavioural problems were being prescribed psychotropic medications. The type of psychotropic medication and the proportion of respite recipients being administered the medication was as follows: sedative - eight (22.9%); antidepressant - 10 (28.6%); antipsychotic - six (17.1%); cognitive enhancer two (5.7%); and, antianxiety - one (2.9%).

## DISCUSSION

Residential respite care programs are one way of supporting carers of older people living at home. There are a variety of reasons why residential respite care is used and it is likely that for some older people residential respite care delays or prevents permanent placement in an aged care facility (Lawton et al 1989). In order to accurately determine the care needs of residential respite care recipients, their characteristics must be considered because they differ from permanent residents in aged care facilities. One important factor that may be considered in evaluations is disruptive behaviour, as disruptive behaviour is one of the most stressful aspects of care giving and frequently a precursor to permanent placement in an aged care facility.

The present study identified that widows who lived alone in the community were the largest single group admitted for residential respite care. The most common reason for using residential respite care was 'giving carers a break' (whether they resided with the respite care recipient or not). It may be the case that caring for an older person who resides elsewhere may be as stressful as living with them in the same residence (Almberg et al 1997). In some situations, it may be more beneficial if carers and care recipients are supported to live together as an extended family thus mitigating some of the worry of relatives not being there all the time.

Almost half of the respite recipients in the category of 'giving the carers a break' had behaviour problems. Disruptive behaviour is as stressful to carers as cognitive and functional disabilities (Coen et al 1997). Thus, it is likely that disruptive behaviour is a strong reason for seeking residential respite care. Using the DBDS, older people with dementia were rated by nurses as having more disruptive behaviours than older people without dementia. This finding reaffirms those of earlier studies that highlighted the presence of disruptive behaviour in older people with dementia (Nagatomo et al 1997; Chappell and Penning 1996; Baumgarten et al 1990).

The older people diagnosed with dementia were prescribed a greater number of psychotropic medications. While there may be some possible reduction in the frequency of disruptive behaviours due to the effects of these medications (Class et al 1997), the disruptive behaviour persisted in the group treated with psychotropic

medications. This suggests that non-pharmacological interventions still have a major role to play in the management of behavioural problems in older people with dementia (Opie et al 1999).

In the interpretation of the results, several limitations should be taken into account. The sample size is small and this reflects the fact that even though the study was conducted over a three-month period in 16 aged care facilities, there were only 25 beds available for residential respite care. However, there have been no other studies of this kind conducted in Australia and the study used the DBDS, a valid and reliable scale for measuring disruptive behaviour.

## CONCLUSION

One purpose of residential respite care is to relieve the burden of caring for an older person. The strongest predictor of carer burden has been identified as disruptive behaviour, particularly for carers of older people with dementia. Despite the prevalence of disruptive behaviour in respite recipients it is not the main reason older people are being admitted for residential respite care. Whether these people are being excluded or their respite needs are being met adequately elsewhere are questions worthy of further study.

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