

night respite care: relieving the burden on people caring for relatives with dementia

key words

- Alzheimer's disease
- respite care
- carers

The Bexley ACE Night Centre was established in 1992 to help ease the burden on those who care for relatives with dementia. Adrian Treloar and colleagues report on a study designed to assess its effectiveness

There are few published reports of night-time respite care for people with dementia. We review the literature on effectiveness of respite care and report on an audit of the Bexley ACE Night Centre. Night-time respite care is well received by carers who say that it helps them cope better and for longer with relatives who have dementia. Many carers say they would be willing to pay for the service if it were not free. We argue that models of very brief night-time respite should be developed further and researched more fully as they meet an important need of carers.

literature review

Respite services for patients with Alzheimer's disease exist widely throughout the western world and have become accepted as a standard component of services for Alzheimer's disease (Brodaty and Gresham 1992). Even in very different cultures there appears to be a convergence toward similar models of respite provision, driven by the needs of carers and patients (Jarrott 1998). The primary aim of respite care services is the alleviation of carer stress and burden (Brodaty and Gresham 1992, Koffman and Taylor 1997) in the hope that this will maintain independent living for as long as possible. There is, however, limited evidence that respite care produces significant effects upon measures of carer burden.

The most commonly recognised form of respite care is a period (often two weeks) in a hospital, residential or nursing home setting. Adler *et al* (1993) studied the effects of a two-week hospital stay upon caregiver burden and depression and found that although stress levels improved during the stay they quickly returned to baseline following the patient's return home.

A review of the effects of respite care upon patients with dementia and their caregivers (Flint 1995) found little evidence that formal respite care has a significant effect on caregiver burden or rate of institutionalisation. However, there have not been many controlled studies. In one study of 130 caregivers receiving respite (Theiss *et al* 1994) none of the measures of quality of life, mood and response to caregiving was found to change statistically. Graesel (1997) concluded that temporary institutional respite care results in only a slight reduction in the subjective burden, and that benefits in terms of activities of daily living, or health of the care recipients, are unconfirmed.

Concern has been raised that two-week periods of respite care may be associated with increased mortality. Howarth *et al* (1990) found a non-significant increase in mortality attributable to admission to hospital for respite. Studies of patients have shown that respite may lead to patient decline, adverse events and institutionalisation (Larkin and

Hopcroft 1993), although others suggest that adverse effects resolved within two weeks of discharge (Hirsch *et al* 1993).

Daytime respite care has been shown to reduce carer stress. Conlin *et al* (1992) found positive effects upon the relative's stress scale and profile of mood states for recipients of six to eight hours of care twice a week. Zarit *et al* (1999) showed that users of day care had lower scores than the control group in two of the three measures of overload, strain, depression and anger. Day centre programmes have been found to be financially viable and thought by carers to be worth paying for (Cox and Reifler 1994). Professionals (Nolan and Grant 1992) and carers have, however, expressed a wish for greater flexibility of service type (Homer and Gilleard 1994, Erlich and White 1991).

Night respite is an unusual model of care whereby users stay in a centre for one or two nights in a row to enable the carer to have a reasonable night's sleep. Users will usually go home again during the day. Clearly such interventions will be most appropriate for those who regularly have to provide care during the night, perhaps due to behavioural problems or the nursing needs of a relative.

A six-bed night centre in America was described by Rosenheimer and Francis (1992). Although the unit was under-used initially, the service grew and after two years considered itself to be meeting the needs of a severely impaired population who remained at home with their families. However, the unit closed after three years due to lack of funding. A night service was set up in south west London in 1989 and continues to operate successfully (Thomas 1989, Besson 1999).

At-home respite care has been described for hospice clients and their carers, of whom many had less than four hours of sleep per night. A search of Medline and Psycinfo found no other publications on night centres apart from one passing reference to the use of overnight respite care (Cotrell 1996) in a paper where carers were described as needing a variety of respite services, including night-time respite.

audit of the Bexley ACE Night Centre

The Bexley ACE Night Centre was established in 1992 with joint funding from both health and social services and has provided a service three nights a week for seven clients.

The centre is managed and operated by Bexley Association of Carers of the Elderly (ACE), a voluntary organisation, and its original aim was to relieve carer burden. The service was provided by one qualified mental health nurse with untrained carers. A minibus driver and escort collected the clients at 8pm and returned them home at 8am the following day. The service was supported by a consultant from the local psychogeriatric service and by officials from Bexley Council.

It was well received by users, but because of the poor evidence that

respite care affects carer burden we decided to examine the ability of the night centre to achieve its stated objective of supporting carers. We therefore undertook an audit that consisted of a questionnaire about the service to users and measures of carers' stress using the Relatives Stress Scale (Greene *et al* 1982), the General Health Questionnaire 12 (Goldberg and Williams 1988) and the Beck Depression Inventory (Beck *et al* 1961). These were administered just before the person started using the night centre and four weeks later. A control group of regular attenders was also studied using a similar four-week interval.

It was found that mean carer burden scores fell for new attenders during the first month and that 95 per cent confidence intervals for change in the three measures of carer burden did not include zero, while for those who were already attending the night centre, the confidence intervals for the same measures did include zero. Larger samples were not possible due to the slow turnover of clients at the centre and its small number of beds.

results

Seventeen regular users of the centre completed a questionnaire on their experience of the night centre and 88 per cent reported that the centre helped them to feel better and to cope longer (81 per cent). The most frequently identified benefits were to enable a good night's sleep (76 per cent; some used it to enable them to go to work on a night shift), rest and relaxation (88 per cent), watching TV (82 per cent), and phoning family and friends (41 per cent). Users reported that these activities were impossible if their relative was not at the night centre.

No users reported that their relatives were more disturbed after attendance at the night centre and 29 per cent reported improvements in behaviour after attendance. Sixty-five per cent were attending a day centre as well, and of these 36 per cent reported that after day centre attendance their relative's behaviour was worse.

We asked carers whether they thought that if the service was not free, if it would be worth paying for. Some were very poor and said they had no spare money, but despite this 65 per cent said they would still use the centre if there was a charge. While 89 per cent reported feeling better the day after their relative had attended the night centre, only 38 per cent said that the benefit persisted after three days. This finding echoes the observation that the benefits of phased respite are short-lived.

conclusions

Our experience of the use of a night centre has been positive. This has also been the case elsewhere (Besson 1999). We believe that the availability of night-time respite is an important component of respite services for people with dementia and that its benefits and effects are distinct from other forms of respite.

Perhaps the greatest advantage of such forms of care is that by being provided regularly, they are less prone to the problem of rapid return to baseline stress levels seen with phased care. Indeed, the concerns about short-term efficacy of phased respite care, along with carers' desire for greater flexibility in models of care, suggest that ongoing, regular respite of one to two nights per week, enabling secure sleep, is a model that should be developed further and spread to other settings. Indeed the possibility of one night with a day's

respite care either side, or perhaps two nights surrounding one day, may be the sort of flexible option that many carers would wish for.

Perhaps the time has come for residential and nursing homes that provide phased respite to re-examine their schedules and to give respite care for shorter periods more often. Further research alongside development of such centres would be welcome.

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References

- Adler G *et al* (1993) Institutional respite care: benefits and risks for dementia patients and caregivers. *International Psychogeriatrics*, 5, 1, 67-77.
- Beck AT *et al* (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561-571.
- Brodsky H, Gresham M (1992) Prescribing residential respite care for dementia: effects, side-effects, indications and dosage. *International Journal of Geriatric Psychiatry*, 7, 5, 357-362.
- Conlin M *et al* (1992) Reduction of caregiver stress by respite care: a pilot study. *Southern Medical Journal*, 85, 11, 1096-1099.
- Cotrell B (1996) Respite use by dementia caregivers: preferences and reasons for initial use. *Journal of Gerontological Social Work*, 26, 34, 35-55.
- Cox N, Reifler B (1994) Dementia care and respite services program. *Alzheimer's Disease and Related Disorders*, 8, Suppl 3, 113-121.
- Erlach P, White J (1991) TOPS: a consumer approach to Alzheimer's respite programs. *Gerontologist*, 31, 5, 686-691.
- Flint J (1995) Effects of respite care on patients with dementia and their caregivers. *International Psychogeriatrics*, 7, 4, 505-517.
- Goldberg D, Williams P (1988) *A User's Guide to the General Health Questionnaire*. Windsor, NFER-Nelson.
- Graesel E (1997) Temporary institutional respite in dementia cases: who utilises this form of respite care and what effect does it have? *International Psychogeriatrics*, 9, 4, 437-448.
- Greene JG *et al* (1982) Measuring behavioural disturbances on elderly demented patients in the community and its effect on relatives: a factor analytic study. *Age and Ageing*, 11, 2, 121-6.
- Hirsch C *et al* (1993) Effects of a nursing-home respite admission on veterans with advanced dementia. *Gerontologist*, 33, 4, 523-528.
- Homer A, Gilleard C (1994) The effect of inpatient respite care on elderly patients and their carers. *Age and Ageing*, 23, 4, 274-276.
- Howarth S *et al* (1990) Mortality in elderly patients admitted for respite care. *British Medical Journal*, 300, 6728, 844-7.
- Jarrott S *et al* (1998) Adult day care for dementia: a comparison of programs in Sweden and the United States. *Journal of Cross Cultural Gerontology*, 13, 2, 99-108.
- Koffman L, Taylor S (1997) The needs of caregivers. *Elderly Care*, 9, 6, 16-19.
- Larkin L, Hopcroft B (1993) In-hospital respite as a moderator of caregiver stress. *Health and Social Work*, 18, 2, 132-138.
- Nolan M, Grant G (1992) Respite care: challenging tradition. *British Journal of Nursing*, 1, 3, 129-31.
- Personal Communication (2000) Nigel Brassington, Robinson Health Care.
- Rosenheimer L, Francis E (1992) Feasible without subsidy? Overnight respite for Alzheimer's. *Journal of Gerontological Nursing*, 18, 4, 21-29.
- Theiss S *et al* (1994) Respite for caregivers: an evaluation study. *Journal of Community Health Nursing*, 11, 1, 31-44.
- Thomas L (1989) Respite service under cover of night. *Geriatric Nursing and Home Care*, 9, 2, 12-3.
- Zarit S *et al* (1999) Useful services for families: research findings and directions. *International Journal of Geriatric Psychiatry*, 14, 3, 165-177.