Caring at night for people with multiple sclerosis

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Although there have been many studies of informal carers,[1] few have studied substantial numbers of subjects or specific conditions. The Southampton multiple sclerosis survey is based on all people in the health authority with confirmed multiple sclerosis. We investigated whether relatives caring for these people had to perform care activities at night.

Subjects, methods, and results

Three hundred and five people with multiple sclerosis (207 women, 98 men; 74% of those identified) were interviewed by the research physician (MHWR). Whenever possible the nearest relatives of those living in the community were interviewed by the research sociologist (AJS). The 229 relatives interviewed comprised 194 spouses or cohabitees, 22 parents, and 13 offspring or siblings. The ratio of husbands and male cohabitees to wives and female cohabitees was 2:1, but the overall sex ratio was 132 men to 97 women owing to the number of mothers, daughters, and sisters given as nearest relatives.

Most of the close relatives were not carers in the sense used in the survey, in which the term was restricted to people regularly helping a person with multiple sclerosis with at least one personal, domestic, or social care activity from a specified list. Eighty relatives met this definition. Each was asked to keep a 24 hour diary listing and timing all care activities undertaken. The 74 who did so lived at the same address as the person with multiple sclerosis for whom they cared, and 66 were spouses or cohabitees. Their mean age was 57, and 25 were 65 or older. The people being cared for were moderately or severely disabled, scoring $\geq 5{\cdot}0$ on the Kurtzke expanded disability status scale.[2] Forty two had periodic urinary incontinence, 32 on a daily basis. None had seen a continence advisory nurse.

Disturbance at night was normal for 52 carers and was recorded by 44 of those who kept diaries, 42 of whom were the sole carers while two were helped by relatives. None received help from community health or social services. Most disturbances (18) were associated with toiletting; others were to make the people comfortable (10), to help them turn in bed (eight), and to help back to bed those who could get out of bed unaided (eight). Lesser activities included giving drugs, preparing drinks or food, dressing or undressing, and being sociable with those unable to sleep.

Although 31 of the 44 carers spent less than half an hour helping in total, the disturbances tended to be spread throughout the night, averaging 2·6 per carer. During the day the carers spent a mean of five and a half hours on caring activities.

Comment

Caring for people with multiple sclerosis not only entailed appreciable amounts of daytime care but meant for 52 (70%) of the carers that nights were interrupted on two or more occasions. Other studies have shown how stressful and poorly tolerated unremitting nights on call are for carers.[3,4] Disturbance at night emphasised the carers' loneliness and social isolation: as one put it, "You look out of the window, all the houses are in darkness, and you realise you are on your own."

How could this strain be reduced? The most obvious help would be to increase the availability of services that offer to sit with people at night. As toiletting was the most common cause of disturbance a review of the management of incontinence might also be useful. Both possibilities should be considered if the informal care is a long term arrangement.

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Paradoxical bronchoconstriction in wheezing infants after nebulised preservative free iso-osmolar ipratropium bromide

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Nebulised solutions may cause transient paradoxical deterioration in lung function in wheezy infants.[1] The cause of this transient deterioration in infancy is not clear but may be related to the hypo-osmolality, the acidity, or the preservatives in the nebuliser solution. A new iso-osmolar nebuliser solution of ipratropium bromide, free of preservatives, was given to a group of acutely wheezy infants to assess their response.

Patients, methods, and results

Eleven infants (mean age 9 (SD 3) months) who had been admitted to hospital with an acute episode of wheezing and who were thought on admission to respond clinically to nebulised ipratropium bromide were studied. All but two had a history of bronchiolitis. All drugs were stopped eight hours before the study. Infants were sedated with chloral hydrate (120 mg/kg), and thoracic gas volume and airways resistance were measured by total body plethysmography, as detailed elsewhere.[1] Specific conductance was calculated. After baseline lung function was measured each infant was given nebulised normal saline (2 ml) via a cirrhus nebulising chamber with a flow rate of 6 l/minute for five minutes. Fifteen minutes later the infants were given 2 ml of ipratropium bromide from the unit dose phial nebulised via the same cirrhus chamber running at the same flow rate for five minutes. Lung function was measured every five minutes until the child awoke. The solutions used were iso-osmolar. The pH of the normal saline used was 6·85. The pH of ipratropium bromide from the unit dose phial was 3·6.

Three of the infants awoke during baseline measurements and were not included in the results. The figure shows the individual change in specific conductance in the eight remaining patients after nebulised