



# Carers' understanding of Alzheimer's disease

KATE JOHNSTON and RACHEL MAIDMENT describe their research.

*...it may be due to sexual frustration as we couldn't have a normal married life for a few years.*

It was this explanation of the hallucinations and delusions commonly seen in dementias that led us to ask the question 'What do carers think causes problems in Alzheimer's disease?' We were working on a large naturalistic study of people with Alzheimer's disease (AD) and their carers and decided to explore carers' understanding of the illness. We found little research into how people attribute the symptoms of dementia, so we devised a simple questionnaire exploring these issues.

We interviewed 205 carers of people with AD (12 per cent professional carers), all of whom were aware of the diagnosis. We asked them which behaviour or symptom they found most troubling and what they thought caused this. Most identified short-term memory loss as the problem most troubling to them, but other symptoms such as aggression, apathy, hallucinations and delusions were also commonly identified. Despite being aware of the diagnosis, most carers did not attribute symptoms to AD, instead attributing problems to factors such as normal ageing, denial, poor diet, attention seeking, loneliness and sexual frustration.

We also asked carers to rate the amount of control the person with dementia had over the troublesome behaviour. A quarter of carers believed that the person with dementia had complete control of the behaviour, others thought the person had voluntary control

at least for part of the time: 'Sometimes he could try [to control his behaviour] a little harder.'

Finally, we asked carers about the prognosis of dementia. Nearly all understood that the person with dementia would not get better or return to normal. But 10 per cent thought a full recovery would be possible or even probable.

These findings suggest that there are widespread misconceptions about AD and its symptoms. We believe this is especially concerning in a population of family and professional carers who were all informed about the

diagnosis. General models of helping behaviour suggest that people are more likely to provide assistance when the causes of behaviour are perceived to be beyond the individual's control.

This study has implications for all those working with both professional and family carers. We suggest that information about dementia should be given with the focus on the carer's understanding of the symptoms they have observed and not simply handed out as if it were a prescription. While information provided in forms such as leaflets can be very useful, we feel it should be

complemented by discussions with the carer about their understanding of the symptoms being related to dementia. If, for instance, a carer believes the symptom most troubling to them is due to something other than dementia, then the information in leaflets may simply be ignored.

Paton, J., Johnston, K., Katona, C. & Livingston, G. (2004). What causes problems in Alzheimer's disease: Attributions by caregivers. A qualitative study. *International Journal of Geriatric Psychiatry*, 19, 527-532.

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## QUEEN BEE SYNDROME?

JON SUTTON on research suggesting women in science may face unexpected prejudice.

THE underrepresentation of women in science has become a recurrent political issue in recent years, but it's still rare to find university departments with more than a quarter of female staff. So what is holding them back?

Naomi Ellemers (Leiden University) and colleagues from the Netherlands and Italy sampled doctoral students in those two countries. These young male and female scientists reported similar levels of commitment and job satisfaction, although male students in the Netherlands reported spending longer on their work than females did.

However, interesting differences emerged when more senior members of staff were asked about doctoral students. Women, but not men, tended to assume that female students are less committed to a scientific career than their male colleagues. When splitting the Italian sample by age to investigate generational effects, the only subgroup that perceived male doctoral students as significantly more committed to their careers than female students was the older female faculty.

This subgroup of older female scientists also gave surprisingly masculine self-descriptions. The authors argue that 'this heightened awareness of differences (rather than similarities) between the self and the gender in-group not only involves adopting a masculine self-image, but can also imply that other women are contrasted with this self-view, and as a result are perceived in gender stereotypical terms'. This is known as the 'queen bee' syndrome, and the authors reach what they admit is a 'provocative conclusion': '...recent measures intended to prevent biases against women may help perpetuate them. Specifically, involving senior female scientists in supervision and review procedures may harm rather than help the cause it is intended to serve, as chances are that this eventually results in the provision of less rather than more encouragement and opportunities to young female scientists.'

Ellemers, N., van den Heuvel, H., de Gilder, D., Maass, A. & Bonvini, A. (2004). The underrepresentation of women in science: Differential commitment or the queen bee syndrome? *British Journal of Social Psychology*, 43, 1-24.