Giving dementia a voice

Heather B Wood

"When Milton's Satan stood in the pit of hell and raged at heaven, he was merely a trifle miffed compared to how I felt on that day." This was the reaction of bestselling author Terry Pratchett on being diagnosed with posterior cortical atrophy, a variant of Alzheimer disease. Pratchett provides the foreword to a new report, entitled *Dementia: Out of the Shadows*, which was published in October 2008 by the Alzheimer's Society in the UK. The report aims to highlight the realities of living with dementia, an area that is often neglected by the media in the rush to announce new breakthroughs in the treatment of the condition.

The report presents the results of a research project conducted by the Mental Health Foundation, which set out to examine the experiences of people with dementia, from assessment and diagnosis of the condition to adjustment and coping in the wake of the diagnosis. The study consisted of a series of focus groups and one-to-one interviews, involving 32 people with dementia and their carers (61 individuals in total). Crucially, the voices of the patients themselves were given top priority, with the carers mainly filling in gaps where the patients were unable to provide information.

One strong theme that emerged from the study was the stigmatization of people with dementia. The report criticizes the media for their tendency to portray dementia in its most severe form—described by one study participant as the "dribbling and nodding" stage—thereby perpetuating negative perceptions of the condition. Several of the study participants felt that they were treated differently by friends or family after their diagnosis, with one commenting, "My son is looking but he doesn't know me, my daughter...never mentions it." Others, however, reported more-positive experiences, with one carer saying, "Wrongly I tried to hold this to myself...and try to deal with it...once I shared it they all understood what

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the problem is now and I get a lot of support from my family."

Worryingly, it seems that misconceptions about dementia exist not only among the general public, but also within the medical profession. Younger individuals reported difficulties in persuading clinicians that they had dementia because they were considered to be in the 'wrong' age bracket. In addition, a number of the participants reported being misdiagnosed with depression, and one was even told that he was "just lazy".

The report advocates a holistic approach towards patient care. Some participants felt that undue emphasis was placed on the results of clinical tests, as opposed to assessing how they coped with their daily activities. This sentiment was echoed by Terry Pratchett in an interview on the BBC's *Breakfast* program. Highlighting the subtle and selective nature of his cognitive problems, he said, "If I have a shirt with a sleeve that's been pulled inside out, the topographical problem is one that I'll need a little time to work out—on the other hand, a word like 'topographical' comes to my head quite easily."

The issue of coping strategies, such as trying to keep the mind active through listening to music or doing puzzles, was also addressed in the report. It was noted that such strategies are often passed on through word of mouth, and the report suggested that little harm could come from clinicians disseminating information about these potentially helpful approaches, even though evidence for their efficacy is largely anecdotal at present.

The development of new treatments for dementia clearly remains an important priority. In the absence of a cure, however, reports such as *Dementia: Out of the Shadows* have a vital role in raising much-needed awareness—both among the general public and within the medical profession—of the day-to-day reality of living with dementia.

HB Wood is the Editor of Nature Clinical Practice Neurology.

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