One cannot imagine that an individual with dementia could be abused by their carers who, more often than not, are close family members. Yet sufferers stand a high chance of falling victim to abuse because of their vulnerability. In this next article, Colm Owens and Claudia Cooper explain how they went about finding out from family carers of dementia sufferers how far abuse can go in order to understand what drives an individual to act in such a way.

People who depend on others for their basic needs are most likely to be abused. This is as true in infirm elderly people as it is for children or those with learning disabilities. Dementias are a group of conditions that affect one in 20 people over the age of 65 and one in five people over the age of 80. There is a range of severity; however, sufferers with all but the mildest forms of the condition will require a degree of assistance in day-to-day living including personal care. Difficulties with memory will mean that tasks such as managing finances may become impossible.

Caring for people with dementia is demanding and stressful work. Society at large tends to undervalue older people and is uncomfortable with the thought of infirm elderly people. The work of caring for older people may, therefore, also become undervalued.

People with forms of dementia exhibit a wide range of behaviours, which will be influenced by their pre-existing personality, the extent of their illness and the environment around them. So-called ‘challenging’ behaviours may develop. They may become aggressive, resistant to care and repetitive. We live in a youth-centred culture and many of us carry fears of becoming dependent in our older age. Looking after an elderly infirm person may remind us of vulnerable aspects of ourselves that we dislike. Dementia could, therefore, be seen as conferring an extra degree of risk of abuse in a population that is already vulnerable.

‘Abuse’ is a word with many connotations; it conjures up images of extreme behaviour and violence. It may be more helpful, however, to view abusive behaviour on a continuous spectrum rather
than dichotomising it. It may range from subtle interactions or tone of voice through to physical abuse. It can be defined as a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person.

Elder abuse is a priority for the UK government, which recently consulted about a revision of the current policy for safeguarding vulnerable adults (Department of Health, 2008). This review was entirely focused on preventing abuse by paid carers, suggesting that abuse is confined to the formal care system. This is in line with the House of Commons Select Committee (2004) statement that ‘few incidents of abuse are committed by loving, supportive people who have lashed out’.

It is unpaid or ‘informal’ carers who provide the bulk of dementia care in the UK. Often untrained family members, they may find themselves struggling to care for a loved one with a condition that they may not fully understand. There may be challenging behaviours to contend with and they may have only limited support available to them. Human beings are complex, and a carer (who may be a wife or child) and the person they care for may have a difficult relationship prior to the onset of the dementia. In contrast to the House of Commons Select Committee’s (2004) contention, we found in a recent review that the prevalence of elder abuse reported by family carers ranged from 12% to 55% (Cooper et al., 2008). None of these studies, however, used a standardised set of questions for enquiring about and quantifying abuse.

How far does abuse go?

This prompted us to design the ‘CARD’ (or CAring for Relatives with Dementia) study. This was the first UK survey to ask family carers of a representative group of dementia sufferers recruited from secondary care about abusive acts towards the people they cared for. Results were published in the British Medical Journal (Cooper et al., 2009a).

We recruited 220 family carers of people with dementia living at home. A family carer was defined as someone who provided four or more hours of care per week. The individuals with dementia whom the carers looked after were known to one of four mental health teams for older people in north London and Essex. These areas were chosen so as to give a representative mix of urban, suburban and rural areas. We consecutively recruited family carers of people with dementia referred to the teams. There were 98 family carers that refused to be involved in the study or could not be contacted. There were no significant differences of demographic detail between participants and non-participants.

The study used a questionnaire called the Modified Conflict Tactics Scale to ask carers about potentially abusive acts. The Modified Conflict Tactics Scale is a well-recognised instrument that has been repeatedly validated in studies examining abusive behaviours in a number of populations (Beach et al., 2005). The carers were asked how many times in the last three months they have engaged in the following 10 behaviours with the person they care for.

1. Screamed or yelled at them.
2. Used a harsh tone of voice, insulted or sworn at them.
3. Threatened to send them to a care home.
4. Threatened to stop taking care of or abandon them.
5. Threatened to use physical force.
6. Felt afraid that they might hit or hurt them.
7. Hit or slapped them.
8. Shaken them.
9. Otherwise handled them roughly.
10. Withheld food.

There are five possible answers to each question: never (0); almost never (1); sometimes (2); most of the time (3); all the time (4).

Just over half (115, 52%) of the family carers reported some abusive behaviour (ie. scoring one or more on at least one item. One third (74, 34%) of the carers reported that abusive behaviour(s) had occurred at least ‘sometimes’ in the last three months, the threshold used in the study to denote significant abuse. This was the first representative survey to ask family carers about abusive acts. Our finding that family carers commonly reported acting abusively towards people with dementia, with a third scoring as ‘abuse cases’, suggests that any policy for safeguarding vulnerable adults must consider strategies directed towards families who provide most care for older people, rather than exclusively concentrating on formal carers.
All or nothing

There is often reluctance among professionals to ask family carers about abuse, perhaps because of a fear that discussing and acknowledging it would necessitate an adult protection referral and trigger a punitive response, such as removal of the person with dementia. This may result in an ‘all-or-nothing’ approach to abuse, where it is ignored until the problem becomes very serious. Similarly, clinicians may not consider abuse when seeing most carers if abuse is perceived as a rare action purposefully perpetrated by amoral abusers, in contrast to the great majority of carers who would never act abusively.

While professionals have a duty to make an adult protection referral if they believe that a person is being harmed, or is at significant risk of being harmed, it is also important to detect and manage abusive behaviour below this threshold. This may help to prevent more serious abuse.

Although individuals are always responsible for their actions, it is inevitable that abusive behaviours will always be more prevalent in people who are put under strain. In the CARD study, we found that more anxious and depressed carers reported more abuse; this seemed to be because carers under stress used less helpful coping strategies to deal with the stresses of caring. Those who spent more hours caring, and who were at the receiving end of more abusive behaviour from care recipients and reported higher levels of stress also reported more abusive behaviour.

These results are interesting because they suggest that interventions directed at reducing carer anxiety, depression or changing unhelpful coping strategies, and/or reducing care recipient aggression where possible, may help to reduce abuse (Cooper et al, 2009b). No studies have yet tested interventions to reduce abuse, and we think this is a logical and urgent next step. We asked the carers who reported any abusive behaviour about their views on what might help to reduce or prevent this abusive behaviour. They thought that medication to help memory (endorsed by 18.6% of carers), home care (15.0%), residential respite and sitting services (10.6%) were most important. This highlights the importance for carers, who often feel isolated and unsupported, of being able to take a break from caring and having some help to care.

Responding to the spectrum of abuse

Most family carers reported some abusive behaviour, and a third reported significant levels of abuse. We found few cases of physical or frequent abuse. We suggest that any policy for safeguarding vulnerable adults must consider strategies directed towards families who provide the majority of care for older people, rather than exclusively formal carers.

Considering elder abuse as a spectrum of behaviour rather than an ‘all-or-nothing’ phenomenon could help professionals to feel more able to ask about it and therefore offer appropriate help.

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References


Further reading
