

Abuse of people with dementia by family carers: representative cross sectional survey

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ABSTRACT

Objective To determine the prevalence of abusive behaviours by family carers of people with dementia.

Design Representative cross sectional survey

Setting Community mental health teams in Essex and London.

Participants 220 family carers of people newly referred to secondary psychiatric services with dementia who were living at home.

Main outcome measure Psychological and physical abuse (revised modified conflict tactics scale).

Results 115 (52%, 95% confidence interval 46% to 59%) carers reported some abusive behaviour and 74 (34%, 27% to 40%) reported important levels of abuse. Verbal abuse was most commonly reported. Only three (1.4%) carers reported occasional physical abuse.

Conclusions Abusive behaviour by family carers towards people with dementia is common, with a third reporting important levels of abuse and half some abusive behaviour. We found few cases of physical or frequent abuse, although those with the most abusive behaviour may have been reluctant to report it.

INTRODUCTION

Elder abuse is a priority of both the UK government¹ and the US federal government.² In the UK it is 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.¹

In the UK the government is consulting about a revision of the current policy for safeguarding vulnerable adults.³ This review is entirely focused on preventing abuse by paid carers, suggesting that abuse is confined to the formal care system. This is in line with the 2004 statement by the House of Commons select committee that “few incidents of abuse are committed by loving, supportive people who have lashed out.”¹ Abuse can be psychological, financial, sexual, physical, or by neglect. Despite the select committee's contention, many family carers for people with dementia report acting abusively when asked and might see no alternative way to manage the situation and be unaware

that their behaviour would be defined as abusive.^{4,5} No studies of abusive behaviours in representative populations of family carers currently exist, but our systematic review found that the prevalence of elder abuse reported by family carers ranged from 12-55%.⁶ Few of these studies used instruments with known psychometric properties.⁶ We determined the prevalence of abuse by family carers of people with dementia in a representative population of care recipients referred to secondary care.

METHODS

We recruited family carers of people with a clinical diagnosis of dementia who were living at home and referred to community mental health teams covering London and Essex (which included inner city, suburban, and rural areas).

A researcher attended team meetings and reviewed the notes of all people consecutively referred to the team after being assessed. The clinical team initially contacted potentially eligible family carers (defined as providing care for four or more hours a week), and gave them an information sheet on the study. One week later a researcher telephoned the carers, unless they had asked not to be contacted. Interviews took place at a time and place convenient to the carer, usually their home.

Participants gave written informed consent. The information sheet specified that “we respect confidentiality but cannot keep it a secret if anyone is being seriously harmed.” The care recipients were asked for consent to access their medical notes but not interviewed. When they lacked capacity to consent (judged from psychiatrist and carer reports), we asked the carers whether they thought that the care recipient would have agreed when they had capacity. Three experienced psychiatrists carried out interviews between January 2007 and April 2008.

Measures

We collected data on the age of the carer and care recipient, sex, ethnicity, qualifications, the carer's relationship to the care recipient (spouse, child, other), if the carer lived with the care recipient, and whether the carer worked. Our main outcome measure was abuse

using the validated modified conflict tactics scale, completed by the carer.⁵⁷ This scale asks how often in the past three months the carers had acted in each of five psychologically and five physically abusive ways towards the care recipient, on a Likert scale from 0 (never) to 4 (all the time). A score of 2 or more (sometimes) on any question denotes important abuse. The scale has subscales for psychological and physical abuse. From the care recipient's medical notes we also obtained the most recent mini-mental state examination score and drugs. Carers were asked about the care recipient's neuropsychiatric symptoms using the neuropsychiatric inventory.⁸

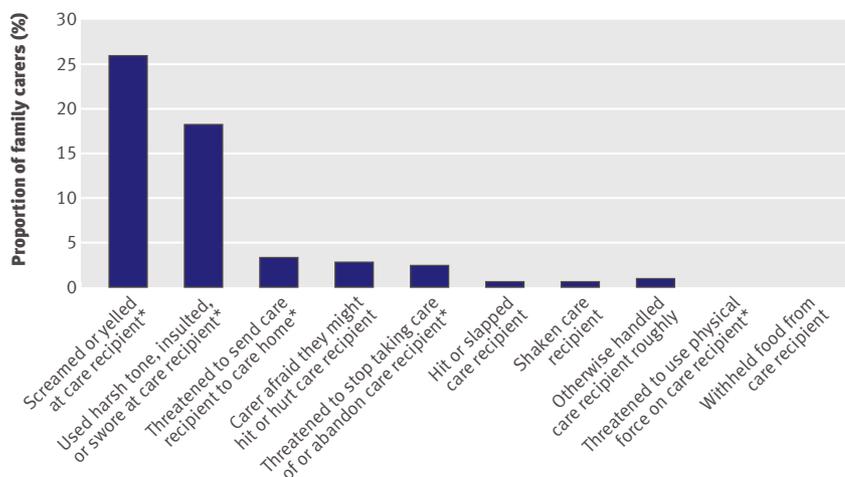
Data analysis

Using appropriate summary statistics we reported the sociodemographic characteristics of the sample and the illness characteristics of the care recipient. We also reported the proportion of carers meeting criteria for abuse (caseness), and the proportion who indicated that each of the 10 behaviours occurred "at least sometimes." We used online software to calculate 95% confidence intervals.⁹

RESULTS

Overall, 220 of 319 (69%) eligible carers participated; 98 refused or were not contactable. Participants and non-participants did not differ for sex of the carer and care recipient ($\chi^2=1.3$, $P=0.26$; $\chi^2=0.0$, $P=1.00$), whether they lived together ($\chi^2=2.2$, $P=0.14$), or the relationship (partner, child, other) between them ($\chi^2=2.7$, $P=0.26$).

One hundred and forty four (66%) family carers were women, 182 (83%) were of white UK ethnicity, 157 (71%) were living with a partner, and 118 (54%) were living with the care recipient. Their mean age was 61.7 (SD 13.1) years (range 24-92 years). One hundred and twenty (56%) were caring for a parent, 72 (33%) for a spouse, and 28 (13%) for another relative or friend. Ninety (41%) had remained in education until age 18, and 86 (39%) were in full time or part time employment. One hundred and fifty nine (72%) of the care



Proportion of family carers reporting each abusive behaviour occurring "at least sometimes" in previous three months. *Scale item for psychological abuse; remainder for physical abuse

recipients were women (mean age of 81.6 (SD 7.8) years, range 58-99 years). Mini-mental state examination scores were available for 211 care recipients (mean score 18.4 (SD 7.0), range 0-29). The mean neuropsychiatric inventory score was 18.3 (SD 1.1, range 0-75). According to the family carers, the care recipients had experienced problems with their memory for a mean of 33.7 (SD 38.9) months (range 0-300).

Prevalence of abusive behaviour

In total, 115 (52%, 95% confidence interval 46% to 59%) carers reported some abusive behaviour. Total scores on the abuse instrument ranged from 0 to 11, with a median score of 1 (interquartile range 0-2). Seventy four (34%, 27% to 40%) family carers reported abusive behaviours occurring "at least sometimes" in the past three months (figure), the threshold used in this study to denote important abuse. The verbal abuse items were most commonly reported. Only one carer stated that any of the abusive behaviours were taking place "most of the time," and none that any abuse was happening "all of the time."

Seventy two (33%, 27% to 39%) carers reported that psychological abuse occurred sometimes and eight (4%, 1% to 6%) that physical abuse occurred sometimes. Seven (3%) of the cases of physical abuse was because the carer reported that they were sometimes afraid that they might hit or hurt the care recipient. Only three (1%) carers reported that actual physical abuse sometimes occurred. Four people said "almost never" (subthreshold for case level) to physical abuse items of whom three were "afraid that they might hit or hurt" and one reported "almost never" handling the care recipient roughly.

DISCUSSION

Family carers commonly reported acting abusively towards people with dementia, with a third scoring equivalent to cases of abuse. This 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.

The prevalence of elder abuse reported by family carers in previous studies has ranged from 12-55%,⁶ with some of the variation due to differences in definitions of what constitutes a case of abuse. Different definitions of abuse would have changed our figures for prevalence as half of family carers interviewed in our study reported abusive behaviour, mostly verbal, whereas few reported frequent or physical abuse. It is unsurprising that disagreement exists about what form of behaviour constitutes elder abuse and what is part of normal family relationships. In one US study, for example, 5% of older couples, and a higher percentage of younger couples, reported physical violence within their relationship over the previous year.¹⁰ Abusive behaviour may be a continuation of an earlier, possibly mutually aggressive relationship,¹⁰ which could become abusive if the care recipient no longer has the

WHAT IS ALREADY KNOWN ON THIS TOPIC

People with dementia are particularly vulnerable to abuse
 Many family carers of people with dementia report acting abusively
 Professionals are reluctant to ask about elder abuse

WHAT THIS STUDY ADDS

A third of family carers reported significant abusive behaviour towards people with dementia in a secondary care setting
 Most carers reported some abusive behaviour but few reported more serious and physical abuse
 Elder abuse may be more realistically considered on a spectrum rather than as an “all or nothing” phenomenon

capacity to decide whether to stay in that relationship or to leave it and live independently.

Professionals are often reluctant to ask about abuse,¹¹ perhaps because of a fear that discussing and acknowledging it would necessitate referral of an adult for protection 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 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 most carers who would never act abusively. This paradigm has been used to describe societal reactions to child abuse, where abusers are construed as evil and other, who can be removed from society,¹² thus eliminating abuse.

We suggest that considering abusive behaviour on a continuous spectrum rather than dichotomising it would be more helpful in clinical practice. While professionals have a duty to make a referral for the protection of an adult if they believe that someone 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.

Limitations

Although many carers were willing to report abusive actions, some may not have been or may have under-reported the severity, so our numbers could be an underestimate. Compared with an earlier study,¹⁰ the rate of actual physical abuse was low and people may have been particularly reluctant to report serious physical abuse. Our study could not detect these and any other behaviours that the carer wanted to hide. Similarly, despite our high response rate and the comparability in sociodemographic characteristics between non-participants and participants, non-participants may have been more likely to abuse. The study comprised an hour long interview on a range of topics and was not presented specifically as being about elder abuse, but carers who were abusing may well have been more reluctant to meet with a researcher than those who did not consider themselves to be abusive. Although this was a representative (rather than convenience) sample of people with dementia, as new referrals to secondary care they

comprise disproportionately those with a new diagnosis or with acute problems. Thus our population was less cognitively impaired than the population with dementia.¹³ Care recipients may have had untreated neuropsychiatric symptoms (although the mean score was almost identical to that of a previous representative sample).¹⁴

Conclusions

Most family carers reported some abusive behaviour, and a third reported important 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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