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A systematic review of the prevalence and odds of domestic abuse victimisation among people with dementia.

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Abstract

Background

Little is known about the prevalence of domestic abuse in later life or after the onset of dementia. Given the expanding population of dementia sufferers, it is imperative to identify the degree to which domestic abuse occurs within this population.

Objectives

To establish the prevalence (lifetime and past year), odds and trajectory of domestic abuse victimisation among people with dementia.

Methods

Systematic searches of twenty electronic databases were performed from inception to October 2014, using a pre-defined search strategy for English language articles containing data on the prevalence and/or odds of adult lifetime or past year domestic abuse among people with dementia.

Results

Six studies met the inclusion criteria. Among patients with dementia, the past year median prevalence of physical and psychological domestic abuse victimisation is 11% and 19% respectively. Findings show an increased odds of domestic abuse among people with dementia compared to those without dementia; Trajectory information indicated that domestic abuse was more prevalent in relationships with a premorbid history of abuse.

Conclusions

The lack of research into this area is highlighted by the small number of includable studies. There is a need for further research into the impact of dementia on domestic violence.

Introduction

Domestic abuse is a major public health concern which does not cease as a person ages. The intimacy between abuser and victim often results in more frequent and severe violence than that perpetrated by acquaintances and strangers (Kropp et al., 2005), and is associated with significant physical and psychiatric morbidities at all ages (Bundock et al., 2013; McCauley et al., 1995; Trevillion et al., 2012).

The World Health Organisation (WHO) predicts doubling of the over-sixty population worldwide by 2025 (WHO, 2011), and it is estimated that over one million people in the UK will be affected by dementia by 2021. Dementia is a recognised risk factor for elder abuse (Choi & Mayer, 2000; WHO, 2011), but its relationship with domestic abuse and abuse trajectories over time are ill defined. Current research indicates that domestic abuse may be poorly identified among older people, and will often be subsumed into 'elder abuse', which includes violence from non-familial perpetrators (e.g. paid carers) (Band-Winterstein & Eisikovits, 2009; Lombard & Scott, 2013). Existing research into elder abuse also fails to contextualise abuse from a gender-based or intimate partner violence perspective (Lombard & Scott, 2013).

Objectives

1. To establish the prevalence (adult lifetime and past year) and odds ratios of intimate partner and family member domestic abuse victimisation among people with dementia.

2. To gain insight into the trajectory of violent relationships in this cohort relating to changes in the pattern or severity of violence pre- and post-dementia diagnosis.

Methods

Search strategy and Selection criteria

MOOSE and PRISMA reporting guidelines were followed (Moher et al., 2009; Stroup et al., 2000). The protocol is registered on the PROSPERO database of systematic reviews (<http://www.crd.york.ac.uk/PROSPERO/>), registration number: CRD42014014622. The search strategy comprised 1) electronic searches of 20 biomedical and social science databases from their inception to 31st October 2014, Appendix 2; 2) hand searches of two non-indexed journals (The Journal of Dementia Care and Australian Journal of Dementia Care); 3) screening reference lists of included studies; 4) citation tracking of included studies; 5) expert recommendations.

Medical Subject Headings (MeSH) and text words were used to search the databases. Domestic abuse search terms were adapted from published Cochrane protocols and reviews (Friedman & Loue, 2007; Ramsay et al., 2002; Smedslund et al., 2007). Elder abuse search terms were adapted from a 2014 review of elder abuse and dementia (Dong et al., 2014). Dementia search terms were adapted from a Cochrane systematic review (Fage et al., 2013); We used the following (combination of) search terms: “elder abuse”, “domestic violence”, “domestic abuse”, “family violence”, “partner violence”, “partner abuse”, “spouse abuse”, “elder mistreatment”, “financial exploitation”,

“dementia”, “delirium, dementia, amnestic, cognitive disorders”, “alzheimer”, “AD”, “lewy body” or DLB or LBD or FTD or FTLD or “frontotemporal lobar degeneration” or “frontotemporal dementia”, “cognitive impairment”, “memory complaint, decline or disorder”.

Studies were eligible for inclusion in the review if they: 1) included men and/or women with any form of dementia 2) presented the results of peer-reviewed English-language research using the following study designs: experimental studies (e.g. randomised controlled trials, non-randomised controlled trials, parallel group studies), before and after studies, interrupted time series studies, case note reviews, cohort studies, case-control studies, and cross-sectional studies; 3) measured the prevalence and/or the odds ratio of adult lifetime and/or past year domestic abuse, or collected data disaggregated by perpetrator, from which these statistics could be calculated.

As there is no gold diagnostic standard, searches were not restricted to papers that used a validated dementia diagnostic or screening instrument, but if stated the method of assessing dementia was recorded. If multiple eligible papers from the same study were identified, the paper with the largest total N was included in the analysis.

The UK Home Office definition of domestic violence is used in this review (Home office 2013), ‘any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless

of gender or sexuality. The abuse can encompass, but is not limited to: psychological, physical, sexual, financial, emotional.

Data extraction and quality appraisal

Identified abstracts were downloaded to EndNote© software and assessed against the inclusion criteria by the main reviewer; a randomly selected 10% sample was screened by a second reviewer LK as a quality check. Potentially eligible studies were downloaded and evaluated against a standardised checklist assessing inclusion eligibility. Excluded references were categorised by the primary reason for exclusion. If necessary the corresponding authors were contacted for further information and/or raw data for analysis.

The data extraction form included bibliographic information, study design, study sample, measures of abuse and dementia, type and severity of violence and trajectory of domestic abuse before and after dementia.

Two reviewers BM and LK, methodologically appraised studies, using a standardised appraisal form which included items on selection and measurement bias, developed by Trevillion et al using criteria adapted from validated tools (Downs & Black, 1998; Loney et al., 2000; Saha et al., 2005). The searches were updated in May 2016; results are included in figure 1.

Data analysis

Analysis of the prevalence, odds ratio and 95% confidence intervals for domestic abuse victimisation were performed in STATA. For each estimate

the comparison group was participants without dementia. Basic descriptive analyses were conducted to summarise information about the study population. The results were tabulated; odds ratios were displayed graphically using forest plots. Funnel plots for detecting publication bias were not possible due to the paucity of data. Cochrane's I^2 statistic for quantification of study heterogeneity was calculated but is unreliable as only two papers qualified for inclusion in this test. The extracted summary statistics were pooled to determine an overall prevalence and estimated odds ratio of domestic abuse victimisation among people with dementia. A critical conceptual analysis of included papers was also conducted, examining how domestic abuse was measured and conceptualised across studies.

Results

The final selection for this review comprised 6 studies (Cooper et al., 2010; Coyne et al., 1993; Friedman et al., 2011; Sasaki et al., 2007; Yan & Kwok, 2011; Yan, 2014:).

The most commonly used sampling was convenience sampling, and 4 of the 6 studies did not specify how dementia was determined. The assessment of violence was variable, and lacked rigour, and the types of abuse measured were not consistent.

Summary of key characteristics of included studies

Author (year)	Country	Community or clinical samples	Sampling method	How dementia was assessed	Sample size, age and gender of dementia sufferers	How violence was assessed	Type of violence assessed	Prevalence of DVA with odds ratios	Quality appraisal score
Cooper et al (2010)	UK	Clinical sample, patients referred to community mental health services	Cross-sectional study between 2007-2008	Recorded clinical diagnosis of dementia	61 Male and 159 female average age 81.6	Past-year abuse, assessed using the modified Conflict Tactics Scale.	Physical Psychological	<i>Physical abuse:</i> With dementia: 11/217 (5%) <i>Psychological abuse:</i> With Dementia 41/217 (19%) OR not possible	34/40 (85%)
Coyne et al (1993)	USA	Community sample, users of a telephone helpline for Alzheimer's Disease	Cross-sectional study between 1990-1991	Dementia assessment measure was not specified	97 Male and 243 female average age 75.9	Past-year physical abuse, assessed using a questionnaire developed by the authors	physical	<i>Physical abuse:</i> With dementia: 33/299 (11%) OR not possible	26/40 (65%)
Friedman et al (2011)	USA	Clinical sample. Hospital trauma cases referred to a level 1 Acute Trauma Unit, with elder abuse coding	Case-control study	Dementia assessment measure was not specified	89 males and 75 females, average age 73.3	Physical abuse cases were identified using elder abuse coding	physical	<i>Physical abuse:</i> With dementia: 3/7 (43%) Without dementia 32/157 (20%) OR 2.93 CI (0.624-13.755) P= 0.156 (>0.05)	31/40 (78%)

Sasaki et al (2007)	Japan	Community, sample of principal caregivers utilising visiting nurse services	Cross-sectional study	Cognitive impairment was assessed using Japanese version of Short Memory Questionnaire tool	159 males and 239 females average age 80.5	Potentially harmful behaviours by the caregiver were assessed using a checklist developed by Ueda (2000)	Physical, psychological, financial, neglect	<i>Potentially abusive behaviour</i> With dementia: 78/208 (38%) Without dementia: 4/21 (19%) OR 2.55 CI (0.828-7.853) P=0.093 (>0.05)	27/40 (68%)
Yan and Kwok (2011)	China	community dwelling dyads using local NGO services in 2008	Cross-sectional study	Dementia assessment measure was not specified	31 males and 91 females average age 82.6	Past year abuse assessed using the physical assault and psychological aggression subscales of the revised Conflict Tactics Scale (CTS2)	Physical, psychological	<i>Physical abuse:</i> With dementia: 22/122 (18%) <i>Psychological abuse:</i> With Dementia 76/122 (62%) ORs not possible	30/40 (75%)
Yan (2014)	China	community dwelling dyads using local NGO services between 2009-2011	Prospective cohort study	Dementia assessment measure was not specified.	27 males and 122 females average age 91.7	past year and lifetime abuse; assessed using the physical assault and psychological aggression subscales of the revised Conflict Tactics Scale (CTS2)	Physical, psychological	<i>Lifetime physical abuse:</i> With dementia: 40/149 (27%) <i>Past year physical abuse:</i> With dementia: 15/149 (10%) <i>Lifetime psychological abuse:</i>	35/40 (88%)

								With Dementia 60/149 (40%) <i>Past year psychological abuse:</i> With Dementia 23/149 (15%) ORs not possible	
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Fig. 1 Flow diagram of literature search

Prevalence and odds of domestic abuse in dementia

The prevalence of domestic abuse victimisation was calculated for each study. Median prevalences with interquartile ranges are the only measure calculable for the four studies lacking controls without dementia (Cooper et al., 2010; Coyne et al., 1993; Yan, 2014; Yan & Kwok, 2011). Sex-specific prevalence estimates were not possible from the primary data.

Odds ratios were only calculable for two studies. Neither reached significance (P values >0.05) but suggest increased odds of domestic abuse among people with dementia compared with those without (Fig. 2). The pooled odds ratio for the two studies is significant at 2.68 (CI 1.06-6.64) $P<0.05$; a doubling of abuse odds in victims with dementia versus controls is implied, however this calculation is not statistically robust as only two studies are included. Prevalence rates were reported separately for physical and psychological violence; this was not possible for the odds ratio.

Fig. 2 – Odds estimates for past year domestic abuse with dementia

Physical abuse

Lifetime domestic abuse

One study (Yan, 2014) disaggregated adult lifetime and past year abuse; the prevalence of lifetime physical abuse among people with dementia was 27%.

Past year domestic abuse

Four papers reported on the prevalence of past year physical abuse among men and women with dementia (Cooper et al., 2010; Coyne et al., 1993; Yan, 2014; Yan & Kwok, 2011). The pooled median prevalence was 11% (interquartile range (IQR) 9-13%; range 5-18%).

Incident cases of physical abuse

Friedman et al (2011) analysed cases of physical abuse resulting in admission to a trauma centre. Physical assault prevalence resulting in admission among dementia sufferers was 43% versus 20% for those without dementia. The odds ratio for abuse in dementia was 2.93 (0.62-13.75) $P>0.05$.

Psychological abuse

Lifetime domestic abuse

The prevalence of lifetime domestic psychological abuse experienced by people with dementia was reported by one study as 40% (Yan, 2014).

Past year domestic abuse

Three papers reported past year psychological abuse prevalence (Cooper et al., 2010; Yan, 2014; E. Yan & Kwok, 2011). The pooled median prevalence was 19% (IQR 17-41%; range 15-62%).

Abuse not disaggregated by type

Sasaki et al (2007) did not specify the type of violence perpetrated against people with dementia. Abuse was termed 'potentially harmful behaviours'; and included: ignoring, leaving alone, verbal aggression, neglecting to care, slapping or pinching, restriction to their bedroom, physical restriction, deprivation of health services and deprivation of money. The calculated prevalence by family caregivers was 38%. The odds ratio for abusive behaviour in dementia was 2.55 (0.83-7.85) $P > 0.05$.

Trajectory of violence

Two studies included information relating to the trajectory of violent relationships after dementia diagnosis. Cooper et al. (2010) found that pre-morbidly less rewarding relationships were more likely to feature abuse following a diagnosis of dementia. The strongest predictor for abusive behaviour in the carer was the recipient being abusive, either as part of a continuing history of violence or as a new symptom of their dementia.

Coyne et al. (1993) found that 33.1% of carers interviewed were abused by care-recipients with dementia. Where there was no pre-morbid history of abuse, the proportion of carers abused was 30.1%. Where carers reported a history of abuse in the relationship (8.6%), with the previously abusive partner

going on to develop dementia, this figure rose to 62.5%. Carers were in turn found to be 21.3% more likely to abuse the care-recipient if abused by them. Carers with a lifetime history of abuse from the care-recipient were over twice as likely to act abusively towards the recipient compared with those with no prior abuse.

Discussion

Key findings

There is a lack of primary data in this area, and a lack of clarity around the groups of individuals being investigated.

Prevalence and odds of domestic abuse in dementia

Dementia is a growing public health crisis garnering worldwide attention. This review has found dementia to be associated with a high prevalence and approximately two-fold greater odds of experiencing domestic abuse, compared with controls without dementia. The past year median prevalence of physical and psychological domestic abuse in dementia is reported as 11% and 19% respectively. One study reported lifetime prevalence of domestic abuse as 27% for physical and 40% for psychological abuse (Yan, 2014). These results exceed commonly quoted prevalence rates for the older population (Cooper, 2009). It was expected that financial abuse would be prevalent in this population, but none of the included studies reported separately on this. None of the studies measured sexual abuse. Sexual

assault is underreported across all ages, but perhaps particularly in older people, where asexuality may be assumed (Burgess & Phillips, 2006).

Trajectory of violence

Relationships with a prior history of violence were associated with greater prevalence of past year abuse among people with dementia (Cooper et al., 2010; Coyne et al., 1993) which contradicts assumptions that abuse tapers with age. It also seems that families in which domestic abuse is established are likely to continue behaving abusively, as it was reported that pre-dementia relationship satisfaction was important in predicting abuse (Band-Winterstein & Eisikovits, 2009; Cooper et al., 2010); Coyne et al. (1993) reported that one third of dementia patients acted abusively towards their carers, and that these carers were more likely to reciprocate violently. It could be speculated that shifts in the power balance of a relationship may result in role reversal, which would create the setting for mutual domestic abuse (Band-Winterstein & Eisikovits, 2009).

It seems likely that those with a history of premorbid domestic abuse within their relationship, will continue abusive behaviours post a dementia diagnosis, but this cannot be concluded from our review. For those without pre-morbid domestic abuse, it is not clear whether dementia is the trigger for the onset of domestic abuse, but the causes of this are likely to be multifactorial, and need further investigation. More research is needed to address these questions.

Critical appraisal

For the cross-sectional studies convenience sampling was most often used to source participants (Cooper et al., 2010; Coyne et al., 1993; Sasaki et al., 2007; Yan & Kwok, 2011). This method may introduce bias, as the pooled group may not represent the comparative community, limiting result extrapolation. In four of the studies there was no comparison group of non-demented individuals, and therefore odds ratios could not be estimated and inferences could not be made regarding the differences in odds of violence for older people with dementia compared with those without. (Cooper et al., 2010; Coyne et al., 1993; Yan, 2014; Yan & Kwok, 2011). Longitudinal studies are lacking from this review's data set; only one six-month prospective cohort study is included. This may be because practically this patient group is difficult to study. Longitudinal studies where abuse is known are ethically challenging, and support must be provided to the abused party.

Carer self-report of abusive behaviour was the most common method for ascertaining violence in the included papers (Cooper et al., 2010; Coyne et al., 1993; Sasaki et al., 2007; Yan, 2014; Yan & Kwok, 2011). The Conflict Tactics Scale (CTS) (Straus, 1987) and its variations were used in three of the included papers. Even where such validated tools were used, they were not used in full; Cooper et al. (2010) utilised only five out of the eight-twelve physical and psychological abuse subscales. Using non-validated measures of domestic abuse may increase the likelihood of under-reporting (Trevillion et al., 2012). Only one paper used objective measures (Friedman et al., 2011) and none assessed abuse by victim self-report. This fundamentally weakens

the strength of the evidence due to response, recall and social desirability bias, as it is suggested that perpetrators may under-report domestic abuse (Trevillion et al., 2012; Yan & Kwok, 2011). Even the validated and reliable CTS (Straus, 1987) is limited by systematic under-reporting of abuse by both victims and perpetrators (Archer, 1999). Self-reporting is much more complicated if the victim has dementia, which is why some commentators prefer carer self-reports for domestic abuse identification (Sasaki et al., 2007). This methodology directly contrasts with domestic abuse research among those of working-age, which advocates self-reported experiences of violence.

Research among working age victims reports that women are at a greater risk of experiencing repeated, coercive and severe violence compared with men (Finney, 2006; Houry et al., 2008). Across all psychiatric disorders, women experience a higher prevalence of domestic abuse versus men (Trevillion et al., 2012). These points are noteworthy given the absence of examination of gender difference found by this review. The lack of gender-disaggregated data prohibits investigating whether older women, like women of working age, are at increased risk of abuse versus older men when one of the parties has dementia. The gender neutrality of the abuse measures used by the included papers means that abusive acts may be measured out of context (i.e. not reporting whether acts of violence were in attack or defence) and this could result in differential misclassification bias across sexes.

The papers are heterogeneous, being sourced from different countries with varying cultural beliefs, and utilising different measures of sampling, data

collection and measures of both domestic abuse and dementia. However, the small number of studies qualifying for review made statistical measures of study heterogeneity invalid. Only two of the six included studies defined how they identified dementia in their participants (Cooper et al., 2010; Sasaki et al., 2007). If the risk factor itself is difficult to identify and commonly underreported, it is clear to see how difficult identifying abuse in this population is.

Conceptual analysis

One finding of this review was that violence, otherwise viewed as domestic abuse, was referred to as elder abuse in older victims. Elder abuse was defined in three studies (Coyne et al., 1993; Yan, 2014; Yan & Kwok, 2011); the remaining studies used a broader definition of abuse (Cooper et al., 2010; Friedman et al., 2011; Sasaki et al., 2007). All three of the elder abuse studies only analysed family caregivers, which in any other age group would be considered domestic abuse (Coyne et al., 1993; Yan, 2014; Yan & Kwok, 2011).

Does this terminology alter the identification of abuse or the management of the victims? This review argues that there is a qualitative difference between domestic abuse and elder abuse and that their conflation is a major hindrance to epidemiological studies, resulting in selection bias (Lachs & Pillemer, 1995). Both elder abuse and domestic abuse are ways of describing interpersonal violence, but elder abuse views violence from an aging and disease based perspective, and domestic abuse from a relational perspective.

The literature for both of these types of abuse has developed in separate spheres with individual theory bases, intervention approaches and social bodies involved (Hester, 2013; Lombard & Scott, 2013). This has meant that areas of overlap between the two spheres have been largely ignored, and opportunities for deepening the understanding of the whole sphere of interpersonal violence may have been overlooked.

These different views have also been a flaw of this review and of the literature; the aim was to identify patterns of domestic abuse in persons with dementia. The data was sourced primarily from elder abuse studies qualifying this review's definition of domestic abuse. Such studies fail to recognise and tackle coercive domestic abuse control patterns (only two studies recorded past relationship violence), and largely ignore the gender issues within domestic abuse. Dementia is clearly a factor in changing the power balance within couples and families, but none of the included papers considered 'elder abuse' to be a continuation or evolution of long standing domestic abuse or intimate partner abuse and so this perspective is not investigated. ,.

Older victims of domestic abuse are starting to be seen as a separate niche within elder abuse (Straka & Montminy, 2006). Is there value in retaining both terms or should domestic abuse definitions be adapted to include elder abuse in care homes and by non-relatives? Domestic abuse needs to be viewed longitudinally, with periods of exacerbation and quiescence, not as separate entities by age (Lachs & Pillemer, 1995); this would allow a deeper understanding of the longevity of domestic violence, and enable a more

integrated and holistic response to domestic violence across the lifespan by the public and voluntary sector. . Multi-agency work across the spheres is essential to tackling this problem effectively, requiring recognition, joint working and understanding of domestic abuse issues across health services, criminal justice services, social services and the voluntary sector.

In the UK in some areas Multi Agency Risk Assessment Conferences (MARAC) are being used effectively. These are local, multi agency victim-focused meetings where information is shared on the highest risk cases of domestic violence and abuse between different statutory and voluntary sector agencies. However, only a small proportion of cases are managed in these forums, with the majority of domestic abuse cases not reaching the threshold for this type of intervention.

Strength and limitations

Strengths

This was a systematic review of the literature using an inclusive search strategy following PRISMA and MOOSE guidelines (Moher et al., 2009; Stroup et al., 2000). Efforts were made to standardise and validate each step of the process: an independent reviewer screened 10% of the abstracts and two reviewers performed the included article methodological appraisal checklist. Direct author correspondence means that all figures included in the analyses are accurate and up to date. The review expands upon previous

work examining abuse in older people, but is unique in examining the sub-population of dementia sufferers for domestic abuse rather than elder abuse.

Limitations

There were few eligible studies. In many studies that had potential for inclusion, the perpetrators of abuse were not identified as being a partner or family member so that we could not establish domestic versus non-domestic abuse. None of the studies allow for inference of direction of causality between risk factors and abuse. No papers measured self-reported violence, which is the gold standard; perpetrator reporting is unreliable. No studies from low-income countries were identified. Publication bias results from studies from more economically developed countries and written in English being more likely to be published than those from less developed countries. Although steps were taken to minimise this bias, this review is likely to be affected by it as domestic abuse affects every sphere of society worldwide.

Conclusions

There is evidence to suggest that domestic violence occurs more often in partners or families where someone is suffering dementia. However, the research is very limited in this area, does not focus clearly on domestic abuse rather than elder abuse, and does not look in any detail at the trajectory of violence in relationships after the onset of dementia. More research is needed in this area, particularly to define the subset of intimate partner abuse within the larger cohort of elder abuse, and investigate the link here with dementia.

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