Elder Abuse of People with Dementia: A Review

Ms. Carmel Downes, Professor Gerard Fealy, Dr. Amanda Phelan & Ms. Nora Donnelly
Overview

- Background and Rationale
- Review Objective
- Methods
- Findings
  - Prevalence; Risk factors; Perpetrators; Detection and recognition; Prevention and management strategies and interventions
- Conclusion and Recommendations
Ireland:
Creating Excellence in Dementia Care: A research review for Ireland’s National Dementia Strategy (Cahill et al. 2012)

- Evidence-based research to inform development of a National Dementia Strategy for Ireland.

- Key statistics on the prevalence of dementia and on the provision of dementia care in Ireland
In Ireland:

- 38,157 older people with dementia
- 23,058 older people with dementia living in the community
- Bulk of care for people with dementia is provided by family caregivers. 50,000 family carers
- Estimated that by 2041, between 140,000 and 147,000 people will have dementia. The most marked increase expected among those aged 85 and over.
- Community support services for people with dementia and their carers, such as, home care packages, day care and respite care are fragmented, inequitable and under-developed.
Elder Abuse

- Recognised as a socio-political problem in the 1970s

- “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, or violates their human and civil rights” (Working Group on Elder Abuse, 2002)

- ‘Impressionistic estimates’ – Under recognised and underreported (WHO, 2008)
Types of abuse

- Physical abuse – Slap, grab, kick, threaten with knife, restrain, over-drugged
- Sexual abuse – Talk/Touch in a sexual way that makes a person uncomfortable
- Psychological abuse – Insult, verbal threaten, undermine, ignore, threaten to harm, prevent contact
- Financial abuse – Steal/ pressurise (money, possessions), fraud, abuse Power of Attorney, not contributing to rent
- Neglect – Dependent person not receiving help with activities of daily living- shopping, personal care
Background

Ireland

- Protecting Our Future report (Working Group on Elder Abuse, 2002) Recommendations
  - Services to protect older people
  - Staff training
  - Public awareness
  - Research

- National recording system for referrals of elder abuse: dementia one of the most prevalence issues among referred older people along with physical and mental ill health (HSE, 2012).
Rationale

- Rising number of older people with dementia
- Dementia recognised as a source of vulnerability
  The effects of dementia can impair a person's ability to seek help, advocate for themselves or remove themselves from potentially abusive situations
- Paucity of research on elder abuse of people with dementia
  “The vulnerability of people with dementia to abuse and neglect is widely recognised, although incidence, prevalence and precise risk factors are not well established” (NICE, 2007)
- Need to establish what research has been done to inform future research directions
Aim

To collate, analyse and summarise literature on elder abuse of people with dementia living in the community in order to inform future research in this area.

Objectives

To establish the prevalence rate of abuse among community dwelling older people with dementia

To examine the risk factors for and perpetrators of elder abuse of people with dementia

To identify strategies and interventions for preventing and managing abuse of older people with dementia
Review Methods

- **Comprehensive search** of published literature and unpublished literature.

- **Databases:** Cochrane, Medline, PsychInfo, PubMed, CINAHL and Google Scholar.

- **Supplementary searching strategies:** Citation searching and reference list checking of included items.

- **Search keywords:** elder abuse, elder mistreatment, elder neglect, cognitive function, cognitive impairment, dementia and Alzheimer’s disease.
Inclusion criteria

- Aged 60 and over
- Community-dwelling
- Some form of dementia
- Elder abuse:
  - Experienced one or more forms of abuse, including physical, psychological, sexual, financial abuse and/or neglect, involving someone with whom the older person had a relationship of trust.
  - Feelings or thoughts of violence towards the older person with dementia.
  - Studies on the general topic of elder abuse that highlighted aspects related to dementia.
- English language publications
- 1985–2012
A total of 38 research studies were included in the review.

11 review/discussion papers
Focus on physical abuse, psychological abuse and neglect. Financial and sexual abuse under researched.

Primary caregivers or family caregivers. Additional inclusion criteria relating to co-residence or a minimum number of hours of caregiving per week.

Most studies relied on caregiver self-reporting of abusive behaviour. A few studies interviewed older people with dementia but this was usually in tandem with carer interviews.

Other methods: observer-rated elder abuse and analysis of abuse case referral investigations.

A number of elder abuse definitions and measures were used to measure elder abuse.
Findings

- The prevalence of elder abuse of people with dementia
- The risk factors for elder abuse of people with dementia
- The perpetrators of elder abuse of people with dementia
- Detecting and recognising elder abuse of people with dementia
- Strategies and interventions for preventing and managing elder abuse of people with dementia
Prevalence of elder abuse of people with dementia

<table>
<thead>
<tr>
<th>Study</th>
<th>Prevalence of some form of abuse</th>
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<tbody>
<tr>
<td>Cooper et al. 2008 (UK)</td>
<td>27.9% (including physical or verbal)</td>
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<tr>
<td>Cooney &amp; Wrigley, 1996 (Ireland)</td>
<td>30.8% (including physical, verbal or neglect)</td>
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<tr>
<td>Cooper et al. 2009 (UK)</td>
<td>33.6% (includes psychological or physical)</td>
</tr>
<tr>
<td>Compton et al. 1997 (NI)</td>
<td>37% (including verbal, physical or neglect)</td>
</tr>
<tr>
<td>Wigglesworth et al. 2010 (US)</td>
<td>47.3% (including verbal, physical or neglect)</td>
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<tr>
<td>Cooney et al. 2006 (UK)</td>
<td>52% (including physical, verbal or neglect)</td>
</tr>
<tr>
<td>Cooney &amp; Mortimer, 1995 (UK)</td>
<td>55% (including verbal, physical or neglect)</td>
</tr>
<tr>
<td>Yan &amp; Kwok, 2011 (Hong Kong)</td>
<td>62.3% (includes psychological or physical)</td>
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### Physical abuse

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<tr>
<th>Study</th>
<th>Physical Abuse</th>
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<tr>
<td>Cooper et al. 2009 (UK)</td>
<td>1.4%</td>
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<tr>
<td>Cooper et al. 2008 (UK)</td>
<td>3.5%</td>
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<tr>
<td>Pillemer and Suitor, 1992 (US)</td>
<td>5.9%</td>
</tr>
<tr>
<td>Wigglesworth et al. 2010 (US)</td>
<td>10.1%</td>
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<tr>
<td>Compton et al. 1997 (NI)</td>
<td>10.5%</td>
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<tr>
<td>Pot et al. 1996 (Netherlands)</td>
<td>10.7%</td>
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<tr>
<td>Coyne et al. 1993</td>
<td>11.9%</td>
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<tr>
<td>Cooney &amp; Mortimer, 1995 (UK)</td>
<td>11.9%</td>
</tr>
<tr>
<td>Yan &amp; Kwok, 2011 (Hong Kong)</td>
<td>18%</td>
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<tr>
<td>Cooney et al. 2006 (UK)</td>
<td>20%</td>
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<tr>
<td>Cooney &amp; Wrigley, 1996 (Ireland)</td>
<td>23.1%</td>
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## Psychological/verbal abuse

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<tr>
<th>Study</th>
<th>Psychological abuse</th>
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<tr>
<td>Cooper et al. 2008 (UK)</td>
<td>27.9%</td>
</tr>
<tr>
<td>Cooney &amp; Wrigley, 1996 (Ireland)</td>
<td>30.4% (chronic)</td>
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<tr>
<td>Cooper et al. 2009 (UK)</td>
<td>33%</td>
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<tr>
<td>Pot et al. 1996 (Netherlands)</td>
<td>30.2% (chronic)</td>
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<tr>
<td>Compton et al. 1997 (NI)</td>
<td>34%</td>
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<tr>
<td>Wigglesworth et al. 2010 (US)</td>
<td>41.9%</td>
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<tr>
<td>Cooney et al. 2006 (UK)</td>
<td>51%</td>
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<tr>
<td>Cooney &amp; Mortimer, 1995 (UK)</td>
<td>52.2%</td>
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<tr>
<td>VandeWeerd &amp; Paveza, 2005 (US)</td>
<td>60.1%</td>
</tr>
<tr>
<td>Yan &amp; Kwok, 2011 (Hong Kong)</td>
<td>62.3%</td>
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# Neglect Abuse

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<th>Study</th>
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<tr>
<td>Cooney et al. 2006 (UK)</td>
<td>4%</td>
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<tr>
<td>Cooney &amp; Mortimer, 1995 (UK)</td>
<td>11.9%</td>
</tr>
<tr>
<td>Wigglesworth et al. 2010 (US)</td>
<td>14%</td>
</tr>
<tr>
<td>Cooney &amp; Wrigley, 1996 (Ireland)</td>
<td>15.8%</td>
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- No prevalence figures for either financial or sexual abuse
Four key areas:

- Characteristics and symptoms of the older person with dementia: socio-demographic characteristics; level of cognitive impairment; severity of dementia; behavioural disturbance/aggression; level of functional impairment.

- Caregiver’s characteristics: socio-demographic characteristics; physical and mental health; substance abuse.


- Caregiving environment: caregiver burden; hours spent caring and duration of caring; caregiving tasks; a shared living arrangement; use of coping strategies; use of services; social networks and support.
Risk factors of elder abuse of people with dementia

**Strong predictors:**

- Abuse or aggression by the person with dementia
- Caregiver’s psychopathology
- Poor premorbid relationship between the older person with dementia and their caregiver
- Caregiver burden
- More involved caring
Mixed evidence:

- Level of cognitive impairment
- Level of functional impairment in the older person with dementia
- The role of social networks and social support.
Subtypes of Abuse

- Most studies comprised insufficient sample size numbers to be able to delineate risk factors for subtypes of abuse.
- Five studies identified
  - Physical abuse: better caregiver health, more involved caring, co-residence and a higher number of psychological complaints.
  - Psychological abuse: poor premorbid relationship, lack of assistance with care and high caregiver burden.
Perpetrators of elder abuse of people with dementia

- Socio-demographic characteristics: age, gender, education
- Relationship to care recipient (spouse v offspring)
- No clear profile
Detecting and recognising elder abuse of people with dementia

- No screening tools for older people with dementia
- Health and social care professional’s judgments and assessments.

Key components:

- Comprehensive thorough multidisciplinary assessment.
- Attention to behavioural signs of distress.

- Clinician assessment of abuse not as sensitive to detecting abuse compared to caregiver reports of abusive behaviour. Cooper et al. (2008)
- Open disclosures of abuse by caregivers reported
Detecting and recognising elder abuse of people with dementia

Approaches and techniques for:

Interviewing the carer:

- Sensitive, empathetic and non-judgemental approach.
- Ask the carer about the demands and difficulties of caring for the older person with dementia and about any feelings and frustrations they may have about their caring role (Cooney and Howard, 1995).

Interviewing older persons with dementia:

- Those in early stages
- Interview away from the suspected perpetrator
- Use of direct, clear and emotionally non-threatening language (Teitleman and Copolillo, 2002)
**Strategies and interventions**

**Anetzberger et al. 2000**

- Developed a model of elder abuse intervention for older people with dementia focused on improving multiagency collaboration in the management of elder abuse.
- Key components included the development of educational curricula for cross-training, screening tools and referral protocols as well as a handbook for caregivers to aid identification of elder abuse risk factors and to direct them to community resource supports and services.
- No information regarding the content and reliability of the screening tool developed is outlined.
- Analysis of pre-post referrals and reporting of abuse indicated increases in abuse case detection and multiagency collaboration.
- Improvements in perceived understanding reported but lack of detail regarding this finding.
Drossel et al. (2011)

- Evaluated the effectiveness of a cognitive-behavioural training intervention targeted at caregivers of older people with dementia at-risk of abuse.
- The intervention was comprised of a brief, evidence-based training protocol implemented with 16 caregivers over a nine week period.
- Significant improvement in caregiver’s psychosocial functioning following the intervention: Problem-focused coping, emotional well-being, and energy level.
- Monitoring of mandated reports to Elder Protective Services during group participation showed that two of the 16 caregivers were reported to the authorities for elder neglect.
- The increased frequency of individual therapy in tandem with the group participation may have confounded the results.
Higher and wide ranging prevalence rates

Elder financial abuse and sexual abuse under researched

Risk factors identified as strong predictors should be the focus of interventions.

Rigorous evaluations needed.

Education and training for carers and professionals: clinical course of dementia; care recipient’s likely needs; appropriate dementia care; diagnosis of dementia; detection and management of abuse; stress reduction and coping strategies.
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