



Office of the Public Advocate

## Are national elder abuse prevalence studies inclusive of the experiences of people with cognitive impairment? Findings and recommendations for future research

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## Abbreviations

|               |                                                                                                                                                             |
|---------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|
| AGAC          | Australian Guardianship and Administration Council                                                                                                          |
| AIFS          | Australian Institute of Family Studies                                                                                                                      |
| ALRC          | Australian Law Reform Commission                                                                                                                            |
| CTS           | Conflict Tactics Scale                                                                                                                                      |
| Downes Review | <i>Abuse of Older People with Dementia: A Review</i> , by Downes et al, 2008, published by the National Centre for the Protection of Older People (Ireland) |
| MCTS          | Modified Conflict Tactics Scale                                                                                                                             |
| MDS           | Minimum Data Set (abuse screen)                                                                                                                             |
| MMSE          | Mini Mental State Exam                                                                                                                                      |

## Introduction

The problem of elder abuse in Australia is receiving a lot of deserved attention at the moment, not only as a topic of an inquiry being conducted by the Australian Law Reform Commission (ALRC).

Recognising the dearth of data on the incidence and prevalence of elder abuse in Australia, and the need for information to ensure evidence-based policy development, the ALRC's Elder Abuse Discussion Paper (December 2016)<sup>1</sup> put forward as its second proposal that "a national prevalence study of elder abuse should be commissioned". This proposal is likely to be included in its final report to the Australian Government, due May 2017.

The Australian Institute of Family Studies' (AIFS') research report on Elder Abuse<sup>2</sup>, commissioned by the Attorney-General's Department, found "there is very limited evidence in Australia that would support an understanding of the prevalence of elder abuse, and there is emerging recognition of the need for systematic research in this area".<sup>3</sup>

Looking to address this gap the Attorney-General's Department has provided further funding to AIFS to scope a national prevalence study.

The importance of including older people with cognitive impairment in any future research into the prevalence of elder abuse in Australia is clear. Because, while "the link between cognitive impairment...and elder abuse is well established",<sup>4</sup> the details of this relationship, including our understanding of the risk factors, are not. Many Australians are likely to be affected by elder abuse if our understanding of this issue does not improve, as this prevents the establishment of evidence-based prevention and response programs.

In 2015, an estimated 342,000 Australians had dementia, with approximately 89,000 living in permanent residential aged care.<sup>5</sup> Hence, it is likely that 250,000 or so dementia sufferers would have been residing in the community.<sup>6</sup> Those total numbers of Australians suffering from dementia are expected to increase to 400,000 by 2020 and 891,000 by 2050. More than half will likely remain living in the community with support from family, friends and community services.

With increasing numbers of dementia sufferers in line with Australia's aging population, and the strong likelihood that cognitive impairment is a risk factor for elder abuse (evidence discussed below), further research examining the experiences of people with cognitive impairment is warranted.

This paper hopes to provide a stepping stone to such research.

### Purpose of this paper

This report was prepared by the Office of the Public Advocate for the Australian Guardianship and Administration Council (AGAC). It is intended to inform AIFS' work by exploring existing research into the prevalence of elder abuse among people with cognitive impairment and to provide insight into potentially helpful research methods being used with this cohort. This report also provides an overview of the current knowledge about elder abuse suffered by people with cognitive impairment. As almost all of the existing research with this cohort has focused on elder abuse perpetrated

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<sup>1</sup> ALRC Discussion Paper 83, 2016

<sup>2</sup> Kaspiew, Carson and Rhoades, 2016

<sup>3</sup> Kaspiew, Carson and Rhoades, 2016, p. 5

<sup>4</sup> Kaspiew, Carson and Rhoades, 2016, p. 8

<sup>5</sup> Data from the Australian Institute of Health and Welfare, accessed 16 March 2017

<http://www.aihw.gov.au/aged-care/residential-and-home-care-2014-15/care-needs>

<sup>6</sup> A small number of people would have been in hospitals or transition care programs, or in Supported Residential Services.

against older people with dementia<sup>7</sup> who reside in the community, much of this report similarly focuses on this narrower group.

## **Method**

This report draws on a systematic international review by Downes et al published in 2013 which examined existing English-language research into the relationship between dementia and elder abuse. Their review found 15 studies that measured the prevalence of elder abuse against older people with dementia.<sup>8</sup> The same review included an additional 28 studies that did not speak to prevalence rates, but to other aspects of the relationship between dementia and abuse. This project undertook a targeted literature search to build on Downes' review by identifying studies published from 2013 to February 2017. This search failed to identify any further papers that measured prevalence of elder abuse against people with dementia, however, it did identify an additional seven research papers on the topic of dementia and elder abuse.

These studies, along with consideration of national and regional prevalence studies to date,<sup>9</sup> form the basis of this report.

## **Format of this report**

This report will be presented in three parts.

The first part will present 'What we know'—that is, what this review found about the prevalence of elder abuse among people with cognitive impairment. It will also present information about the relationship between elder abuse and cognitive impairment.

The second part will look at 'How we know what we know'—that is, the research methods used to understand elder abuse risk factors and prevalence, with a focus on cognitive impairment.

Section 3, 'Doing better research' will present recommendations for future Australian research in this space that overcome the methodological problems identified with much of the existing research around elder abuse of people with cognitive impairment. Research built on these recommendations would advance our understanding of elder abuse prevalence and our understanding of the relationship between elder abuse and cognitive impairment.

## **Other issues**

### **Defining elder abuse**

Before moving onto the body of the report, it is important to acknowledge the key issues that limit the generalisability and transferability of the results of existing research in this area. They are: lack of agreement about elder abuse definitions (to the level of detail that can be operationalised in research studies); limitations of sampling techniques; and the impact on findings of differences in research methods (what is measured and how). Of these problems, developing a national (and, ideally, international) consensus on how we define elder abuse is by far the most pressing. Indeed, without this, solutions to the other problems may be irrelevant. However, considering and providing recommendations about how to define elder abuse are beyond the scope of this review.

For further information on this subject see AIFS report<sup>10</sup> which engaged this issue.

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<sup>7</sup> Dementia is the most common cause of cognitive impairment among people over 65 years of age, and rates of dementia are positively correlated with increasing age. While only 1 to 2 per cent of people aged 65 to 74 years suffer from dementia, around 30 per cent of people over 85 years have the condition. (AIHW).

<sup>8</sup> Downes et al, 2013, p. 10

<sup>9</sup> Including Ireland, Northern Ireland, the United Kingdom, Spain, Portugal, the United States of America, and Canada. Other largescale studies considered include the New York State Elder Abuse Prevalence Study and the project on the abuse of elderly people in Europe (ABUEL) that was conducted across seven cities.

The ALRC suggested in its 2016 discussion paper that operational definitions of elder abuse for Australia can be engaged through the national prevalence study it has proposed.<sup>11</sup> Any definition agreed here can be used equally well for people both with and without cognitive impairment.

### **People with cognitive impairment in residential care**

This research did not extend to the consideration of studies of elder abuse in aged care settings, as no prevalence studies were identified that involved such settings. However, a few brief comments are included below.

The few studies looking at elder abuse of people in aged care have involved either asking staff to report abuse of residents (committed by themselves or by other care staff) or analysing complaints data. Paid caregivers report high rates of abusive behaviours (for example, one study<sup>12</sup> found 91 per cent of 616 nursing staff in Norway's nursing homes said they had observed at least one act of inadequate care); there was as a study of complaints data against assisted living facilities in the USA<sup>13</sup> that found high numbers of references to elder abuse. These studies fail to shed light on prevalence rates, except so far as they indicate that abuse against aged care residents is likely to be relatively common. In Australia, 52 per cent of people in residential aged care have dementia.

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<sup>10</sup> Kaspiew, Carson and Rhoades, 2016, pp. 2-3

<sup>11</sup> ALRC, 2016, p. 21

<sup>12</sup> Marmedal et al, 2009

<sup>13</sup> Phillips et al, 2013

# Section 1. What we know (or existing knowledge of elder abuse suffered by people with cognitive impairment)

## Introduction

What we know about elder abuse prevalence, and about risk factors for people with cognitive impairment come, broadly speaking, from three sources: national prevalence studies, research that looks at elder abuse among groups of people with dementia, and a handful of elder abuse studies that are designed to be inclusive of older people with and without cognitive impairment.<sup>14</sup>

First, results from largescale national and regional studies provide a baseline for elder abuse prevalence. These studies sample community-dwelling elders free from noticeable cognitive impairment. Hence, the rates of abuse in these studies apply to this cohort as opposed to older people in residential care or those with cognitive impairment living in the community. Based on these studies, in 2015 the World Health Organisation reported the elder abuse rates in high and middle income countries ranged from two to 14 per cent.

Second, results from studies of 'dementia specific' cohorts provide information about estimates of elder abuse prevalence in these cohorts (ranging from 27 to 62 per cent), as well as information about the relationships found between independent variables and rates of abuse. The main issue with results from these studies is that their sampling techniques seriously limit the generalisability of their findings to a broader dementia population or from any meaningful comparison with national prevalence rates.

Third, results from 'inclusive' studies tell us about the role cognitive impairment plays in increasing one's vulnerability to elder abuse.

This section will look at the findings from each of these groups, with very limited discussion of the first group due to its lack of consideration of cognitive impairment. But, first, a brief look at what is known about elder abuse in Australia.

## Australian findings

There have been no studies in Australia to date that have identified rates of elder abuse against people with dementia or other cognitive impairment using a representative sample capable of being generalised to the whole population of dementia sufferers.

Evidence about rates of elder abuse against the general population in Australia is sparse. AIFS considered this issue in its 2016 report. It identified the population-based study the Australian Longitudinal Study of Women's Health as perhaps the most reliable source of abuse and neglect rates (around 8 per cent and 20 per cent respectively in the over 70 age groups).<sup>15</sup>

In 2016, the first Australian population-based study to demonstrate that people with disabilities experience higher levels of violence than the general public was published.<sup>16</sup> The research compared people (over 15 years old) with disability and long-term health conditions to those without these attributes. It found a positive relationship between the presence of disability and/or long-term health condition and rates of abuse and domestic violence. The study did not collect or analyse information on cognitive impairment.

This review noted two studies undertaken in Australia that looked at the relationship between cognitive impairment and elder abuse. In 2015-2016, OPA undertook a file review of older

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<sup>14</sup> While also collecting information on cognitive impairment as an independent variable from the people in the sample.

<sup>15</sup> AIFS, 2016, p. 6

<sup>16</sup> Krnjacki et al, 2016

guardianship clients and found that 13 per cent had experienced some form of elder abuse. This cohort are all affected by some form of cognitive impairment,<sup>17</sup> with around 90 per cent of those who suffered abuse identified as having dementia. Women in this cohort suffered abuse at higher rates than men (17 per cent and 9 per cent respectively).<sup>18</sup> An analysis of calls to the Queensland Elder Abuse Helpline found a relationship between the primary abuse type reported and dementia status of the older person.<sup>19</sup>

## **Findings from national prevalence studies (overseas)**

Findings from this set of studies of national prevalence rates overseas are included here for the purpose of comparison. Of course, differences in methodologies and sampling techniques prevent direct comparison but the order of magnitude of the differences between national and dementia specific prevalence studies is instructive.

As mentioned above, national prevalence rates for elder abuse in middle to high income countries have been estimated at between two and 14 per cent.<sup>20</sup> These estimates come from national (or regional) prevalence studies conducted in the last 15 years that measure rates of elder abuse among community-dwelling elders: these include studies in the United Kingdom, the USA, Portugal, Ireland, Korea, New York State and Spain. These studies almost exclusively sample older adults with the capacity to respond to telephone or face-to-face interviews, and actively screen out people who are considered to lack the capacity to reliably complete the interview.

Some of these studies do look at the relationship between elder abuse and dependency levels<sup>21</sup> in the older person, but, as most of the respondents to national prevalence studies have very low rates of dependency, it is difficult to accurately explore this. With the exception of Spain's national prevalence study,<sup>22</sup> this group of studies did not collect information about the cognitive abilities of the respondents. The findings from Spain will be considered alongside two other 'inclusive' studies which also collected information about a cognitively diverse sample below.

## **Elder abuse findings from 'dementia specific' studies**

### **Studies returning prevalence rates of elder abuse against people with dementia**

This section presents existing estimates of elder abuse prevalence in cohorts selected because of the presence of dementia in the older person. A comprehensive review in 2013<sup>23</sup> (the Downes Review) identified 15 studies which explored the rates of physical and verbal/psychological elder abuse perpetrated by caregivers.<sup>24</sup> Five of the studies also measured rates of neglect. None of these prevalence studies collected data on financial abuse or sexual abuse.

The Downes Review identified a large range of prevalence estimates with overall prevalence rates from the various studies (sometimes including neglect) ranging from 27.9 per cent to 62.3 per cent. It found psychological/verbal abuse at higher rates than physical abuse. The variation in overall prevalence rates are likely largely attributable to study design (for example, biased sample selection, combined with definitional discrepancies in relation to age and to what constituted abuse). Rates of physical violence by caregivers ranged from 5.9 per cent to 11.9 per cent, and

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<sup>17</sup> A decision-making impairment is a legislative requirement for the making of a guardianship order.

<sup>18</sup> Bedson, 2016

<sup>19</sup> Spike, 2015

<sup>20</sup> World Health Organisation, 2015, *World report on aging and health*, Geneva: WHO.

<sup>21</sup> Usually measured by whether the older person requires support with the activities of daily living (ADLs).

<sup>22</sup> Marmolejo, 2008

<sup>23</sup> Downes et al, 2013

<sup>24</sup> Most of the studies collected information about both physical and verbal abuse. Two of the studies looked exclusively at physical violence and one looked exclusively at verbal abuse.

one study further estimated severe violence against people with Alzheimer's disease at 5.4 per cent.<sup>25</sup>

As noted above, this research reports substantially higher prevalence rates for people with dementia than the population as a whole.<sup>26</sup>

Unfortunately these findings cannot be generalised nor easily compared to prevalence rates found in the first set of large-scale national studies. In the main, this is because of sampling issues (discussed below in the section on sampling methods), which mean that the results are not representative of the broader dementia population. They do, with the extremely high rates of abuse they identify, suggest that elder abuse is more prevalent among people with dementia than among people without cognitive impairment.

Correlations identified by these prevalence studies, and other studies that consider elder abuse of people with dementia, have suggested potential risk factors for elder abuse in these populations which are explored below.

### **Is dementia itself as a risk factor?**

Despite plausible theories as to why people with dementia may be more vulnerable to abuse than those without, the evidence supporting a relationship between dementia and elder abuse is somewhat mixed. Some studies found a significantly higher proportion of dementia among older people who experienced abuse or neglect,<sup>27</sup> while others did not find a dementia diagnosis increased the likelihood of elder abuse.<sup>28</sup> To shed some light on why a relationship may not exist, the findings of the two studies (Cooper 2006 and Shaffer 2007) that failed to find a relationship between dementia and elder abuse are considered below.

While the Cooper study<sup>29</sup> did not find a connection between dementia diagnosis and elder abuse, it did, however, find a positive correlation between severity of cognitive impairment and elder abuse. This was a large scale, cross-national study with 3881 people aged 65 and over in the dataset. This study did not require the participant to have the capacity to consent to the interview, substituting caregiver consent and only terminating the interview where the respondent became distressed or appeared not to want to continue.<sup>30</sup> Respondents' levels of cognitive impairment were assessed using a screening tool and respondents were found to be impaired at higher rates than their reported dementia diagnoses. In response to their finding, the researchers suggested that undiagnosed dementia sufferers may be at particular risk of elder abuse. The same study identified other correlations that often show up in research around elder abuse and cognitive impairment, including features that may increase the difficulty of caring for the older person (for example, where they suffer from delusions or actively resist care). It also found expressed conflict with family and friends to increase the likelihood of elder abuse.

The Shaffer study did not find dementia to be a predictor of psychological elder abuse. It did initially find a weak but significant correlation between dementia and abuse, however, this relationship was mediated by what the study referred to as 'proactively aggressive caregiving strategies'.<sup>31</sup> This means that, in this study, a dementia diagnosis forecasts "potentially harmful

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<sup>25</sup> Downes, 2013, p. 11

<sup>26</sup> Ibid.

<sup>27</sup> For example, Dyer et al, 2000 cited in Downes et al, 2013

<sup>28</sup> Cooper et al, 2006 and Shaffer et al, 2007 both cited in Downes 2013, p. 12

<sup>29</sup> Cooper et al, 2006

<sup>30</sup> Ibid, p. 490

<sup>31</sup> A measure for agreement with such strategies was created for the purposes of this study: including whether the caregiver agreed with statements that included "A little threat can go a long way to solve problems when [care recipient] is being difficult".



caregiver behaviour only to the extent that caregivers endorse coercive means of conflict resolution".<sup>32</sup>

Potentially, a diagnosis of dementia is not, in itself, sufficient to predict increased likelihood of elder abuse because of the heterogeneity of symptoms (for example, presence of aggressive or agitated behaviours) and varying levels of cognitive impairment experienced by different individuals. Additionally, there would be some number of undiagnosed dementia sufferers who may increase the strength of correlation (should one exist). Alternatively, as findings from other research suggest (discussed below), the relationship may be better understood as a relationship between 'cognitive impairment and abuse' as opposed to 'dementia diagnosis and abuse'.

## **Risk factors and correlates of elder abuse of people with dementia**

Some studies explored the question of whether there were differences between factors giving rise to verbal abuse in comparison to physical abuse. At least one study found higher rates of anxiety among physically abusive caregivers.<sup>33</sup> The question of whether it is useful to look at correlations across abuse types was also considered by NatCen's *UK Study of Abuse and Neglect of Older People*, which found that prevalence rates of mistreatment in the past year "increased with declining health status" (as well as depression and loneliness).<sup>34</sup> Interestingly, a secondary analysis of the same UK data found "poor quality of life" to be the only risk factor that is positively correlated with each type of mistreatment. The secondary analysis<sup>35</sup> showed, for example, that different types of abuse can be associated with widely different risk factors, with some factors being positively associated with one type of abuse but negatively correlated with another.<sup>36</sup> This suggests that looking for risk factors for the overarching term 'elder abuse' might be problematic.

The findings below relate to overall rates of elder abuse (combinations of physical and verbal abuse types, which in some cases include neglect).

### Level of cognitive impairment

Four studies of people with dementia found a positive relationship between increased levels of cognitive impairment and elder abuse. Two, however, did not.<sup>37</sup> It is notable that the two studies that did not find an association were smaller studies. (More consideration will be given to the relationship between cognitive impairment and elder abuse in the 'inclusive' studies below).

### The reciprocal nature of abuse

A positive correlation between behavioural disturbance in the older person and abuse by the caregiver has been found in at least ten studies. The behavioural disturbances considered here include physical and/or verbal aggression on the part of the care recipient towards the caregiver. Studies identify agitated, rather than apathetic, styles of behaviours on the part of the care recipient as correlating with abuse. These studies highlight the reciprocal nature of abuse that can be present in dementia caregiving.<sup>38</sup>

### Dependency

The relationship between functional dependency and elder abuse of people with dementia is unclear. Six of the studies looked at by the Downes Review show no correlation between the functional impairment and abuse; two studies identified a positive correlation, and two further

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<sup>32</sup> Shaffer, 2007, p. 501

<sup>33</sup> Cooney and Mortimer, 1995

<sup>34</sup> O'Keefe et al, 2007

<sup>35</sup> Biggs et al, 2013

<sup>36</sup> Ibid, p. 8

<sup>37</sup> Homer and Gillear 1990, and Compton et al, 1997 cited in Downes 2013, p. 12

<sup>38</sup> Downes et al, 2013, p. 13; see also Cooper and Livingston, 2014

studies found a negative correlation (that is, caregivers were less likely to abuse those with greater functional impairment).<sup>39</sup>

These findings conflict with findings from Spain<sup>40</sup> and from other prevalence studies of general populations, which have found positive correlations between dependency levels and at least some forms of elder abuse.<sup>41</sup>

### Care recipient and caregiver characteristics

The Downes Review found younger age and lower income on the part of the older person were associated with increased risks of elder abuse in a handful of studies.

Caregiver risk factors identified included poor psychological health, mental health problems, anxiety and alcohol abuse.<sup>42</sup> Not all of these relationships were supported by all the studies, for example, alcohol consumption did not always predict abuse. Depressive symptoms and anxiety in the caregiver were found to correlate with elder abuse in most studies where these were measured.

A higher perceived caregiver burden was found to be associated with higher rates of elder abuse among people with dementia across many studies.<sup>43</sup> Sometimes this burden was also found to be associated with longer time spent caring (longer duration or more hours a week) and with higher anxiety levels. These results suggest that the caregiver's state of mind plays a significant role in elder abuse of people with dementia (caregiver burden has also been found to correlate with abuse in broader population groups).<sup>44</sup> The direction of causality between these factors is unclear, however, they certainly constitute a rich area for future research towards understanding elder abuse precedents.

Key findings from the Downes Review include that: "Numerous studies found that caregiver abuse of the person with dementia was associated with a poor premorbid relationship"<sup>45</sup> and "factors which were most commonly identified as contributing to the risk of elder abuse of people with dementia included perceived caregiver burden, caregiver's psychopathology, abuse or aggression towards the caregiver by the individual with dementia and the quality of the pre-existing relationship between the individual with dementia and the caregiver".<sup>46</sup>

Aside from their higher perceived care burden, and heightened levels of depressive symptoms and anxiety, perpetrators of abuse against people with dementia had no clear socio-demographic profile.<sup>47</sup>

## **'Inclusive' studies that explore the relationship between cognitive impairment and elder abuse**

There are a handful of studies which can be considered 'inclusive' of people with and without cognitive impairment. These are: the national prevalence study from Spain (by Marmolejo),<sup>48</sup> a small-scale study looking at the financial abuse (the Lichtenberg study)<sup>49</sup> and a study which cross-

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<sup>39</sup> Downes et al, 2013, p. 13

<sup>40</sup> Marmolejo, 2008

<sup>41</sup> For example, Laumann et al, 2008, found that physical vulnerabilities of respondents were associated with higher reports of verbal abuse but not of financial abuse.

<sup>42</sup> Downes et al, 2013, p. 13

<sup>43</sup> Ibid, p. 14

<sup>44</sup> Marmolejo, 2008

<sup>45</sup> Downes et al, 2013, p. 14

<sup>46</sup> Ibid.

<sup>47</sup> Ibid, p. 15

<sup>48</sup> Marmolejo, 2008

<sup>49</sup> Lichtenberg et al, 2015

referenced elder abuse reports to social services with an existing older cohort from a community health study.<sup>50</sup>

Their inclusivity allows these studies to reliably compare outcomes for subjects with cognitive impairment to outcomes for those without, as they share the same sample, research tools and data collection methods. These studies all found that cognitive impairment was linked to increased rates of reported elder abuse.

Further findings from the largest and most methodologically sound study from Spain are presented below, followed by insights into the relationship between financial abuse and cognitive impairment from the Lichtenberg study.

## Spain

Only Marmolejo's results were able to elucidate the relationship between cognitive impairment and abuse of older people in a nationally representative study. This study, *Elder abuse in the family in Spain*, included research into two subject groups (people over 64 years living in private homes and caregivers of elderly people living in private homes), both of which constituted a random representative sample. Marmolejo found comparatively low rates of elder abuse in Spain, with older people reporting elder abuse at 0.8 per cent overall and caregivers reporting abuse at 4.6 per cent of total sample.<sup>51</sup>

The study found a positive correlation between dependency rates and both elder self-reports and carer self-reports of elder abuse.<sup>52</sup> The rates of elder abuse also increased with level of dependency reported: people with moderate dependency experienced abuse at rates of 1.0 per cent, people with heavy dependency at 2.2 per cent, and people who were totally dependent on caregivers at 2.9 per cent. While dependent elders experienced higher rates of self-reported abuse than less dependent elders across all abuse types, the rate of financial abuse rose the most: from 0.2 per cent overall to 0.9 per cent for dependent older people. Caregiver reports put physical abuse<sup>53</sup> of dependent elders at 2.4 per cent, compared to 1.8 per cent of total sample.<sup>54</sup>

The study found that the victims of elder abuse (as reported by caregivers) were more likely to suffer from a psychological disorder (72 per cent compared to 41 per cent of non-victims), to have a cognitive impairment (67 per cent compared to 37 per cent of non-victims) and to have an intellectual disability (33 per cent compared to 16 per cent). They also found that where the victim had a disability (64 per cent), that the disability caused total dependency in 74 per cent of cases (compared to 53 per cent of cases among non-victims with a disability).

Caregiver characteristics associated with elder abuse in this study included increased rates of psychological disorders (36 per cent compared with 19 per cent of non-abusive caregivers) and perceived caregiver burden (with 72 per cent feeling overwhelmed by their tasks compared to 53.8 per cent of the time for non-abusers).<sup>55</sup>

This study is particularly interesting because the same research methods and comparable measurement tools were applied to assessment of elder abuse among older people with a caregiver. Hence, the usual methodological reasons for variance in prevalence rates do not apply. We will return to this in the next section on research methods.

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<sup>50</sup> Dong et al, 2014

<sup>51</sup> Marmolejo, 2008, p. 110 & p. 119

<sup>52</sup> Rates of elder abuse increased from 0.8 to 1.5 per cent among dependent elders and from 4.6 to 5.7 per cent among dependent elders with caregivers (from self-reports of caregivers). (Marmolejo, 2008, p. 110 and 119.)

<sup>53</sup> Physical abuse for this group included physical and chemical restraint, which may explain why physical abuse rises with this group when physical abuse rates are not normally found to connect with dependency.

<sup>54</sup> Ibid, p. 119

<sup>55</sup> Ibid, p. 121

## Financial abuse and decisional abilities (Lichtenberg)

The Lichtenberg study reported preliminary findings in relation to a new tool testing capacity for financial decision-making and its relationship to participants' self-reports of financial exploitation. This study was of particular interest because its sample included people with and without cognitive impairment—allowing direct comparability of the results as they differed between the groups. Very few studies on elder abuse have this feature. Based on a small sample of 69 African Americans it found that “impaired decisional abilities may render older adults more vulnerable to financial exploitation”. Statistical testing found that while “financially exploited older adults were not significantly different from non-exploited older adults in terms of age or education, ... they performed significantly more poorly on a measure of general cognitive functioning than non-exploited older adults”.<sup>56</sup>

They found that five out of eight older African Americans' with decisional concerns also reported financial exploitation (63 per cent), compared with eight of 61 without decisional concerns (8 per cent).<sup>57</sup> They additionally had lower Decisional Ability ratings and higher risk scores for 'Financial situational awareness', 'Psychological vulnerability', 'Current decisional ability' and 'Susceptibility to undue influence'.<sup>58</sup>

The same study looked at the differences in 'concerns about money' between the exploited and non-exploited groups, finding significant difference between the groups: people who had been financially exploited were more likely to be concerned or to regret previous decisions than the other group.

Potential reasons put forward for the relationship between financial abuse and cognitive impairment include an older person's increased need for assistance with their finances combined with 'assistance' from people who either lack money management skills or feel a sense of entitlement to the assets of the older person. Further the trust expectations of these relationships mean it is less likely that these arrangements are formalised and carried out in accordance with the law (for example, transacting on someone's behalf without a financial enduring power of attorney, or entering assets for care arrangements without contracts).

## Discussion

Studies of dementia cohorts (in the community) come back with consistently high prevalence rates compared with older people overall. For example, the CARD study found caregivers of people with dementia reported perpetrating physical or psychological abuse on care recipients at a rate of over 50 per cent, and one third met criteria for significant abuse.<sup>59</sup>

The higher prevalence rates are intuitively plausible. Many theories exist as to why people with dementia may be particularly susceptible to abuse. These include the economic and social implications of the condition (dependence) and the fact that cognitive impairment can impair one's ability to seek help or remove oneself from abusive situations. Further, dementia is associated with interacting and reinforcing factors like depression, behavioural difficulties, social isolation and dependency. There are also unique challenges and stresses placed on carers in situations involving dementia. Together these “may place an older person with dementia at increased risk of abuse”.<sup>60</sup>

However, the research presented above suggests that the relationship between cognitive impairment and elder abuse may be more instructive than that between dementia diagnosis and abuse.

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<sup>56</sup> Lichtenberg, 2015, p. 18

<sup>57</sup> Ibid, p. 14

<sup>58</sup> Ibid, p. 19

<sup>59</sup> Cooper et al, 2009

<sup>60</sup> Downes et al, 2013

Studies also suggest that aggregating the various types of mistreatment, or seeing physical violence as part of a spectrum that starts with psychological/emotional violence, is problematic and may mask risk factors for the various abuse types. For example, there is evidence that higher levels of anxiety in the caregiver are linked more strongly to physical abuse than verbal abuse.<sup>61</sup>

Note that the studies reviewed here were all limited to identifying correlations and, so, even where the data analysed was longitudinal, there was no possibility of identifying the direction of causation (for example, was the abuse causing increasingly poorer cognitive functioning (perhaps due to stress) or was the increased cognitive decline resulting in more vulnerability to abuse?).

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<sup>61</sup> For example, Cooney and Mortimer, 1995

## **Section 2. How we know what we know (or study and compare methodologies which have been used to determine prevalence)**

This section will look at the methods that have been used to determine elder abuse prevalence and to explore the relationship between elder abuse and cognitive impairment. As in the previous section, studies are again separated into three broad groups. These are studies which:

- expressly excluded people with cognitive impairment from their sample<sup>62</sup>
- only examined data concerned with the abuse of people with cognitive impairment, or
- were inclusive of people with and without cognitive impairment.

Given the focus of this report on the abuse of people with cognitive impairment, the research methods of the first group are not considered here (except occasionally as a point for comparison). The majority of studies considered in this section fit comfortably into the second group.

Only three studies were identified that fell into the last category (as mentioned previously)<sup>63</sup>, however, the methods they used do hold the most potential for advancing our understanding of elder abuse. This is because studies of the first two types expressly exclude either people with or without cognitive impairment, and, therefore, cannot readily speak to what rates of abuse the excluded group is suffering (and how they would compare with the studied cohort).

Focusing on studies that fall into the final two groups, the strengths and weaknesses of the variety of research methods being used to study elder abuse prevalence are discussed below. The areas considered include:

- who/what was used to identify the abuse
- samples and sampling
- data collection
- measuring abuse
- measuring independent variables
- statistical analysis.

Finally, note that studies determining prevalence are conducted at a point-in-time. This enables the researcher to look for correlations (patterns and statistically significant relationships) in the information gathered. 'Point-in-time' research does not allow findings to be made about the causes or direction of the relationships found. Longitudinal research is required to answer such questions, for example, whether the onset of dementia was related to increased abuse or some other pattern.

### **Where is the information about abuse coming from?**

A key aspect of study design in this type of research is where the information about abuse comes from. National (and regional) prevalence studies have, to date, collected information about abuse directly from community-dwelling older people without cognitive impairment. The researcher asks

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<sup>62</sup> For example, the New York State Study employed a cognitive screening procedure that consisted of three questions: "marital status, date or year of birth, and age. If [they]...were unable to provide answers to any of these questions, or if their reported age differed by more than one year..." considering their date of birth, they were not eligible to participate in the study. (Lachs et al, 2011, p. 17)

<sup>63</sup> Marmolejo 2008; Lichetberg et al, 2015; Dong et al, 2014.

them questions about their own experience of a range of types of elder abuse (in person, via telephone, or written postal survey). I will refer to these as 'self-reports by the older person'.

Where the older person has dementia or other cognitive impairment the usual practice is to avoid collecting self-reported information from them. It is likely that the researchers consider the person unable to provide a reliable report on their experience, or perhaps they consider it too difficult to obtain informed consent from the older person. The research tools, themselves, may also preclude the person's effective participation—being too long or requiring written responses—where they are designed for people without cognitive impairment.

All 15 of the prevalence studies identified by the Downes Review relied on caregiver self-reports to obtain information on elder abuse.<sup>64</sup> Five of these studies also collected some information directly from or about the older person through their medical records or in-home observation conducted by the researcher. One such study used an expert panel to determine whether elder abuse had occurred. The panel was given information about the caregiver's self-reports of abuse (if any) alongside in-home researcher observations and interviews with the care recipient.<sup>65</sup>

One study included in the Downes Review, but which did not report on abuse prevalence, used information from a longitudinal community-health study of older people in a particular geographic area to obtain a representative sample and then cross-referenced that sample with elder abuse reports to Adult Protective Services to identify abuse matters.<sup>66</sup> This falls in the category of 'analysis of documented abuse cases'. The New York State prevalence study included findings from such data sources<sup>67</sup> (however, it did not collect information on level of cognitive impairment of the victim).<sup>68</sup>

## Caregiver self-reports

While there are downsides to relying solely on caregivers' self-reports of their own abusive behaviours (not least of which is whether abusive caregivers will disclose or even participate in the research at all), there is substantial evidence that this method identifies a greater proportion of elder abuse instances than other methods used to identify elder abuse against people with cognitive impairment.

Downsides of caregiver self-reports include:

- potential for under-reporting of abuse (due to shame or not understanding what behaviours constitute abuse)
- under-representation in the sample of caregivers perpetrating more serious abuse (because they decline to participate)
- under-representation of caregivers with mental ill-health, alcohol or drug abuse issues (because they decline to participate).

Good survey design may ameliorate some of the potential for under-reporting, however, the other issues would still be present.

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<sup>64</sup> Downes et al, 2013, p. 8

<sup>65</sup> Wigglesworth et al, 2010, p. 493

<sup>66</sup> In 2014, a review of research analysing Adult Protective Services Data in the United States of America identified 50 studies spanning a 16 year period. These studies did not speak directly to prevalence of elder abuse, but sought to answer questions about the relationship between elder abuse or self-neglect and a wide variety of independent variables (including physical and mental health, cognitive function and mortality). (Ernst et al, 2014)

<sup>67</sup> Sources included Community Based Agencies, Law Enforcement, Adult Protective services, District Attorneys offices, Domestic Violence Programs and Shelters (Lachs et al, 2011, p. 37)

<sup>68</sup> Ibid, p. 37

Nevertheless, evidence that this method identifies high rates of elder abuse in spite of the factors listed above attests to its usefulness. One study (involving a sample where 40 per cent of the care recipients had dementia) found caregivers reported abuse at higher rates than care recipients.<sup>69</sup> Another study in 2008, found that a technique to identify abuse which involved observation and interview of the older person<sup>70</sup> was less effective than the caregivers' self-reports.<sup>71</sup> Furthermore, results from studies using this method show caregivers willingly and openly discuss abusive behaviours (at rates ranging from 30 to 60 per cent). Researchers pondering this issue suggest that perhaps this is because they regard themselves not as abusers but as victims of circumstance making the best of a bad situation.

One potential limitation of this method is the types of abuse that data can be collected on. Of all of the studies considered in the Downers Review which involved caregiver interviews and surveys, none of the 15 collected information about financial or sexual abuse. The studies all collected data about physical and/or verbal abuse (the vast majority 13 of 15 on both).<sup>72</sup> One third of the studies collected information about neglect. While the relationship between the source of the data (the caregiver) and the types of data able to be collected was not referenced anywhere that could be found, it is plausible that it may be more difficult to elicit answers from caregivers about financial or sexual abuse.

The Spanish study did, however, include questions to the caregiver about whether they perpetrated financial or sexual abuse on the care recipient, with 1.9 per cent of caregivers in the sample admitting to some form of financial abuse, and 0.1 per cent admitting to committing sexual abuse.<sup>73</sup>

While studies using caregiver self-reports to identify abuse did not, in the main, collect data on financial abuse, there were studies that looked at the relationship between cognitive impairment and financial abuse. Some of these studies analysed cases that had been reported to authorities (for example, Adult Protective Services), one interviewed caregivers about the substitute decision-making arrangements in place for the older person they were providing care for,<sup>74</sup> and at least one study interviewed older people about recent financial decisions as well as testing their global cognitive functioning.<sup>75</sup>

While the studies identified in the Downes Review focused on identifying elder abuse suffered by cohorts with dementia, and may have had few other options for identifying abuse, the Spanish prevalence study used caregiver self-reports to identify abuse of older people with a wide range of care needs (including people without cognitive impairment).<sup>76</sup> This study found a relationship between elder abuse and level of dependency of the care recipient.

## Samples and sampling

As AIFS has pointed out, "a rigorous assessment of prevalence needs to be based on a population-level sample applying aged-based criterion for selection".<sup>77</sup> National prevalence studies conducted overseas have largely met these requirements, however, these studies screened out

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<sup>69</sup> Homer and Gilleard, 1990

<sup>70</sup> The Minimum Data Set – Abuse Screening tool

<sup>71</sup> Cooper 2008 cited in Downes 2013, p. 8

<sup>72</sup> Downes, 2013

<sup>73</sup> There were two questions on the interview schedule: "Have you ever engaged in sexual activity with them without their consent?" and "Do you manage their pension without their permission, use their money to pay bills they did not authorize, or have you ever forced them to sign documents or change their will, or faked their signature?" (Marmolejo, 2008, p. 152)

<sup>74</sup> Rowe et al, 1993 cited in Downes, 2013, p. 11

<sup>75</sup> The study used the Mini Mental State Exam (MMSE) and also a financial decision-making tool the study was designed to test (Lichtenberg, Flicker and Rahman-Filipiak, 2015, pp. 10-11)

<sup>76</sup> The same study also surveyed older people directly—however, not necessarily the care recipients of the surveyed caregivers (Marmolejo, 2008).

<sup>77</sup> Kaspiew, 2016b, p. 4



most people with cognitive impairment. The prevalence studies that have examined elder abuse among people with cognitive impairment have not met the requirements for a representative sample: “Most samples...were recruited from clinical settings or select populations rather than from representative community populations”.<sup>78</sup>

These sampling methods may have biased such samples towards higher levels of cognitive impairment and behavioural problems, or, potentially limited the samples to people at a common point in their dementia progression (for example, recent referral to aged mental health services). Accordingly any “prevalence figures must be interpreted with caution”.<sup>79</sup> The Downes Review was particularly concerned with the representativeness of samples selected through contact with a dementia support helpline and support organisation, as such, samples were likely to disproportionately represent caregivers struggling with their responsibilities.

Some samples, for example the Spanish national prevalence study mentioned above, applied more rigorous sampling techniques to obtain a random representative sample of both the elderly and caregivers (in terms of locality, age and sex).<sup>80</sup>

Another study piggy-backed on an existing, geographically representative, longitudinal epidemiological study of a particular community.<sup>81</sup> Adding questions about abuse to such a study, or using that sample to identify and survey caregivers, may be one way of obtaining a representative sample. AIFS referred to such an option when flagging the possibility of adding questions to national population health surveys.<sup>82</sup>

A definitional issue specific to studies involving caregiver self-reports are the requirements the caregiver was required to meet (in terms of level of contact with the older person/care recipient) before they were accepted as a caregiver in a given study. Different studies had different levels of the minimum number of hours of care provided to the older person before the helper was defined as the primary ‘caregiver’.

Other definitional issues include the influence of local laws and funding regimes. This has resulted in, for example, the inclusion or exclusion of ‘self-neglect’ and sometimes, for example in the New York State prevalence study, the inclusion of abuse perpetrated by strangers (as opposed to people in a relationship normally characterised by trust). Minimum age for inclusion in different studies have varied from 50 to 65 years of age. All of these decisions have the potential to dramatically sway the resulting prevalence rates. For more information on the problems and complexities of defining elder abuse see AIFS report.<sup>83</sup>

## Data collection

All of the studies reviewed here used one of three main forms of data collection: phone interviews, postal surveys and face-to-face interviews. On occasion, studies chose to use a combination of face-to-face and postal survey tools in order to reduce the length of the face-to-face interviews. No differences in findings were found to result from these different methods of data collection. One notable downside of one of the postal surveys was the inability to accurately code the perpetrator relationship to the victim.

## Measuring abuse

When measuring elder abuse, studies needed to determine both what situations constituted a case of elder abuse and what tools they would use to identify those cases. The first is a definitional issue, the second a practical one.

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<sup>78</sup> Downes et al, 2013, p. 8

<sup>79</sup> Ibid, p. 9

<sup>80</sup> Marmolejo, 2008, pp. 102-103

<sup>81</sup> Dong et al, 2014, p. 599

<sup>82</sup> Kaspiew, 2016b, p. 3

<sup>83</sup> AIFS, 2016, p. 2

## Definitions

As discussed above, local and regional laws and funding arrangements influenced the definitions of elder abuse used (especially in national prevalence studies and studies involving case file analysis).

There is broad agreement that elder abuse includes physical, psychological (verbal/emotional), financial and sexual forms of abuse, as well as neglect. However, the seriousness and frequency of these forms that are required to constitute elder abuse, as well as some cultural variations of form, are not agreed across the board. Age criterion also varied by study, from mid-50s upward. The requirement that the perpetrator is a person in a relationship of trust with the victim is widely accepted, however, some researchers have recently proposed that the perpetrator occupy a 'position of trust' to improve the operationalisation of the concept.<sup>84</sup> While none of the studies reviewed here took this approach, it seems a valuable way to reduce definitional variability and it also has direct application to measurement of abuse in institutional settings.

The study also needed to determine whether the abusive behaviour was 'serious' enough or frequent enough to identify a particular person as suffering elder abuse. Most studies identified all instances of physical abuse sufficient to constitute elder abuse, but required at least ten instances of verbal or emotional abuse to have occurred in the previous year to identify that case as an example of elder abuse.<sup>85</sup>

Cultural factors also influenced the types of behaviours determined to constitute abuse, for example, studies from Asian countries sometimes included questions about respect for elders.<sup>86</sup>

## Tools

The studies used a wide variety of measurement tools and instruments to identify abuse, Pillemer and Finklehor's (1988) criteria for abuse was the most commonly used of more than ten measurement techniques.<sup>87</sup> Studies mainly focused on physical and psychological abuse and neglect, with comparatively little focus on financial and sexual abuse (and, so, fewer measures relate to these abuse types).

Some of the more commonly used tools for identifying abuse included variations on the Conflict Tactics (CTS), which included the Modified CTS (or MCTS) and the CTS2. The MCTS was investigated for "acceptability and validity" and found to have "convergent and discriminant validity for measuring carer abuse".<sup>88</sup> Violence and abuse questions on existing population health surveys were also referred to, but were not used to measure abuse of people with cognitive impairment.

Some studies also used the Minimum Data Set (MDS) abuse screen administered by an independent observer (for example, a health care professional). This tool has been demonstrated to be less effective than caregiver self-reports at identifying abuse. For example, in the LASER-AD study the MDS abuse screen did not identify any of the 24 of 86 cases of abuse that were identified by the MCTS.<sup>89</sup> This highlights the benefits and importance of caregiver reports in identifying instances of abuse that do not have a clear observable impact on the bodies or behaviours of the person suffering the abuse.

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<sup>84</sup> Dixon et al, 2009, p. 6

<sup>85</sup> Gil et al, 2015, p. 176; Lachs et al, 2011

<sup>86</sup> Yan et al, 2014, pp. 2-3

<sup>87</sup> Downes et al, 2013, p. 9

<sup>88</sup> Cooper et al, 2008, p. 283

<sup>89</sup> Ibid.

One study<sup>90</sup> used an expert panel to determine whether a particular case involved elder abuse. In practice the panel used both caregiver self-reports and observational tools administered by independent researchers to base their determination on.

Interestingly, a recent review of elder abuse prevalence studies<sup>91</sup> found that “prevalence estimates differ according to the tool used to evaluate abuse but not the method through which subjects were recruited in terms of sampling from the community or health care settings.”

## Measuring independent variables

Data was collected on a huge number of independent variables across the different studies reviewed. Frustratingly, for purposes of comparison, different studies collected different sets of information. This likely influenced some of the variation seen between the outcomes of tests for statistical significance as studies could only look at relationships between abuse and the variables they had collected information about.

The independent variables that were measured generally included standard demographic and socio-demographic data about the care recipient and the caregiver (where they were interviewed), for example, age, gender, marital status, educational attainment, income, home ownership status. Where possible, studies often collected information on the relationship between the perpetrator and the victim (for example, whether they were a spouse, daughter, or friend).

Other common (or interesting) areas of data collection were in relation to:

- cognitive impairment of the older person (including medical records, dementia diagnosis, impairment reported by the caregiver, Mini Mental State Exam (MMSE))
- functional impairment of the older person (usually measured by assessment of Activities of Daily Living and Instrumental Activities of Daily Living)
- mental health status of the older person (including depression and psychiatric history)
- problematic behaviours (symptoms) of the older person related to their dementia (in one study this was measured by the NeuroPsychiatric Inventory (NPI) which looks at 12 psychiatric symptoms). Note that irritability and aggression symptoms were often of particular interest due to their association with reports of carer abuse.<sup>92</sup>
- perceived caregiver burden (as measured by the Zarit Burden Scale or alternative, which links care recipient behaviours with how the caregiver feels those behaviours impact on themselves)
- depression and anxiety of caregiver (measures included the Hospital Anxiety and Depression Scale (HADS)<sup>93</sup> and Center for Epidemiological Studies Depression Scale (CES-D)<sup>94</sup>)
- quality of the care recipient-caregiver relationship (current or premorbid)<sup>95</sup>

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<sup>90</sup> Wigglesworth et al, 2010

<sup>91</sup> Sooryanarayana et al, 2016

<sup>92</sup> Cooper et al, 2008, p. 286

<sup>93</sup> HADS “has been validated in all ages and settings...to measure generalised anxiety and depression...over the last week” (Cooper et al, 2008, p. 286)

<sup>94</sup> CES-D is internally consistent (Cronbach’s alpha was 0.89 when used in study by Shaffer et al, 2007, p. 496)

<sup>95</sup> In one study this was measured by the Quality of Life—Alzheimer’s Disease Scale (Cooper et al, 2008, p. 286)

- caregiver and care-recipients' use of formal and informal supports (for example, use of services in the home, access to informal supports and networks).

One final variable worth mentioning comes from a study which looked at caregiver endorsement of “proactively aggressive caregiving strategies”<sup>96</sup>—in effect, coercive strategies intended to elicit compliance with care tasks on the part of the care recipient. The study defined its own measure, a series of statements (for example, “I feel good if I can make him/her do what I want”) with which the caregiver could agree or disagree on a five-point Likert scale. This study found a significant relationship between abuse and these types of strategies.

Information was sometimes collected using statistically validated tests (like the MMSE) or, alternatively, through questions designed specifically for the study's interview.<sup>97</sup>

## Statistical and other data analyses

A wide range of statistical tests were used to determine whether the independent variables predicted or increased the likelihood of abuse—that is, whether the correlations were statistically significant.

Many studies conducted univariate tests (looking for a statistically significant relationship between abuse and the relevant variable). Univariate tests are not always that informative as certain relationships (for example, a relationship between age and cancer) may be explained by other relationships (for example, long-term exposure to harmful chemicals and cancer). The Downes Review determined that many of the dementia-specific studies also performed multivariate analyses to examine risk factors for abuse of people with dementia. Some employed logistic regression analyses which are even more rigorous tests for important relationships. However, at least one study ‘cherry-picked’ the data they used in the regression and so potentially skewed the findings.<sup>98</sup>

A range of other statistical tests were used by various studies reviewed, which varied with the size of the sample, sampling methods and other factors.

Small sample sizes would have affected the results of some tests (making it more difficult for relationships to reach statistical significance).

## Overview of findings on research methods

The key findings of this review in relation to research methods used to determine prevalence are:

- national prevalence studies to date, with the exception of Marmolejo's research in Spain, explicitly exclude people with noticeable levels of cognitive impairment, and, therefore, do not contribute to existing knowledge of the prevalence of elder abuse among people with cognitive impairment.
- dementia-specific studies of elder abuse prevalence do not result in prevalence findings (results) that are comparable with more general studies of elder abuse prevalence. They do not shed sufficient light on the role of dementia or cognitive impairment as a risk factor for abuse. (Because dementia-specific studies recruit from dementia-specific services, support groups and helplines, they are not representative of all people with dementia and so are not generalisable).
- different definitions, data sets and methodologies (which influence the rates of abuse found) makes studies difficult to compare with each other

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<sup>96</sup> Shaffer et al, 2007, p. 494

<sup>97</sup> See Marmolejo, 2008, Appendices: Questionnaires for Elderly Persons and Caregivers

<sup>98</sup> Cooper et al, 2008, pp. 286-287

- a nationally representative prevalence study, which included findings on the prevalence of elder abuse of people with cognitive impairment would need to bridge the current divide between the two cohorts (people with cognitive impairment and people without) which characterises many current studies.

## **Crossing the divide—studies that are inclusive of people with varying levels of cognitive ability**

Just three studies reviewed for this report span the usual gap separating the vast majority of national prevalence studies into elder abuse from most studies examining the relationship between cognitive impairment and elder abuse. While most studies exclude or include a person in the sample on the basis of whether they have a noticeable or diagnosed cognitive impairment, these three studies include people with and without impairment in their samples. This section will consider the most salient aspects of those three studies (for the purposes of this review).

The three studies (as mentioned earlier) include:

- the largescale research project by Marmolejo, whose report is entitled *Elder Abuse in the Family in Spain*
- the small study by Lichtenberg, Ficker and Rahman-Filipiak in 2015 that sought to further validate “a new person-centred approach to assessing capacity to make financial decisions, and its relationship to self-reported cases of financial exploitation in 69 older African Americans” (Lichtenberg et al, 2015, p. 2)
- a study entitled ‘Decline in Cognitive Function and Elder Mistreatment: Findings from the Chicago Health and Aging Project’, which cross-referenced a large community epidemiological study with reports to social services of elder mistreatment. It identified 143 cases of abuse out of the sample of 6159 older people.

The Lichtenberg study did require the person to have a baseline level of cognitive functioning: the ability to participate in a telephone interview. The aspect of the study that is of most interest here, however, is the assessment of the participants’ general cognitive ability (MMSE) alongside the tool they were testing—the Lichtenberg Financial Decision Making Rating Scale (LFDRS)—which indirectly “elicited responses indicative of past financial exploitation”.<sup>99</sup> It was this relationship—between cognitive impairment and experiences of financial abuse—that proved significant in this small but cognitively diverse cohort. While a number of dementia-specific studies also used the MMSE to assess the older person’s level of cognitive impairment, they did not include in their sample older people who did not suffer from cognitive impairment.

The national prevalence study from Spain involved two subject groups: 2401 interviews with elderly people over 64 years of age; and 789 interviews of caregivers of “elderly people who are dependent (physically or intellectually) to a lesser or greater degree”.<sup>100</sup> The respective samples were representative with respect to geography, sex and age.

While the report does not make it completely clear whether or not the caregiver and elderly people interviewed were from the same households, where possible, this approach would lead to further understanding of the reporting of abuse as the caregiver-care recipient dyads could have their rates of reporting directly compared.

The research tools used in the Spanish study did enable analysis of the relationships between reports of abuse, and some of the most commonly identified risk factors for elder abuse including caregiver’s perceived burden, level of dependency of the care recipient, aggressive behaviours on the part of the care recipient, and caregivers own mental health (including depressive and anxiety

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<sup>99</sup> Lichtenberg et al, 2015, p. 12

<sup>100</sup> Marmolejo, 2008, p. 101

disorders). There were also questions for the caregiver about whether the care recipient had dementia (around 9 per cent) and whether they had a cognitive impairment (39 per cent).

While the report did not specify the statistical tests of significance carried out, it did report that the “percentage of elderly people suffering cognitive impairment is significantly higher among victims (66.7 per cent) than among non-victims (37.2 per cent)”.<sup>101</sup> While a small number of the elderly persons’ sample did report suffering from neurological problems (1.7 per cent), whether there was a relationship between this type of impairment and elder abuse was not mentioned in the body of the report. Instead, the report focused on the positive relationship between dependency<sup>102</sup> of the older person and reported rates of elder abuse. For example, the prevalence of abuse was found to be 0.8 per cent in the sample of elderly people, with the rate increasing to 1.5 per cent of those who were dependent on daily assistance from caregivers.

Marmolejo identified the presence of cognitive impairment in the elderly person through questions in the questionnaires for both subject groups about a range of forms of cognitive impairment and neurological disorders. While this enabled the direct comparison of the characteristics of people suffering abuse with those who were not on the basis of cognitive impairment, it would have been better if the presence of cognitive impairment was determined by a validated tool like the MMSE.

The last study<sup>103</sup> included older people with varying levels of cognitive impairment, as measured in a longitudinal community health study using the MMSE and other cognitive tests over a period of 17 years. This study cross-referenced the 6159 participants in the original study with a database recording reports of abuse to social services, with 143 cases of abuse identified (2.3 per cent of sample). The study found that a “decline in global cognitive function, MMSE and perceptual speed scores were associated with increased risk for EM [elder mistreatment]”. The rates of abuse are likely to be an underestimate as other studies have found reported cases of abuse are only the ‘tip of the iceberg’.<sup>104</sup>

These studies will be referred to again in the final section of the report: recommendations for an Australian national prevalence study which could capture information about the relationship between cognitive impairment and abuse.

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<sup>101</sup> Marmolejo, 2008, p. 122

<sup>102</sup> Dependency was measured by a question asking whether they required help everyday with activities of daily living (Marmolejo, 2008, p. 110).

<sup>103</sup> Dong et al, 2014

<sup>104</sup> Lachs et al, 2011

## **Section 3. ‘Doing better research’ (or recommendations about methodologies by which an Australian study could capture information about elder abuse prevalence among people with cognitive impairment)**

This section presents the most important findings of this review: lessons for future studies interested in the relationship between elder abuse and cognitive impairment and in the prevalence of elder abuse in this cohort; and what a model of an ‘inclusive’ Australian National Elder Abuse Prevalence Study might look like.

### **General requirements for future research into elder abuse and cognitive impairment**

The following six points should inform the design of future elder abuse prevalence studies.

#### **1. The importance of a generalisable sample**

A nationally/geographically/cohort-specific representative sample would enable the results to be generalised across the relevant population.

#### **2. The importance of an inclusive sampling technique**

It is essential that future research finds a way to include people with and without cognitive impairment so that studies can speak directly to the relationship between cognitive impairment and elder abuse.

#### **3. The importance of caregiver self-reports as a method for identifying elder abuse**

Where the older person is unable to report abuse themselves, caregiver self-reports identify abuse much more effectively than other research methods, including observer reports.

#### **4. The importance of using validated tools to measure cognitive impairment**

Accurate measurement of cognitive impairment in future studies will enhance our understanding of the relationship between cognitive impairment and elder abuse. This review found that a dementia diagnosis may not be sufficient to fully understand this relationship.

#### **5. The importance of collecting information on key independent variables**

The independent variables identified by this review as having a potentially significant relationship with elder abuse include caregiver mental health, perceived carer burden, quality of premorbid relationship, length of time spent caring (both years in role and hours per week), aggressive or agitated behaviours on the part of the older person, and the mental health and general wellbeing of the older person.

#### **6. The importance of making sure, as far as possible, that any new studies are comparable to existing international studies.**

Comparability might be promoted by, for example, using existing, commonly used, validated measures to measure general cognitive ability.

## Potential model for an 'inclusive' Australian National Prevalence Study

The 'bare bones' model put forward above addresses and seeks to overcome the key limitations that this review identified as characteristic of the vast majority of existing research into elder abuse prevalence and the relationship between cognitive impairment and elder abuse. To this end, the research study would need to keep at the forefront the six lessons listed above. These are listed in order of importance.

The proposed national prevalence study would employ a population-based nationally representative sample that does not automatically exclude people with cognitive impairment from participation.

The study would be modelled on the Spanish national elder abuse prevalence study, involving nationally representative samples of two subject groups: older people (over 65 years of age) and caregivers of older people. The Spanish study focused on older people living in the community; an Australian study would have the option of considering whether to extend its sampling technique to include older people in residential care.

The study would use the same tools, as far as possible, to measure the same variables whether they were collected from the older person themselves or, where necessary, due to severe cognitive impairment, from the caregiver. For example, the Spanish study administered questionnaires to each subject group that were very closely aligned and reported on the same variables.

The study would collect information from competent, independent older people identified by the sampling method, and, where the older person had an informal caregiver (to be defined by a minimum number of hours of care provided), the study would also seek to interview or survey that person.

Where the study identified older persons who did not meet a baseline cognitive ability that would allow them to participate in the study, the researcher would again seek to interview or survey the informal caregiver where there was one. Potentially, an MMSE (or other cognitive functioning test) could be carried out to determine the level of cognitive impairment of the older person. If this was not possible, a validated measure of cognitive impairment that could be administered through the caregiver would be required.

Hence, the study is designed to be inclusive of both older people with cognitive impairment, and of caregivers.

This joint sampling method would enable the study to report more comprehensively on national prevalence.

Further, by keeping the responses of older people and their caregiver (where they have one) connected, this research model would enable exploration of the relationship between elder abuse reported by the older person themselves with any caregiver self-reports of abusive behaviours.

## Conclusion

Research done using this model would shed substantial light on the prevalence of elder abuse and on its relationship to cognitive impairment. It would also collect valuable information about the risk factors of abuse (especially in relation to carer mental health, caregiver burden and caring styles).

Though 'bare bones', there is no doubt that this proposed model would be more resource-intensive than the vast majority of prevalence studies conducted to date. However, given the inability of existing studies to speak to the relationship between cognitive impairment and elder abuse, it is imperative that efforts be made to ensure that any Australian national prevalence study be 'inclusive' of people with cognitive impairment. And, ideally, that it be inclusive of people living both in the community and in residential aged care.



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