

Abuse of Older People with Dementia: A Review

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Dementia is an umbrella term used to denote progressive conditions that develop as a result of degenerative changes in the brain. Dementia primarily affects older people and is characterised by the loss of cognitive, social and behavioural functions that impacts a person's mood and personality and the ability to think, speak, comprehend, reason, communicate, remember and perform basic self-care functions like dressing and eating. As dementia progresses, the associated behavioural and functional disabilities necessitate the provision of increased daily assistance and care to the individual. Hence, the role of family caregivers in providing care can be significant (The Law Reform Commission, 2006; Cahill *et al.* 2012; Alzheimer's Association, 2012).

A review undertaken for Ireland's National Dementia Strategy (Cahill *et al.* 2012) provides evidence on the prevalence of dementia and on the provision of dementia care in Ireland. Findings indicate that there are 41,740 people with dementia in Ireland, most of whom are over 65 years of age. A significant proportion of these older people, 23,058, live in the community where care is provided, in the main, by family caregivers, primarily women, within an embryonic and disjointed community support services infrastructure (Cahill *et al.* 2012). Family caregivers of older people with dementia may be unaware of actions that are abusive (Beech *et al.* 2005). Moreover, such actions may have consequences for the older person. For example, in a study entitled Caring for Relatives with Dementia (CARD) (Cooper *et al.* 2009), over half of caregivers self-reported perpetrating physical or psychological abuse of their care-recipient and one third met the criteria of significant abuse.

Elder abuse has received considerable attention in public discourses, policy reports and research as the issue has increasingly been discussed and studied and attempts have been made to address it. At the same time, new perspectives have transcended the traditional, medical perspective of dementia, allowing new understandings from other disciplines to emerge, which draw attention to the economic and social implications of the condition (Cahill *et al.* 2012). In this context, a link between dementia and a higher risk of elder abuse has been established (Hansberry *et al.* 2005; Cooney *et al.* 2006). It is widely accepted that the effects of dementia can render older people more susceptible to exploitation by others and can severely impair their ability to seek help, advocate for themselves or remove themselves from

potentially abusive situations (Bonnie and Wallace, 2003). Moreover, the higher risk of elder abuse for this population cohort may be related to a number of interacting and reinforcing factors, including the greater likelihood of cognitive impairment, depression, behavioural difficulties, social isolation and dependency (Coyne *et al.* 1993; VandeWeerd and Paveza, 2005; Hansberry *et al.* 2005; Selwood and Cooper, 2009). Several authors attest to the unique challenges, demands, stresses and burdens associated with caregiving in dementia (Coyne *et al.* 1993; Lachs and Pillemer, 2004; Schulz and Martire, 2004; Hansberry *et al.* 2005; Bertrand *et al.* 2006; Drossel *et al.* 2011). These factors, in combination, may place an older person with dementia at increased risk of abuse.

Similar to global estimates (WHO, 2012), it is projected that the prevalence of dementia in Ireland will increase dramatically over coming decades with the most marked increase expected among those aged 85 years and over (Cahill *et al.* 2012). With the continuing rise in the number of older people with dementia and the recognition of their particular vulnerability to abuse and neglect, it is important to examine the issue of abuse of this subgroup of the older population. Moreover, in the recent Irish National Positive Ageing Strategy (DoH, 2013), the national goals emphasise protecting the health of older people throughout the life-course, enabling older people to live in confidence, security and dignity in their own homes and using evidence-based research to respond to population ageing issues in Ireland. Within these foci, ascertaining the extent of elder abuse in people with dementia, the risk factors for its occurrence and the particular challenges that the presence of dementia presents when dealing with suspected cases of elder abuse are necessary steps in the development of best practice approaches to detecting, preventing and managing abuse of older people with dementia and for informing future research.

1.1 Aims and objectives

The overall aim of this review of literature was to collate, analyse and summarise published literature on abuse of community-dwelling older people with dementia, in order to inform future research in this area. The objectives of the review were to identify published evidence relating to:

- the prevalence and risk factors for the abuse and neglect of older people with dementia.
- the characteristics of perpetrators who abuse older people with dementia.
- the means of recognising abuse and neglect of older people with dementia.
- the strategies for preventing and managing cases of abuse of older people with dementia.

2.1 Search strategy

A comprehensive search of peer-reviewed published works indexed in the databases Cochrane, Medline, PsychInfo, PubMed and CINAHL was conducted. This was supplemented by a search of Google Scholar in order to identify relevant grey literature on the topic. The search keywords used either singularly or in various combinations were: 'elder abuse', 'elder mistreatment', 'cognitive function', 'cognitive impairment', 'Alzheimer's disease' and 'dementia'. Bibliographies of retrieved articles were examined for the key search terms in their titles and ancestral searching of the reference lists of retrieved items was also conducted to identify further items not identified through the keyword searches.

2.2 Inclusion and exclusion criteria

The focus of the literature review is abuse of community-dwelling older people with dementia. Preliminary database searches indicated that there was a relatively small body of literature that dealt specifically with abuse and neglect of community-dwelling older people with dementia. As a result, it was necessary to include studies on the general topic of elder abuse that highlighted aspects related to dementia. The focus of this review was on 'older people' who were operationally defined as those aged 60 years and over, in line with the United Nations and the World Health Organisation's commonly used definition of an older person. However, five studies which included older adults below this age threshold were included since the mean age of people in these studies was above 70 years.

The review included studies of older people with some form of dementia, including clinically-diagnosed dementia and dementia where no reference to diagnostic criteria was made. 'Elder abuse' was operationally defined using the Irish policy definition (WGEA, 2002: 25) as: 'a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person or violates their human and civil rights'. The material selected for review included primary research, review articles and policy documents. Dissertations, theses, case histories and meeting abstracts were excluded. The search was confined to English language publications and the review period was 1985 to April

2013. Self-neglect was excluded as this category is not recognised as elder abuse within Irish policy (WGEA, 2002).

2.3 Search outcome, data extraction and synthesis

The search strategy yielded an initial total of approximately 500 titles. Following screening of the abstracts, report summaries and full papers, 43 items were deemed relevant for inclusion in the review. Relevant data from included studies were extracted according to a standard template in order to facilitate the description and synthesis of the main body of literature on elder abuse of people with dementia. The data extracted included methodological details, such as the study design and the sample characteristics as well as findings on the nature and prevalence of elder abuse of people with dementia, and the risk factors and correlates related to the abuse of older people with dementia. Additional themes were identified through reading of the material and these are presented in the findings section.

3.1 Researching elder abuse of people with dementia

Most of the studies of abuse of older people with dementia cited in this review are primary research studies. Twelve reviews or discussion papers were also identified and are included in the review (Cooney and Howard, 1995; Coyne *et al.* 2001; Teitelman and Copolillo, 2002; Flannery, 2003; Lingler, 2003; Lachs and Pillemer, 2004; Hansberry *et al.* 2005; O'Connor *et al.* 2009; Selwood and Cooper, 2009; Kohn and Verhoek-Oftedahl, 2011; Pisani and Walsh, 2012; Johannesen and Logiudice, 2013). Three of the included papers on the abuse of older people with dementia were derived from the same study data, but reported on different research questions (Cooper *et al.* 2009; Selwood *et al.* 2009; Cooper *et al.* 2010a) and were therefore included as distinct studies. In addition, a study by Kilburn *et al.* (1996) involved secondary analysis of data generated by Pillemer and Sutor (1992) and examined the relationship between social networks and elder abuse. See Table 1 in the Appendix for a detailed summary of study designs, samples, and the prevalence and risk factors of abuse among older people with dementia.

Study designs

The prevalence of abuse of older people with dementia was identified mainly through caregiver reports of abuse, usually from the primary caregiver (Paveza *et al.* 1992; Pillemer and Sutor, 1992; Cooney and Wrigley, 1996; Pot *et al.* 1996; Compton *et al.* 1997; Cooney *et al.* 2006) and family carers (Lee and Kolomer, 2005; VandeWeerd and Paveza, 2005; Cooper *et al.* 2008a; Cooper *et al.* 2009; Cooper *et al.* 2010b; Perez-Rojo *et al.* 2009; Cooper *et al.* 2010a; Yan and Kwok, 2011). Although caregivers have provided important data on abuse, the use of caregivers as informants may be of limited value, as self-disclosure of abuse may be influenced by both a lack of recognition of abusive behaviours and under-reporting of perpetrated abuse. Some caregivers may be reluctant to self-disclose abusive behaviours because of the stigma attached to it while pathologically-abusive carers who perpetrate more severe abuse are unlikely to contribute to research studies of abuse (Cooney and Howard, 1995; Lee and Kolomer, 2005; Cooney *et al.* 2006; Cooper *et al.* 2009). Caregiving may be described as pathological when factors within the abuser, such as alcohol abuse, sociopathic behaviour or psychiatric morbidity are the

sole determinants of violence (Wrigley *et al.* 1991). Nevertheless, many studies indicate that carers openly and willingly discuss abusive behaviours (Cooney and Howard, 1995; Pot *et al.* 1996; Cooney *et al.* 2006; Shaffer *et al.* 2007; Cooper *et al.* 2009). Possible reasons for this include perpetrators not perceiving their behaviours as abuse, but rather regarding themselves as victims who are managing as best they can in difficult circumstances (Shaffer *et al.* 2007). For example, in an early study by Homer and Gilleard (1990), carers of older people in receipt of regular respite care in their own homes, – two fifths of whom had dementia – found that a higher proportion of carers self-reported abusive behaviour when compared to disclosures made by abused care-recipients. Similarly, Cooper *et al.* (2008a) reported that screening using the Minimum Data Set Abuse screen (MDS-A) was not as effective in detecting abuse when compared with caregiver self-reports of abuse. Other methods adopted by researchers to identify abused older people with dementia included observer-rated elder abuse and analysis of abuse case referral investigations (Dyer *et al.* 2000; Cooper *et al.* 2008a; Wigglesworth *et al.* 2010).

Samples and sampling

Non-probability sampling methods, such as convenience sampling, purposive sampling, snowball sampling and consecutive sampling, were employed to identify the target population in most of the studies generating prevalence estimates (Compton *et al.* 1997; Lee and Kolomer, 2005; Cooper *et al.* 2008a; Wigglesworth *et al.* 2010; Yan and Kwok, 2011). Researchers obtained their samples via a range of different recruitment methods. Many older people with dementia and their caregivers were recruited through dementia or Alzheimer's register lists or by referral or selection through hospital-based psychiatry of old age services, including specialist dementia services or dementia screening programmes, through community mental health teams and through community or day centres (Paveza *et al.* 1992; Pillemer and Sutor, 1992; Pot *et al.* 1996; Compton *et al.* 1997; Cooney *et al.* 2006; Cooper *et al.* 2009; Perez-Rojo *et al.* 2009; Yan and Kwok, 2011). Several studies used a combination of these methods to recruit their target sample. Thus, most samples of community-dwelling older people with dementia were recruited from clinical settings or select populations rather than from representative community populations. Accordingly, these methods may have yielded an overrepresentation

of older people with higher levels of cognitive impairment, dementia or behavioural problems. Given the potential for sample bias introduced by some of the recruitment methods employed, prevalence figures must be interpreted with caution.

Two of the studies generated prevalence data through postal questionnaires to carers of older people with dementia (Cooney and Mortimer, 1995; Coyne *et al.* 1993). Cooney and Mortimer (1995) targeted members of a voluntary support organisation, which provided information and support to carers of older people with dementia while Coyne *et al.* (1993) targeted carers who called a dementia support helpline. These methods not only elicited poor response rates, but recruiting carers in this way may have increased the likelihood of oversampling carers who were experiencing difficulties related to their caring role, thereby raising questions about sample representativeness and the generalizability of the findings.

Data collection

The methods of data collection included direct administration of a questionnaire and interviews with caregivers and, in a small number of studies, interviews with the older people with dementia (Homer and Gilleard, 1990; Cooney and Wrigley 1996). A small number of studies collected data via postal questionnaires (Coyne *et al.* 1993; Cooney and Mortimer, 1995) and telephone interviews (Langan, 1997; Perez-Rojo *et al.* 2009).

Inclusion and exclusion criteria

Inclusion and exclusion criteria in the included studies varied. As previously mentioned, most of the studies involved data collection from primary caregivers and family caregivers; however some studies specified more stringent inclusion criteria, such as co-residence (Compton *et al.* 1997; Cooney *et al.* 2006; Shaffer *et al.* 2007) or minimum number of hours of caregiving per week (VandeWeerd and Paveza, 2005; Lee and Kolomer, 2005; Cooper *et al.* 2008a; Cooper *et al.* 2009). All of the included primary research studies comprised older people or carers of older people with a diagnosis of dementia or Alzheimer's disease, with some studies referring to clinical diagnostic criteria (Paveza *et al.* 1992; Pot *et al.* 1996; Compton *et al.* 1997; Dyer *et al.* 2000; VandeWeerd and Paveza, 2005; Yan and Kwok, 2011).

Other dementia-related studies made no reference to whether a clinical diagnosis of dementia had been established (Coyne *et al.* 1993; Cooney and Mortimer, 1995; Lee and Kolomer, 2005). Most of the studies comprised samples of older people with dementia aged 60 years and over; however, five studies in which the age profile of the sample was slightly below this threshold were included since the mean age of people in these studies was above 70 years (Paveza *et al.* 1992; Cooney *et al.* 2006; Perez-Rojo *et al.* 2009; Wigglesworth *et al.* 2010; Kishimoto *et al.* 2013). Caution must be exercised when selecting age cohorts below 60 years, since dementia increases with advancing age. For example, Plassman *et al.* (2007) reported that the prevalence of dementia was 5 per cent of those aged 71–79 years and 37.4 per cent of those aged 90 years and older. However, it should be noted that approximately 8.6 per cent of the estimated 41,740 people with dementia in Ireland are under 65 years (by applying the EuroCoDe prevalence rates to the 2006 Irish census) (Cahill *et al.* 2012).

Measuring abuse

A number of definitions and measures of elder abuse were used to identify the occurrence of abuse, including the Conflict Tactics Scale (CTS) developed by Straus (1979) (Paveza *et al.* 1992; VandeWeerd and Paveza, 2005), the Modified Conflict Tactics Scales (MCTS) (Cooper *et al.* 2008a; Cooper *et al.* 2009; Yan and Kwok, 2011; Kishimoto *et al.* 2013), Pillemer and Finklehor's (1988) criteria for abuse (Homer and Gilleard, 1990; Cooney and Mortimer, 1995; Pot *et al.* 1996; Cooney and Wrigley, 1996; Compton *et al.* 1997; Cooney *et al.* 2006), the Caregiver Abuse Screen (Perez-Rojo *et al.* 2009), the Texas Department of Protective and Regulatory Services (TDPRS) definitions of abuse and neglect (Dyer *et al.* 2000), the Minimum Data Set Abuse screen (MDS-A) (Cooper *et al.* 2006; Cooper *et al.* 2008a), a six-item elder abuse scale (Lee and Kolomer, 2005), the Potentially Harmful Behaviour (PHB) instrument (Shaffer *et al.* 2007) and Homer and Gilleard's (1990) abuse questions (Pot *et al.* 1996). Wigglesworth *et al.* (2010) reported the use of an expert panel of clinicians to judge the occurrence of abuse using medical records and home visit observations in conjunction with three elder abuse screening instruments. In two studies, only a subset of carers who had reported feelings of aggression towards their care-recipient was asked about abusive behaviour (Pillemer and Sutor, 1992; Pot *et al.* 1996).

3. Findings

Although there are many forms of abuse, physical, psychological and neglect were the subtypes of abuse most frequently measured, with relatively little focus on financial or sexual abuse. The review identified three studies which addressed elder financial exploitation of people with dementia (Rowe *et al.* 1993; Means and Langan, 1996; Langan, 1997) and four studies which examined elder sexual abuse of persons with dementia (Holt, 1993; Teitelman and Copolillo, 2002; Lingler, 2003; Burgess and Philips, 2006).

Data analysis

Despite the relatively small sample sizes of most of the included studies in this review, many studies performed multivariate analysis in order to identify associations between risk factors and elder abuse of people with dementia (Paveza *et al.* 1992; VandeWeerd and Paveza, 2005; Lee and Kolomer, 2005; Cooney *et al.* 2006; Cooper *et al.* 2008a; Cooper *et al.* 2010a; Yan and Kwok, 2011; Kishimoto *et al.* 2013). Correlates and associations of elder abuse of people with dementia identified in studies that did not perform multivariate analysis are only tentative indicators of abuse and must be interpreted with caution (Homer and Gilleard, 1990; Pillemer and Suito, 1992; Cooney and Mortimer, 1995; Cooney and Wrigley, 1996; Compton *et al.* 1997). Some studies adopted a qualitative design to examine financial management within the context of abuse and neglect of older people with mental incapacity (Rowe *et al.* 1993; Means and Langan, 1996; Langan, 1997).

In summary, there is evidence of much variability in the study designs of included studies. Various data collection methods and techniques, sampling designs, recruitment methods, definitions and instruments to measure elder abuse and inclusion and exclusion criteria have been employed. This variability undermines to some extent the ability to highlight cross-study comparisons in relation to prevalence rates and risk factors for abuse in older people with dementia. Furthermore, there is much variability in the quality of the research examining elder abuse in general and in research focusing on people with dementia as evidenced in Cooper *et al.*'s (2008b) systematic review which used standardised criteria of study quality to evaluate 49 studies, some of which are included in this review. Given the variability in both approaches to and the quality of study designs that characterise research of elder abuse of people with

dementia, any attempt to conduct a cross-study comparison of results and prevalence rates should highlight inconsistencies and proceed with caution in drawing conclusions.

3.2 Prevalence of elder abuse of people with dementia

Fifteen studies were identified that measured the prevalence of abuse against older people with dementia. Estimates of the prevalence of elder abuse and neglect of people with dementia vary enormously between different studies. Of the studies reviewed, the prevalence rate of some form of abuse, usually encompassing measures of both physical and psychological abuse and sometimes neglect, ranged from 27.9 per cent (Cooper *et al.* 2008a) to 55 per cent (Cooney and Mortimer, 1995). Of the types of elder abuse examined, psychological abuse was consistently the most prevalent form of abuse of people with dementia, ranging from 27.9 per cent (Cooper *et al.* 2008a) to 62.3 per cent (Yan and Kwok, 2011). Reports of the prevalence of physical abuse of older people with dementia ranged from 1.4 per cent to 23.1 per cent (Cooper *et al.* 2008a; Cooney and Wrigley, 1996). Five studies examined the prevalence of neglect with prevalence figures ranging from 4 per cent to 15.8 per cent (Cooney and Mortimer, 1995; Cooney and Wrigley, 1996; Compton *et al.* 1997; Cooney *et al.* 2006; Wiglesworth *et al.* 2010).

A number of studies measured the prevalence of either physical abuse, psychological abuse or neglect in community-dwelling older people with dementia. Several UK studies demonstrated a high rate of abuse in older people with dementia, with over half of the caregivers self-reporting abusive behaviour (Cooney and Mortimer, 1996; Cooney *et al.* 2006; Cooper *et al.* 2009). In a representative cross-sectional sample of 220 family caregivers of older people with dementia, a prevalence rate of 52 per cent was reported for abuse while one third of carers met the criteria of significant abuse (Cooper *et al.* 2009). The authors measured abusive behaviour by the same carers one year later and found that it had increased overtime with two thirds of carers reporting abusive behaviour compared to around half of carers at baseline (Cooper *et al.* 2010b). In an earlier UK study by Cooper *et al.* (2008a), a lower prevalence rate was reported for abuse in a purposive sample of 86 caregivers

of older people with Alzheimer's disease (27.9%). Using relatively small sample sizes, two Irish studies, one based in Northern Ireland and the other in the Republic of Ireland, reported a prevalence rate for abuse of 37 per cent (n=14) and 30.8 per cent (n=8), respectively (Compton *et al.* 1997; Cooney and Wrigley, 1996). In a US study, Wigglesworth *et al.* (2010) reported a prevalence rate of 47.3 per cent of abuse in a sample of 129 community-dwelling older people with dementia. The highest prevalence rate for abuse, including both psychological and physical forms of abuse, was reported as 62.3 per cent in a study of 122 family caregivers of older people with dementia in Hong-Kong (Yan and Kwok, 2011).

A number of US studies measured the prevalence of physically abusive or violent behaviours by caregivers of community-dwelling older people with dementia. Pillemer and Sutor (1992) reported a prevalence rate of 5.9 per cent while a prevalence rate of 11.9 per cent for physical abuse was found in a New-Jersey based study of 342 caregivers (Coyne *et al.* 1993). Paveza *et al.* (1992) reported a 5.4 per cent prevalence rate of severe violence in a US-based study of 184 community-dwelling patients with Alzheimer's disease.

Several studies found that psychological abuse was the most prevalent form of abuse in older people with dementia (Cooney and Mortimer, 1995; Cooney and Wrigley, 1996; Compton *et al.* 1997; Cooney *et al.* 2006; Cooper *et al.* 2008a; Cooper *et al.* 2009; Wigglesworth *et al.* 2010). VandeWeerd and Paveza (2005) reported a high prevalence of verbal abuse with a finding of 60.1 per cent in a sample of 254 family caregivers of older people with Alzheimer's disease in the US. Lee and Kolomer (2005) reported the findings of a South Korean prevalence study involving 481 primary family caregivers of older people with dementia. Caregivers reported a higher incidence of both psychologically abusive behaviours, such as often not answering their care-recipient's question (15.2%) or frequently yelling at their care-recipient (16.4%) and physically abusive behaviours, in particular, confinement to a room (19.1%).

Several studies found concurrent abuse with many of the perpetrators engaged in more than one form of abuse (Cooney and Wrigley, 1996; Cooney *et al.* 2006). For example Cooney *et al.* (2006) noted that physical abuse and neglect rarely occurred in isolation while Pot *et al.*

(1996) showed that physical abuse was often accompanied by verbal abuse. Cooney and Mortimer (1996) noted an overlap between verbal and physical abuse and neglect, although they remarked that most abusers reported that they perpetrated only one type of abuse. This clustering of abuse has also been observed in the Irish national prevalence study (Naughton *et al.* 2010).

Cognitive decline is associated with diminished financial capacity and older people with dementia may often rely on caregivers to manage their financial affairs (Marson *et al.* 2009). In this context, caregivers may assume the role of 'risky asset managers' (Setterlund *et al.* 2007), perpetrating abuse through mismanagement of the financial affairs of the older person. A complicating factor in the financial abuse of older people with dementia is the fact that, unlike other forms of abuse, there is often no visible sign of abuse. Moreover, financial abuse is often not recognised as abuse by relatives due to an assumed sense of expectation and entitlement to the assets of the older person (Conrad *et al.* 2010, King *et al.* 2011). Although older people with dementia are regarded as extremely vulnerable to financial abuse (Hansberry *et al.* 2005), just three studies were identified which addressed financial exploitation in older people with dementia (Rowe *et al.* 1993; Means and Langan, 1996; Langan, 1997). These studies demonstrated the particular vulnerability of financial mismanagement for older people with dementia. For example, Rowe *et al.* (1993) investigated the use of substitute decision-making arrangements in the case of 25 community-dwelling older people with dementia who had lost financial competence and found that only one person's financial affairs were being administered appropriately. Thus, social and legal services are encouraged to urgently develop comprehensive policies and practices to protect the finances of older people with dementia (Means and Langan, 1996; Langan, 1997).

In summary, prevalence rates of elder abuse of people with dementia are substantially higher when compared to the rates of elder abuse reported for the general population of community-dwelling older people (Coyne *et al.* 2001; Lachs and Pillemer, 2004; Cooney *et al.* 2006; Cooper *et al.* 2008a). Hence the evidence indicates that there may also be a concurrent clustering of different types (Cooney and Mortimer, 1995; Cooney and Wrigley, 1996). Physical abuse rarely occurred in isolation from psychological abuse (Pot *et al.* 1996; Compton *et al.* 1997;

Cooney *et al.* 2006; Wigglesworth *et al.* 2010). None of the studies reviewed indicated the trajectory of abuse, in terms of whether the occurrence of dementia represented an escalation of abusive behaviour or some other distinct pattern, or whether perpetrators graduated from what might be considered less severe forms of abuse to more severe forms. However, there are difficulties ascertaining reliable prevalence rates of elder abuse of people with dementia. The wide variations in prevalence rates are attributable to differences in definitional, operational, sampling and methodological approaches to study designs. The non-standard definitions and instruments employed to measure elder abuse is just one feature of study design, which contributes to variation in prevalence rates and impairs the comparability of results.

3.3 Risk factors and correlates of elder abuse of people with dementia

A holistic model of risk factors for abuse, encompassing both vulnerabilities that lie within the older person with dementia and within others, is posited as the best approach to examining abuse of older people with dementia (Pillemer and Suito, 1992; Bonnie and Wallace, 2003; VandeWeerd and Paveza, 2005). The literature provides evidence of several risk factors and correlates of elder abuse in people with dementia, which may be summarised as relating to the characteristics of the older person with dementia, the caregiver's characteristics, the carer-recipient relationship and the care environment. A systematic review conducted by Johannesen and Logiudice (2013) identified eleven studies of community-dwelling older people with dementia and found that greater cognitive impairment, problematic behaviour, psychiatric illness or psychological problems, poor relationships within the family and a shared living arrangement were risk factors in at least some of the studies reviewed.

Dementia as a risk factor

The higher prevalence rates of abuse among older people with dementia indicate that dementia is itself a substantial risk factor for elder abuse. Several studies have considered the presence of dementia and the degree of severity of the dementia among an array of potential risk factors for elder abuse by comparing abusive and non-abusive caregivers.

A case-control study of 142 older people in the US demonstrated a significantly higher proportion of dementia among older people who experienced abuse or neglect, as compared to those who had not (Dyer *et al.* 2000); the study included cases of self-neglect and was adjusted only for age, sex and ethnicity. Conversely, in a sample of 417 co-resident caregivers of community-dwelling older people, approximately a fifth of who had dementia or another memory problem, the presence of dementia did not predict potentially harmful behaviour (PHB) (Shaffer *et al.* 2007). Similarly, a diagnosis of dementia did not predict abuse in a representative study of 4,000 community-dwelling older adults (Cooper *et al.* 2006).

Several studies have shown a high risk of sexual abuse in persons with cognitive impairment (Teitelman and Copolillo, 2002). Dementia was the most frequently cited impediment among 90 cases of substantiated and suspected cases of elder sexual abuse by family members and carers identified by health and social care professionals in the UK (Holt, 1993). Burgess and Philips (2006) found that 60 per cent of 284 referrals for elder sexual abuse had some form of dementia.

VandeWeerd and Paveza (2005) reported that fewer dementia symptoms present in the older person was a protective factor against the risk of verbal abuse, leading the researchers to suggest that more severe cognitive impairment in older people with dementia exposed them to a higher risk of abuse. A number of other studies of caregiver abuse of older people with dementia have also shown that increasing cognitive impairment in the care-recipient increased the likelihood of abuse (Pot *et al.* 1996; Lee and Kolomer, 2005; Cooper *et al.* 2008a). This association is also supported by the findings of a study conducted in Japan among older people with mild dementia (Kishimoto *et al.* 2013). The authors suggest that in the early stages of cognitive disorder, undiagnosed cognitive impairment may be a particular source of tension between an older person and their caregiver (Kishimoto *et al.* 2013). However, a small number of studies on older people with dementia reported no association between abuse and the level of cognitive impairment in the older person (Homer and Gilleard, 1990; Compton *et al.* 1997).

Behavioural disturbance

Secondary symptoms of dementia such as aggression are particularly challenging for caregivers. A number of studies reported that many families caring for an older person with dementia perceived aggression from the person with dementia as a serious problem (Colerick and George, 1986; Homer and Gilleard, 1990). The studies examined in this review indicate a correlation between abusive or aggressive behaviour by the older person with dementia and the conduct of elder abuse by the caregiver (Coyne *et al.* 1993; Cooney and Mortimer, 1995; Compton *et al.* 1997; Cooney *et al.* 2006; Wigglesworth *et al.* 2010). For example, Pillemer and Suito (1990) reported that caregivers who feared becoming violent were more likely to be caring for a family member with disruptive behaviour, while verbal abuse by the older person with dementia towards the caregiver was found to increase the likelihood of being verbally abused by the caregiver (VandeWeerd and Paveza, 2005). This reflects observations from an early study by Homer and Gilleard (1990), which found that abusive behaviour by the care-recipient was the most frequently cited trigger for physical abuse of older people with dementia, as identified by carers.

From among several risk factors for elder abuse of persons with dementia considered by Cooper *et al.* (2010a), caring for someone who was themselves abusive was found to be the strongest predictor of abuse. Likewise, Wigglesworth *et al.* (2010) found that both physical assault and psychological aggression by the older person with dementia in receipt of care was the best predictor of elder abuse. Yan and Kwok (2011) reported that caregiver burden, caused by displays of agitated behaviour in the care-recipient, increased the risk of verbal abuse. The stress experienced by caregivers as a result of aggressive behaviour from older people with dementia also contributes to a higher risk of abuse by caregivers (Perez-Rojo *et al.* 2009). Together, these studies highlight the reciprocal nature of abuse in dementia caregiving. According to Coyne *et al.* (1993), this reciprocity initiates and perpetuates a 'cycle of violence', requiring urgent interventions.

Functional impairment

There is mixed evidence for a relationship between level of functional impairment in the person with dementia and elder abuse. A small number of studies have reported that poor functional status was related to elder abuse (Coyne *et al.* 1993; Pot *et al.* 1996); however, most studies found no association between the two (Homer and Gilleard, 1990; Paveza *et al.* 1992; Pillemer and Suito, 1992; VandeWeerd and Paveza, 2005; Cooney *et al.* 2006; Perez-Rojo *et al.* 2009). Two studies, both employing multivariate analysis to examine the risk factors for elder abuse of people with dementia, found that caregivers were less likely to abuse those with greater functional impairment (Cooper *et al.* 2008a; Lee and Kolomer, 2005). In addition, Johannesen and Logiudice (2013) noted that compared to general population studies, functional dependency or functional impairment did not emerge as risk factors in studies of older people with dementia.

Socio-demographic characteristics

Of the socio-demographic characteristics of older people with dementia, younger age (VandeWeerd and Paveza, 2005; Cooney *et al.* 2006), lower income (Wigglesworth *et al.* 2010) and gender were associated with increased risk of elder abuse, with some studies reporting that males are more vulnerable to abuse than females (Pot *et al.* 1996; Dyer *et al.* 2000).

Health-related factors in the caregiver

Caregiver risk factors associated with elder abuse of people with dementia included poor psychological health (Cooney and Wrigley, 1995; Cooney and Mortimer, 1995; Pot *et al.* 1996), mental health problems, such as depressive symptoms (Homer and Gilleard, 1990; Coyne *et al.* 1993; VandeWeerd and Paveza, 2005; Cooney *et al.* 2006; Perez-Rojo *et al.* 2009; Cooper *et al.* 2010a; Cooper *et al.* 2010b; Wigglesworth *et al.* 2010) anxiety (Compton *et al.* 1997, Cooper *et al.* 2010a; Cooper *et al.* 2010b Wigglesworth *et al.* 2010), and alcohol abuse (Homer and Gilleard, 1990; Cooney and Wrigley, 1995). In addition, Pillemer and Suito (1992) found that lower self-esteem was predictive of violent feelings.

Interpersonal relationships

The quality of the relationship between the older person and the caregiver prior to the onset of dementia has been identified as a risk factor for elder abuse. Numerous studies found that caregiver abuse was associated with a poor pre-morbid relationship (Homer and Gilleard, 1990; Cooney and Mortimer, 1995; Pot *et al.* 1996; Compton *et al.* 1997) and also a poor current relationship (Cooney *et al.* 2006). Coyne *et al.* (1993) also found that caregiver abuse of the person with dementia was associated with pre-morbid abuse of the carer by the older person with dementia.

Environmental risk factors

The dynamics of elder abuse may be better understood within the context in which caregiving takes place (Pillemer and Suito, 1992). Contextual or environmental risk factors for elder abuse of people with dementia include high caregiver burden (Coyne *et al.* 1993; Lee and Kolomer, 2005; VandeWeerd and Paveza, 2005; Cooper *et al.* 2008a; Perez-Rojo *et al.* 2009; Cooper *et al.* 2010a; Wiglesworth *et al.* 2010; Yan and Kwok, 2011), more involved caring, in terms of hours spent caring and duration of caring (Coyne *et al.* 1993; Cooney and Mortimer, 1995; Cooper *et al.* 2010a; Yan and Kwok, 2011), the volume of caregiving tasks (Pot *et al.* 1996), a shared living arrangement (Pillemer and Suito, 1992; Kilburn *et al.* 1996; Pot *et al.* 1996; Yan and Kwok, 2011) and the use of dysfunctional coping strategies (Shaffer *et al.* 2007; Cooper *et al.* 2010a). Contrary evidence reported by Kishimoto *et al.* (2013) was that neither hours spent caring nor co-residence were related to the abusive behaviour of caregivers of people with mild dementia. These results may indicate that risk factors vary depending on the stage of the dementia.

Some studies found that less use of services increased the likelihood of elder abuse by carers (Lee and Kolomer, 2005; Perez-Rojo *et al.* 2009; Yan and Kwok, 2011). A perceived lack of support and feelings of social isolation on the caregiver's part were also found to be related to elder abuse (Compton *et al.* 1997; Cooney and Mortimer, 1995). Using a sample of 202 family caregivers of older people with dementia, Kilburn *et al.* (1996) examined the relationship between caregivers' social support networks and caregivers' fear of acting violently towards the care-recipient; the authors found that network contacts with caregiving experience and the provision of instrumental and emotional support from network

contacts lowered the probability of carer violent feelings. The authors concluded that peer groups characterised by intimacy provide a platform for caregivers to share experiences and skills in relation to caregiving and that this benefits them through improved confidence and competence to better manage the challenges of caregiving and thereby reduce the likelihood of abuse occurring. Other studies reported no significant relationship between elder abuse and use of services or between elder abuse and indicators of social support or social isolation (Homer and Gilleard, 1990; Pillemer and Suito, 1992; Cooper *et al.* 2010a).

Risk factors for abuse subtypes

The majority of studies reviewed comprised insufficient sample sizes to permit delineation of risk factors for subtypes of abuse; however five studies presented evidence relating to abuse subtypes and their correlates. Risk factors which were identified as particularly associated with the occurrence of physical abuse included better caregiver health and more involved caring (Cooney and Mortimer, 1995; Cooney *et al.* 2006; Pot *et al.* 1996; Yan and Kwok, 2011). Pot *et al.* (1996) found that physically abusive carers had a significantly higher number of psychological complaints when compared to verbally abusive carers. A poor pre-morbid relationship between the carer and the care-recipient, characterised by conflict and aggression, emerged as a risk factor particular to the occurrence of psychological abuse (Homer and Gilleard, 1990; Cooney and Mortimer, 1995; Cooney *et al.* 2006). Yan and Kwok (2011) reported distinct predictors of verbal and physical abuse; while verbal abuse was predicted by a higher number co-residing days, lack of any domestic assistance, and a high level of caregiver burden, physical abuse was only predicted by a higher number co-residing days.

In summary, factors which were most commonly identified as contributing to the risk of elder abuse of people with dementia included 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. Evidence relating to the level of cognitive impairment in the person with dementia and a lack of social support and use of services as risk factors was mixed. Consequently, purported predisposing risk factors for abuse of older

people with dementia, such as functional impairment, do not appear to be well supported by the literature.

3.4 Perpetrators of elder abuse of people with dementia

Studies into the abuse of older people with dementia by their caregivers show that the caregiver respondents were predominantly women (Homer and Gilleard, 1990; Compton *et al.* 1997; Lee and Kolomer, 2005; VandeWeerd and Paveza, 2005; Cooney *et al.* 2006; Cooper *et al.* 2008a; Cooper *et al.* 2009; Wigglesworth *et al.* 2010; Yan and Kwok, 2011). However, in the literature on elder abuse and dementia there is no evidence that either men or women are more likely to be perpetrators of abuse (Pillemer and Suitor, 1992; Selwood and Cooper, 2009). In one study, females were identified as more likely to perpetrate abuse (VandeWeerd and Paveza, 2005) while in other studies males were found to be more likely (Holt, 1993; Cooper *et al.* 2008a; Kishimoto *et al.* 2013). Holt (1993) investigated 90 cases of sexual abuse of older people in the UK and found that the typical perpetrator of confirmed or suspected cases of sexual abuse was the adult male son while the victim was typically female and had dementia. These findings highlighted the relationship between powerlessness, vulnerability and elder sexual abuse (Holt, 1993). However, in most studies reviewed the caregiver's gender appeared to have no bearing on the likelihood of abuse occurring.

In the studies reviewed, the majority of older people with dementia were cared for by family members, either their spouses or adult offspring, and the findings confirm that abuse by family caregivers is a common occurrence (Paveza *et al.* 1992; Selwood and Cooper, 2009). However, findings on the familial relationship of the abuser can differ. For example, a small number of studies found that the prevalence of abuse was significantly higher among spousal caregivers (Pillemer and Suitor, 1992; Pot *et al.* 1996). Conversely, Paveza *et al.* (1992) found there was a greater likelihood of violence in families caring for people with dementia where a spouse was absent.

Few socio-demographic characteristics of caregivers were found to be related to the perpetration of elder abuse of persons with dementia. Wigglesworth *et al.* (2010) reported an association between a lower level of education and elder abuse, while Pillemer and Suitor

(1992) found that older age was associated with abuse; however, this latter finding was attributed to the higher prevalence of abuse by spousal caregivers who, as a group, tended to be older.

In summary, no clear profile of the characteristics of a typical perpetrator of elder abuse of people with dementia emerged from the literature. Socio-demographic factors related to gender, age, education, and the relationship between caregiver and care-recipient are not sufficiently consistent to enable the building a clear perpetrator profile. Nevertheless, the literature does indicate that a perpetrator of abuse will typically have experienced abusive or disruptive behaviour in their role as carer and may have a history of conflict with their care-recipient.

3.5 Recognising elder abuse of people with dementia

Identifying elder abuse is challenging for many reasons, including the tendency for perpetrators to abuse privately and also because the signs of elder abuse are not easily distinct from the signs associated with morbidity in older age or those resulting from self-neglecting behaviours (Choi and Mayer, 2000; Lachs and Pillemer, 2004). Elder abuse can go undetected by health and social care professionals if they erroneously assume that indicators of abuse and neglect are as a result of degenerative ageing processes (Hansberry *et al.* 2005). Detecting abuse of older people with dementia is even more challenging due to the presence of cognitive impairment as those affected may be unable to articulate what is happening to them or to substantiate suspicions of abuse (Selwood and Cooper, 2009).

Early detection of abusive behaviour at any level, even those actions that do not necessarily meet abuse criteria, is recommended to prevent the potential escalation of the behaviour (Selwood and Cooper, 2009). Screening for elder abuse has been identified as good practice as it promotes the detection of abuse and facilitates early intervention (Pisani and Walsh, 2012). However, generic elder abuse screening tools are not appropriate for use with persons with dementia as they are based on the older person's ability to comprehend the questions and responses may present challenges in terms of the reliability of self-reports (Phelan and Treacy, 2011). To date, screening tools tailored for older people with dementia have not been developed (Phelan and Treacy,

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2011). Furthermore, the efficacy of screening for elder abuse of people with dementia is not established (Pisani and Walsh, 2012).

It is believed that screening instruments, which rely on healthcare professionals' assessment of abuse, may be more advantageous than other methods where direct questioning of the older person with dementia is not possible (Pisani and Walsh, 2012). With this approach, a comprehensive multidisciplinary assessment may be conducted in cases of suspected abuse in order to assess warning signs to determine if they are indicative of abuse or attributable to the natural course of a disease (Flannery, 2003; Lachs and Pillemer, 2004; Hansberry *et al.* 2005). In the course of an assessment, a health or social care practitioner can observe the interactions between the older person and the caregiver, talk to other family members and establish caregiving patterns.

Behavioural signs of distress in older persons with dementia can alert healthcare practitioners to the presence of abuse. Distressful behaviours may manifest themselves in the form of avoidance behaviours, such as limited eye contact, withdrawal from interaction, refusal to accept personal care or medication and overt displays of aggression. Changes in sleeping or eating habits, malnourishment, unexplained fractures and bruises, poor personal hygiene, chronic pain, hyper-vigilance, frightening recollections and nightmares are distress signals that could be related to abuse (Flannery, 2003). Behavioural signs of distress in persons with dementia, such as insistent refusal of personal care, assuming a foetal position, displaying fear or strong ambivalence toward a suspected abuser or sudden changes in behaviour might be indicators of sexual abuse (Burgess and Philips, 2006). Many of these indications of abuse cited are consistent with the signs and behaviours associated with dementia; hence careful assessment to determine the cause of altered behaviour is warranted, in order to rule out abuse. Frequent hospital admissions, missed healthcare appointments or sudden changes to daily routine for mobile patients can alert healthcare professionals to the need to investigate the reasons behind such changes (Flannery, 2003).

Cooper *et al.* (2008a) found that clinician screening for abuse was not as sensitive in older people with dementia when compared to caregiver reports of abusive behaviour, due to the fact that people with dementia

tend to sustain more bruises in the course of care provision as a consequence of resisting care. However, the recent focus on identifying forensic bio-markers of elder abuse may assist accurate assessment of abuse perpetration (Fox, 2012). Several studies of elder abuse of people with dementia have reported open disclosures of abuse by caregivers (Cooney and Howard, 1995; Pot *et al.* 1996; Cooney *et al.* 2006; Shaffer *et al.* 2007; Copper *et al.* 2009). Given the difficulty of detecting abuse that is asymptomatic, direct questioning of carers and care-recipients may be more advantageous (Hansberry *et al.* 2005).

Given the high risk of abuse in older people with dementia, incorporating unstructured questioning about abuse into routine assessments with older people with dementia and their carers may provide opportunities to both perpetrators and victims to report abuse (Hansberry *et al.* 2005; Cooney *et al.* 2006; Pisani and Walsh, 2012). Typically, assessments of older people with dementia involve their family or caregivers in order to facilitate communication; however, it is recommended that for assessing suspicions of elder abuse by family members or caregivers, assessments should be conducted with the suspected victim independently (O'Connor *et al.* 2009). For people in more advanced stages of dementia, information can be obtained from people who are close to the older person, provided they are not suspected of perpetrating the abuse (Teitelman and Copolillo, 2002).

Direct, clear and emotionally non-threatening language has been advocated as the most appropriate and effective way to elicit disclosures of abuse from older people with dementia (Teitelman and Copolillo, 2002). Teitelman and Copolillo (2002) suggest a number of appropriate interviewing techniques and accessible approaches that healthcare professionals can use when questioning older people with dementia about abuse, which are especially useful for older people in the early stages of dementia. These include speaking slowly and clearly; adopting a patient tone and demeanour; using short, clear, direct and non-leading questions; posing only one question at a time; asking questions about who, what, when and where, but not why; using language and terminology that is appropriate to the person being interviewed and using visual aids. Healthcare professionals can also infer a lot from older people's body language and voice intonation in response to questioning related to abuse (Teitelman and Copolillo, 2002).

It is difficult for health care professionals to question carers about abuse as they risk making the situation worse, or cause the caregiver to isolate the victim. Investigations of suspicions or allegations of abuse require a particular set of skills and expertise. A sensitive, empathetic and non-judgemental approach towards carers suspected of abuse has been recommended as the best approach for eliciting information (Lachs and Pillemer, 2004; Hansberry *et al.* 2005). Interview techniques, such as asking 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 before proceeding to direct questioning about abuse have been suggested (Cooney and Howard, 1995).

In summary, elder abuse can be difficult to identify. This is particularly so in the case of older people with dementia where cognitive decline can present a barrier to disclosure and mask the abuse. Thus, healthcare and social care professionals have a critical role in preventing and intervening in elder abuse. Given that the risk of abuse is higher in vulnerable older people, such as those with dementia, health professionals need to be equipped with both the knowledge and the tools to recognise the warning signs of abuse in this group. Routine screening for both subjective and objective evidence of abuse, careful interviewing and observations for forensic biomarkers of abuse are all recommended (Pearsall, 2005). Although a number of approaches and techniques to screening for elder abuse among people with dementia are discussed in the literature, no validated screening instruments for use with older people with dementia have yet been reported. With regard to indicators of abuse, behavioural signs of distress are marked out as something that health and social care professionals should pay particular attention to in older people with dementia.

3.6 Strategies and interventions for preventing and managing elder abuse of people with dementia

A report by the US National Research Council on elder abuse research in the United States concluded that 'no efforts have yet been made to develop, implement, and evaluate interventions based on scientifically-grounded hypotheses about the causes of elder mistreatment, and

no systematic research has been conducted to measure and evaluate the effects of existing interventions' (Bonnie and Wallace, 2003: 121). Ploeg and colleagues conducted a systematic review of interventions for elder abuse and their findings reaffirmed the lack of high quality evidence-based research needed to inform the design of effective interventions for elder abuse (Ploeg *et al.* 2009). Few studies of the effectiveness of interventions in ameliorating the risk of elder abuse of people with dementia have been identified.

Anetzberger *et al.* (2000) describe a model of elder abuse intervention designed specifically for older people with dementia. The design of the model focused on improving multiagency collaboration in the management of elder abuse. The model comprised a number of core elements, including 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. Evaluation of the model indicated an improvement in case identification and interagency collaboration (Anetzberger *et al.* 2000); the authors reported that staff and volunteers who had undertaken the training demonstrated increased understanding in a number of areas, although these areas were not described in the paper. There was also no information regarding the content and reliability of the screening tool.

There is a dearth of research examining the efficacy of interventions targeting caregivers, who, because of physical, mental or emotional challenges, possess a higher predisposition to engage in abusive behaviour (Drossel *et al.* 2011). 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 comprised a brief, evidence-based training protocol implemented with the caregivers over a nine-week period. The results showed an improvement in caregivers' psychosocial functioning, indicating the potential of a cognitive behavioural intervention comprising a brief, evidence-based protocol to prevent or ameliorate elder abuse of people with dementia. However, the increased use of individual therapy during the group intervention may have confounded the results of the intervention. Moreover, the effect of the intervention in relation to abuse outcomes was not established and the authors

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noted that during the study, two of the 16 caregivers were reported to the authorities for elder neglect.

Selwood *et al.* (2009) reported that caregivers of people with dementia favour interventions to reduce abusive behaviour, which address the following: medication to help the care-recipient's memory, written advice on understanding memory problems and what to do and more information from professionals caring for the person with dementia. Selwood *et al.* (2009) noted that while medication to address memory disturbance is the most sought-after intervention by caregivers, the efficacy of this type of intervention, in terms of reducing abuse, had not been established.

Mismanagement of dementia care can precipitate abusive action when the carers feel ill-equipped or unsupported in their caring role (Bonnie and Wallace, 2003). Unintentional neglect, also known as neglect by omission or passive neglect, may result from the caregiver's inadequate knowledge of appropriate dementia care (Hansberry *et al.* 2005). Cooney *et al.* (2006) reported that approximately half of carers of older people with dementia expressed the view that information on available services and dementia was inadequate. Accordingly, caregivers of older people with dementia need to receive adequate information and education about the clinical course of dementia and the care-recipient's needs if they are to care effectively and this may prevent abuse (Hansberry *et al.* 2005). Educational initiatives can also challenge the perception that some people hold that abusive behaviour is 'less abusive' when perpetrated against people with dementia (Yan and Kwok, 2011).

Caregivers of older people with dementia have also highlighted the importance of home care and respite care services as measures that would prevent abuse (Selwood *et al.* 2009). It has also been suggested that strategies aimed at reducing caregiver isolation and enhancing social support may be effective in reducing elder abuse of people with dementia (Cooney and Mortimer, 1995; Hansberry *et al.* 2005). However, Cooper *et al.* (2010) suggest that outside help may be experienced as stressful for family caregivers and thus it may not result in a reduction of caregiver abuse. No interventions to test the efficacy of social support interventions in reducing elder abuse of people with dementia were identified in the literature. Mental health professionals have an important

role to play in preventing elder abuse of people with dementia since they may come into contact with them on a regular basis as a consequence of secondary mental health problems or for cognitive capacity assessments (Pisani and Walsh, 2012).

Elder abuse interventions for persons with dementia are complex because of the additional concerns around cognitive capacity as it relates to decision-making. Dementia can affect a person's memory, comprehension and judgement and, as a consequence, it can impair a person's decision-making capacity in some areas of their lives (The Law Reform Commission, 2006). It is challenging for healthcare professionals to determine whether it is appropriate to take action on behalf of older people with dementia, especially in cases where intervention is warranted, but consent is not granted by the older person. Healthcare professionals are bound by professional ethics to respect an individual's autonomy and yet they are obligated to protect vulnerable older people from abuse and neglect (Hansberry *et al.* 2005). The matter is further complicated by the fact that it is often difficult to make judgements about cognitive capacity or decisional capacity, as a person's cognitive status may fluctuate and a person may possess decision-making capacities with regard to some domains of their life, but not others (O'Connor *et al.* 2009).

It is anticipated that proposed legislative changes in approaches to capacity (Government of Ireland, 2008), whereby a functional approach will replace a status approach, will have an impact on capacity assessment. This will mean that capacity will be presumed, unless otherwise stated, and that older people are assessed for their ability to understand and make informed choices for a particular decision at a particular time. However, different standards for assessing capacity combined with clinicians' varying interpretations of standards and operationalization of standards in practice can further complicate the issue of decisional capacity in the context of abuse.

Work undertaken in residential settings for older people with dementia has produced guidelines for healthcare professionals to help them to assess the older person's capacity to consent to sexual activity (Lichtenberg and Strzepiek, 1990). These have facilitated healthcare professionals in their role in determining the capacity of an older person with dementia. The guidelines included

assessing the older person's insight in areas such as knowing who is initiating the sexual contact and if the person can articulate the level of sexual activity with which he or she would be comfortable. Assessment also involves assessing the older person's ability to avoid exploitation, such as their pre-dementia beliefs and values, level of information with which to make decisions and awareness of potential risks of physical or emotional harm (Lichtenberg and Strzepek, 1990). This is particularly pertinent since dementia can lead the older person to be disinhibited and engage in hypersexual behaviours, which would otherwise not be characteristic of their pre-dementia sexual predilections (Singal and Tomar, 2010).

In distinguishing between sexual activity and sexual maltreatment in persons with dementia, Lingler (2003) argues that a person-centred perspective with emphasis on autonomy in decision-making and explicit consent is invalid for cognitively-impaired older persons. Instead the author argues that a relationship-centred perspective focusing on how trust is gained and managed in the context of marked power differentials and vulnerability and the expression of assent and dissent, as opposed to consent to engage in sexual activity, is a better lens with which to examine the issue of sexuality for older people with dementia. In this context, the author asserts that sexual activity between loving spouses may be morally permissible even when one partner has dementia and cannot consent.

The review identified some older UK studies that examined the legal and administrative arrangements for managing the financial affairs of older people with dementia who were deemed mentally incapacitated. Langan (1997) investigated the policies, procedures and guidance issued by twenty-seven local authorities on managing the financial affairs of older people with dementia who lacked mental capacity and found that they were less developed than policies and procedures for safeguarding against other forms of abuse. The author noted an absence of any systematic and transparent approach to the assessment of mental and financial incapacity that would ensure best practice in the management of financial affairs. Means and Langan (1996) examined 'money handling' issues and concerns encountered by 37 social service field staff working with older people with dementia in the community. Fears and anxieties about becoming involved in the financial affairs

of older people who were mentally incapacitated punctuated accounts given by social service staff. In addition, the study findings highlighted the lack of guidance available to staff to enable them to ensure best practice was adhered to.

In summary, caring for an older person with dementia may be a very demanding and challenging role that can sometimes result in altered psychological health for the caregiver. There is very little research evidence to demonstrate the types of interventions that are effective in preventing and managing elder abuse, either with reference to older people in general or specifically in relation to older people with dementia. The model of elder abuse intervention developed by Anetzberger *et al.* (2000) and the cognitive-behavioural training intervention for caregivers developed by Drossel *et al.* (2011) were the only two interventions identified that were designed specifically for older people with dementia. Several authors recommend preventative strategies that aim to complement the social support resources and networks as well as services that are available to caregivers of older people with dementia.

Abusive behaviours are more often than not unintentional, resulting from poor knowledge of good practice in the care of older people with dementia; hence educational resources and interventions that target these knowledge deficiencies are also recommended. Healthcare professionals often have to consider the cognitive or decisional capacity of older people with dementia in the context of abuse prevention and intervention. Standards in relation to capacity in decision making may vary in both interpretation and implementation; hence guidelines to support healthcare professionals when assessing capacity in older people with dementia would facilitate healthcare professionals in their role in elder abuse prevention and intervention.

4. Conclusions

Dementia is a condition that has significant medical, economic and social implications for the individual, his or her family and society. Older people with dementia are particularly vulnerable to the risk of abuse and neglect. This is substantiated by studies revealing a higher prevalence of abuse among older people with dementia, as compared to the general population of community-dwelling older people. The prevalence figures of abuse in older people with dementia are somewhat supported by the reported willingness of their caregivers to disclose abusive behaviour; however, the hidden and discreet nature of abuse makes it likely that any prevalence figures are underestimations of the true extent of the problem. Furthermore, the wide variation in the prevalence figures due to different methodological approaches makes it difficult to ascertain a true picture of the extent of abuse among community-dwelling older people with dementia. Nonetheless, since abuse is markedly higher when compared to the general population of older people, ways of preventing abuse of at-risk older people with dementia need to be developed and implemented.

Research on abuse of older people with dementia tends to focus on psychological and physical abuse and, to a lesser extent, on neglect, largely overlooking other subtypes of abuse, of which financial abuse is the most common. Thus, it appears that researchers have not yet conceived of a way to examine financial abuse in relation to older people with dementia. This is compounded by the fact that the loss of cognitive function demands that finances are managed by someone acting as an asset manager, since the risk of financial abuse is high and harder to detect in cases of altered cognitive function. Psychological abuse is consistently higher when compared to either physical abuse or neglect, and the evidence indicates that when abuse occurs, it is often of more than one type.

In terms of profiling a typical perpetrator of abuse of older people with dementia, no clear perpetrator profile emerged with regard to socio-demographic characteristics; however there is evidence of a higher prevalence of mental and emotional problems among abusive caregivers when compared to caregivers who did not abuse.

Most of the research literature presupposes that stress and burden associated with caregiving in dementia is one of the most significant factors contributing to the risk of

elder abuse. One stressor is the agitated, aggressive and abusive behaviours that people with dementia may exhibit. This review affirms that disruptive or aggressive behaviour by older persons with dementia and the related burden experienced by the caregiver are significant risk factors in reciprocated abuse. Much of the literature relating to abuse of older people with dementia highlights the presence of pre-existing, intra-familial conflict or abuse, and poor interpersonal relationships between caregivers and care-recipients and that such dynamics may explain manifestations of abuse.

The literature also examined other risk factors relating to the level of cognitive impairment and functional impairment in the older person with dementia and social isolation of the caregiver. These factors may be categorised as possible or contested risk factors for which the evidence is limited or inconsistent (Bonnie and Wallace, 2003).

Ascertaining the risk factors that contribute to a higher risk of abuse or neglect in an older person with dementia is important in order to offer appropriate screening for elder abuse and to deliver effective interventions to prevent or ameliorate its occurrence (Bonnie and Wallace, 2003). Research investigating the mediating effects on the relationship between established risk factors and potentially harmful behaviour indicates that there are complex mechanisms involved in elder abuse (Shaffer *et al.* 2007). Thus, research which aims to understand these nuances better may facilitate the development of more tailored intervention programmes targeting specific outcomes. Furthermore, longitudinal studies examining the progression of both the dementia and the occurrence of abuse over time are needed to enable researchers to establish progressive patterns in the nature of abuse and to determine the direction of causal relationships (Bonnie and Wallace, 2003).

Healthcare professionals who routinely come into contact with older people and their carers have a significant role to play in detecting abuse. To date, no abuse screening instruments have been either developed or validated for use with older people with dementia. Despite this, routine, sensitive screening for elder abuse in people with dementia is recommended and there are a number of approaches and techniques that health and social care professionals can use with older people with dementia and their caregivers. Health and social care professionals

often have to make difficult determinations in relation to the cognitive or decisional capacity of older people with dementia in the context of abuse prevention, and intervention and guidelines to facilitate them in making these judgements should be developed. Such guidelines should promote the autonomy of the older person and comply with legislation related to mental capacity assessment. The literature cites potentially useful intervention strategies for caregivers at risk of abuse, including psycho-educational initiatives, counselling group support and respite care services; however, none of these interventions have been comprehensively evaluated.

In conclusion, the literature relating to elder abuse of community-dwelling older people with dementia remains sparse. Although some studies have advanced the knowledge of abuse in people with dementia, there is a considerable gap in knowledge related to elder abuse in this cohort of at-risk older people. This review provides an important source of existing research on the abuse of older people with dementia in the community. It is limited by the focus of the research which precluded self-neglect and the abuse of older people with dementia in institutional settings. Nonetheless, this review highlights the need for further research, in particular the need to ascertain which preventative measures and interventions are most effective in comprehensively addressing elder abuse of people with dementia.

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Table 1 - Elder abuse and dementia: Study designs, samples, prevalence and risk factors

Author/date	Country	Design	Sample	Prevalence	Risk factors
Anetzberger <i>et al.</i> (2000)	US	A model intervention project to improve multiagency collaboration in the management of elder abuse.	Five organisations were involved in the project.		
Compton <i>et al.</i> (1997)	Northern Ireland	Structured interviews.	38 carers of newly referred people aged 65 and older diagnosed with dementia.	Overall prevalence of abuse was 37%. Physical (10.5%) Verbal abuse (34%) No cases of neglect were reported.	A poor pre-morbid relationship, abusive or aggressive behaviour by the person with dementia, carer anxiety and a perception of not receiving help.
Cooney & Mortimer (1995)	UK	A postal survey using a structured questionnaire.	67 carers of people with dementia.	Overall prevalence of abuse was 55%. Verbal abuse (52.2%) Physical abuse (11.9%) Neglect (11.9%).	Physical abuse: higher GHQ12 scores, caring for a greater length of time and physical abuse by the older person with dementia Verbal abuse: poor pre-morbid relationship, verbal abuse by the person with dementia and social isolation. Neglect abuse: poor pre-morbid relationship.
Cooney & Wrigley (1996)	Ireland	A postal survey using a structured questionnaire.	26 persons diagnosed with dementia and their carers.	Overall prevalence of abuse was 30.8%. Verbal abuse (30.4%) Physical abuse (23.1%) Neglect (15.8%).	Mental illness and alcohol abuse.
Cooney <i>et al.</i> (2006)	UK	A postal survey using a structured questionnaire.	82 co-resident carers of people aged 59-96 (average age 78.4 years) with diagnosed dementia.	Overall prevalence of abuse was 52%. Verbal abuse (51%) Physical abuse (20%) Neglect (4%).	Poor relationship quality Verbal abuse: longer breaks from caring, pre-existing history of arguments, behavioural problems in older person with dementia and the 'younger' old. Physical abuse: higher levels of self-reported good health by the carer.

Author/date	Country	Design	Sample	Prevalence	Risk factors
Cooper <i>et al.</i> (2006)	The Netherlands; Czech Republic; England; France; Italy; Germany; Nordic countries.	A cross-national representative study using face-to-face assessments.	Approx 4000 older people in 11 European countries. 13.1% had a dementia diagnosis.		Dementia diagnosis did not predict abuse.
Cooper <i>et al.</i> (2008a)	UK	Face-to-face interviews and observations.	86 people diagnosed with Alzheimer's disease and their carers.	Overall prevalence of abuse was 27.9%. Verbal abuse (27.9%) Physical abuse (3.5%).	Male carers, carer burden, greater care-recipient irritability, greater cognitive impairment, less functional impairment in the person with dementia.
Cooper <i>et al.</i> (2009)	UK	A representative cross-sectional survey and face-to-face interviews.	220 family carers of older people diagnosed with dementia.	Overall prevalence of abuse was 52%. Psychological abuse (33%) Physical abuse (including actual violence and fear of physical violence) (4%) Actual physical abuse (1.4%).	
Cooper <i>et al.</i> (2010a)	UK	Same Cooper <i>et al.</i> (2009)	Same as Cooper <i>et al.</i> (2009)		Spending more hours caring, higher caregiver burden and more abusive behaviour by care-recipients.
Cooper <i>et al.</i> (2010b)	UK	A follow-on longitudinal study from Cooper <i>et al.</i> (2009).	131 carers of older people with dementia.	Increase in any abusive behaviour from baseline to follow up was 48.1% to 61.8%. Increase in significant abuse cases from baseline to follow up was 31.5% to 34.4%.	Increased anxiety, increased depressive symptoms and less initial domiciliary care.

Author/date	Country	Design	Sample	Prevalence	Risk factors
Coyne <i>et al.</i> (1993)	US	A postal survey using a structured questionnaire.	342 caregivers of people with dementia.	Physical abusive (11.9%).	More hours of care per day, caring for more functionally impaired individuals, higher burden of care and depression.
Drossel <i>et al.</i> (2011)	US	An evaluation study of interventions for caregivers at risk of elder abuse.	16 carers.		
Dyer <i>et al.</i> (2000)	US	A case-control study.	45 older people referred to a geriatrics clinic for neglect or abuse. 97 older persons referred for other reasons (non-abuse).		Analysis included case of self-neglect. Race (white); gender (male); diagnosis of depression; diagnosis of dementia.
Homer & Gilleard (1990)	UK	Structured interviews.	51 carers; 48 older people, 21 of who were diagnosed with dementia.		Alcohol consumption by the carer, abuse by the care-recipient; higher depression scores; verbal abuse, a poor pre-morbid relationship and previous abuse over many years.
Holt (1993)	UK	Structured questionnaire.	90 cases of elder sexual abuse by family members or carers.		The most frequently reported impediments in victims were dementia followed by physical frailty.
Kilburn <i>et al.</i> (1996)	US	Secondary analysis of data from Pillemer & Suitor's (1992) study.	202 family caregivers of older people with dementia.		Low self-esteem, living with the care-recipient and disruptive behaviours by the care-recipient.

Author/date	Country	Design	Sample	Prevalence	Risk factors
Kishimoto <i>et al.</i> (2013)	Japan	Face-to-face interviews.	123 Japanese caregivers and older care-recipients with clinically mild cognitive dysfunction.	Overall prevalence of abuse was 15.4%. Psychological abuse (n=19) Physical abuse (n=2) Physical and psychological abuse (n=2).	Gender (male), greater cognitive impairment, greater neuropsychiatric symptoms.
Means & Langan (1996)	UK	Focus groups.	37 social service field staff.		
Langan (1997)	UK	A telephone survey and documentary analysis.	27 local authorities.		
Lee & Kolomer (2005)	South Korea	Face-to-face structured interviews.	481 primary family caregivers of older people with dementia.	Not answered their older family member's question (15.2%) Often yelled at their care-recipients (16.4%).	Less functional impairment, more cognitive impairment, higher caregiver burden and less use of formal services.
Paveza <i>et al.</i> (1992)	US	Postal questionnaire or phone/personal interview.	184 patient-caregiver dyads. Care-recipients were aged 40 or over (average age 74.6 yrs) and living in the community with a dementia diagnosis.	Overall prevalence of violence (either by the caregiver or care-recipient) was 17.4%. Caregiver severe violence (5.4%) Patient violence (15.8%) Prevalence of mutual violence (3.8%).	Violent caregiving relationship, caregiver depression and living arrangement.
Perez-Rojo <i>et al.</i> (2009)	Spain	Telephone interviews.	45 family caregivers of people with dementia aged 55-93.		Caregiving impact, frequency of aggressive behaviours by care-recipient, stress related to aggressive behaviours, frequency of provocative behaviours, interpersonal burden, auto-efficiency expectations, quantity of help received and depression.

Author/date	Country	Design	Sample	Prevalence	Risk factors
Pillemer and Suitor (1992)	US	Face-to-face interviews.	236 family caregivers to older people with dementia.	Physical violence (5.9%).	A spousal relationship, older age and violence by the care-recipient.
Pot <i>et al.</i> (1996)	The Netherlands	Structured interviews.	169 carers of older people with dementia.	Chronic verbal abuse (30.2%) Physical abuse (10.7%).	Living in the same household, caring for male care-recipients, spousal relationship, caring for those with more cognitive impairment, and caring for those requiring more assistance. Verbal abuse: providing more care. Physical abuse: more psychological complaints.
Rowe <i>et al.</i> (1993)	UK	Semi-structured interviews.	25 primary carers of community-dwelling older persons aged 69-93 with dementia who had lost financial competence.		
Schaffer <i>et al.</i> (2007)	US	Face-to-face structured interviews.	417 co-resident caregivers of community-dwelling people aged over 60, 27% of whom were diagnosed with dementia or another memory problem.		Dementia status didn't predict potentially harmful behaviour (PHB).
Selwood <i>et al.</i> (2009)	UK	Same as Cooper <i>et al.</i> (2009)	Sames as Cooper <i>et al.</i> (2009)		
VandeWeerd & Paveza (2005)	US	Structured interviews.	254 caregivers of people aged 60 and over diagnosed with Alzheimer's disease.	Verbal abuse (60.1%).	Gender (female), providing care to verbally aggressive elders, caregivers' lowered cognitive status, high levels of psychiatric symptoms, depression and a high degree of perceived carer burden.

Author/date	Country	Design	Sample	Prevalence	Risk factors
Wigglesworth <i>et al.</i> (2010)	US	Structured interview assessment. Expert panel reviewed data collected.	129 people aged over 50 years diagnosed with Alzheimer's disease and their caregivers.	Overall mistreatment was 47.3% (n = 61). Of these cases, 88.5% experienced psychological abuse, 19.7% experienced physical abuse, and 29.5% experienced neglect.	
Yan & Kwok (2011)	Hong Kong	Structured interviews.	122 family caregivers of older people diagnosed dementia.	Overall prevalence of abuse was 62.3%. Verbal abuse (62.3%) Physical abuse (18%).	Verbal abuse: number of co-residing days, lack of any assistance from a domestic helper, and caregiver burden. Physical abuse: number of co-residing days.

