



Literature review on the abuse, neglect, and exploitation of adults with disability and older people by carers

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Glossary

ABS	Australian Bureau of Statistics
ADC	NSW Ageing and Disability Commission
CASE	Caregiver Abuse Screen
EAHRU	Elder Abuse Helpline and Resource Unit
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
PSS	Personal Safety Survey
PURFAM	Potentials and Risk Factors of Family Caregiving for Older People
REA	Rapid Evidence Assessment
UNCRPD	United Nation Convention on the Rights of Persons with Disability
WHO	World Health Organisation

1 Introduction

With funding from the Department of Communities and Justice, the NSW Ageing and Disability Commission (ADC) commissioned the Social Policy Research Centre (SPRC) at UNSW, in partnership with Carers NSW, to conduct the ADC Carers Project. The aim of the project is to provide the ADC with clear evidence-based findings, recommendations, and advice to inform their work with carers of adults with disability and older people. Specifically, the research is designed to inform the handling of future reports about abuse, neglect and exploitation by the ADC, ways for the ADC and service systems to better support carers, and opportunities for early intervention and prevention strategies. To inform the aims of the project the overarching research questions are:

1. What are the opportunities for early intervention and prevention strategies of abuse, neglect and exploitation of adults with disability and older people by carers?
2. How can communication by the ADC with carers in the context of the ADC's work be made more appropriate and effective?

The project consists of the following components:

- Literature review of previous relevant research studies and literature
- Research report containing analysis of quantitative and qualitative data held by the ADC in relation to reports in 2020-2021¹
- Advice on improving communications with carers and resources to support carers
- Development of resources to support carers

This report presents the findings from the literature review. This review investigates risk factors associated with neglect, abuse and exploitation of older people and adults with disability and evidence of good practice to guide the development of resources to improve communications with and support to carers.

¹ The completed research report has been published separately: Broady, T., Thomson, C., Katz, I., & Judd-Lam, S. (2024). *Informing strategies to prevent abuse, neglect, and exploitation of adults with disability and older people by carers*. Sydney: UNSW Social Policy Research Centre. <https://doi.org/10.26190/unsworks/30104>

2 Background

According to the Australian Bureau of Statistics (ABS, 2018), in 2018 there were 4.4 million people with disability in Australia (representing 17.7% of the Australian population), including 1.9 million who were aged 65 years and over. The ABS further note that Australia's population continues to age, with 3.9 million people (15.9% of the population) aged 65 years and over. Alongside these figures, the ABS reports that 10.8% of Australians (2.65 million people) provide unpaid care to people with disability and older Australians.

ABS defines a carer 'as a person who provides any informal assistance, in terms of help or supervision, to people with disability or older people (aged 65 years and over)' (ABS, 2018). Assistance must be ongoing, or likely to be ongoing, for at least six months. Carers NSW define a carer 'as any individual who provides care and support to a family member or friend who lives with a disability, mental illness, alcohol or drug dependency, chronic condition, terminal illness or who is frail due to age' (Carers NSW, 2020). This definition of a carer is based on the provision of care and support by a person who is not paid and not acting in the capacity of a volunteer. Further clarification of the term carer is found in the NSW *Carers (Recognition) Act 2010* that stipulates 'to avoid doubt', a person is not a carer by virtue of their relationship such as de facto or partner, parent, guardian, child or other relative, or because of co-residence.

2.1 Abuse, neglect, exploitation of older people

Currently in Australia, there is no legislative or purpose-built definition of abuse of older people (Kaspiew et al., 2019). The World Health Organisation (WHO) defines elder abuse 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' (WHO, 2008:1). This definition is used in the National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023 (Australian Government, 2019).

However, instead of the term 'elder abuse', this plan uses the term 'older Australian' because in Aboriginal or Torres Strait culture, the term 'Elder' means community representatives with cultural and other responsibilities. Also, an Aboriginal or Torres Strait Elder is not always an older person (Australian Government, 2019). In this review, we will therefore use the term 'older people'.

In Australia, Kaspiew et al. (2019) proposed a working definition of abuse to address issues of the level of precision needed to assess the prevalence of abuse:

'a single or repeated act or failure to act, including threats, that results in harm or distress to an older person. These occur where there is an expectation of trust and/or where there is a power imbalance between the party responsible and the older person.' (Kaspiew et al., 2019:4).

This definition incorporates five broad elements: the person who experiences abuse; the act or omission; the perpetrator of the act or omission; the circumstances where there is an

expectation of trust between the older person and the perpetrator; and the consequences are based on a broad and multi-dimensional understanding of the harm or distress to the older person.

The definition also encompasses circumstances where there is an imbalance of power in the relationship of trust. In relation to the perpetrator, this definition identifies a range of people with whom the older person has an expectation of trust including family members, friends, professionals and carers (Kaspiew et al., 2019).

Five types of abuse of older people are generally recognised in policy and practice:

- Financial abuse
- Psychological/emotional abuse (including social isolation)
- Neglect (intentional or unintentional)
- Physical abuse
- Sexual abuse (EAHRU, 2016; Dean, 2019)

2.2 Prevalence and risk factors of abuse and neglect of older people

Much of the literature reviewed below addresses abuse of older people in a general sense, rather than specific situations of abuse by carers. It is important to consider this broader context, as well as the specific factors identified in relation to abuse by carers (as will be noted in the review below). The prevalence of abuse and neglect of older people is difficult to accurately determine, with literature reporting a range of estimates. Internationally, a meta-analysis estimated that around 16% of adults aged 60 years and older living at home experienced abuse over a 12-month period (psychological abuse, 11.6%; financial abuse, 6.8%; neglect, 4.2%; physical abuse, 2.6%; and sexual abuse, 0.9%) (Yon, Mikton, Gassoumis, & Wilber, 2017 cited in Dean, 2019). Other international literature has found that neglect is the most common form of abuse of older people, followed by physical abuse (Mercier et al., 2020). Similarly, neglect was the most commonly reported type of violence among older adults registered with Protection and Specialised Care Service to Family and Individuals in Brazil (Estevam et al., 2021).

Within USA Adult Protective Services data, 29% of cases involved some degree of financial exploitation (Burnett et al., 2020), with a minority of these cases (22%) also involving some other form of abuse. Other analysis of Adult Protective Services case record data has shown that neglect of older people most commonly relates to withholding or refusing medical care (Ernst, 2019). Some research in other countries, however, has indicated a higher prevalence of emotional or psychological abuse (e.g., Rekawati et al., 2018). For example, Dasbas and Isikhan (2019) found that emotional abuse was more than twice as common as neglect and five times more common than financial abuse in Turkey.

Financial abuse may take many forms, such as exerting pressure to transfer money or other assets to another, being connived to take out a loan or guarantee a loan, or making decisions that are not in the financial interest of the person. Internationally, risk factors associated with financial abuse of older people include a family member having a strong sense of entitlement to an older person's property or an older person having diminished capacity; an older person being dependent on a family member for care; a family member having a drug or alcohol problem; an older person feeling frightened of a family member; and an older person lacking awareness of his or her rights and entitlements (Bagshaw et al., 2013).

In Australia, although prevalence data is lacking, Kaspiew et al. (2018) estimate that between 2% and 14% of older people have experienced abuse and the prevalence of neglect may be higher. Evidence suggests that most abuse of older people is 'intra-familial and intergenerational, with mothers most often being the subject of abuse by sons, although abuse by daughters is also common, and fathers are victims too' (Kaspiew et al., 2018: 46). The authors note that when adult children are the perpetrators, financial (39%) followed by psychological (38%) abuse were common forms of abuse in Australia, whereas abuse by a partner was more likely to be psychological abuse (41%) (Kaspiew et al., 2018). It is important to note that partners and family members who are the perpetrators of abuse, neglect and exploitation may not be necessarily the carer of that person and the statistical analysis does not identify carers as a particular group distinguished from family members or partners.

In the Australian context, a comprehensive analysis of existing ABS datasets including Australian Personal Safety Survey (PSS) 2005, 2012 and 2016 conducted by Hill and Katz (2019) found that in relation to physical abuse or physical violence, risk factors for older people include: presence of disability; fair or poor health; no social participation; not able to raise \$2000 in a week; presence of cashflow problems; and living in a more disadvantaged neighbourhood (Hill & Katz, 2019).

Discussions of physical abuse of older people in Aboriginal and Torres Strait Islander communities must recognise the context of histories of colonialism and marginalization (Cripps, 2008, cited in Hill & Katz, 2019) and ongoing trauma. Although not comparable to the other ABS datasets, analysis of the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) indicated that increased risk of abuse was associated with: self or family members ever removed; ever homeless or recent homelessness; financial stress; poor health; presence of a disability; and high levels of stress. The authors note that it was not possible to establish the direction of causality (Hill & Katz, 2019).

In Australia, Hill and Katz note that existing ABS datasets are a limited source of information about types of abuse of older people such as neglect, financial, emotional-psychological or sexual abuse compared to physical abuse (Hill & Katz, 2019). There is therefore a need for more targeted research to investigate risk and protective factors related to these forms of abuse in Australian contexts.

Overall, a range of factors have been found to be associated with abuse of older people, both generally and specifically related to carers. These factors relate to the older people,

perpetrators, relationships, and contextual factors. Evidence suggests that social isolation and poor-quality relationships are key risk factors for abuse of older people living in the community (Dean, 2019, Hill & Katz, 2019). In addition, the presence of a disability, poor health, financial stress and living in more disadvantaged areas were also associated with abuse of older people. Social support and healthy relationships have been identified as key protective factors for the prevention of abuse and neglect of older people (Dean, 2019).

2.3 Prevalence and risk factors of abuse and neglect of adults with disability

Similar to abuse and neglect of older people in Australia, there is no consistent approach to defining abuse neglect and exploitation for people with disability. In recognition of social and other barriers to participation in different aspects of life for people with disability, the United Nation Convention on the Rights of Persons with Disability (UNCRPD) defines disability as an 'interaction between persons with impairments and attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others.'²

Research shows that people with disability, both men and women, are more likely to experience abuse, neglect and exploitation compared to people without disability (Sutherland et al., 2021; Koh et al., 2021). Risks factors associated with abuse for people with disability are being female, past experiences of violence of abuse, low socioeconomic status or poverty, and psychological and cognitive impairments (Sutherland et al., 2021; Koh et al., 2021). In Australia, an analysis of the ABS 2016 PSS conducted by Sutherland et al., (2019) showed that 64% of people with a disability experienced all types of violence (physical violence, sexual violence, intimate partner violence, emotional abuse and/or stalking) in comparison to 45% of those without disability (Sutherland et al., 2021). Over 50% of people with disability reported experiencing physical violence compared to around one-third of people without disability and one-fifth of people with disability experienced sexual violence compared to 10% of those without disability (Sutherland et al., 2021). Around one-third of people with disability experience emotional abuse, compared to 10% of people without disability (Sutherland et al., 2021). The analysis showed that one-quarter of people with disability experienced violence from their intimate partner. However, data on carers as perpetrators of violence or abuse is not available in the PSS and as noted above, a partner should not necessarily be assumed to be a carer.

² Convention on the rights of a person with disability, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 29.

3 Literature review method

The literature review undertaken for this project was completed in December 2021 and comprised a rapid evidence assessment (REA) of Australian and international literature. Rapid reviews are designed to synthesize information in a shorter timeframe than a systemic review but are more rigorous than ad hoc literature searching. Literature searches can be limited by the number of databases used and covering particular time periods. However, transparent methods for conducting the searches are used so that they can be replicated. The focus of the review and research questions investigated tend to be narrower than those in a systematic review. This REA examined the following research questions:

1. What are the risk factors associated with neglect, abuse and exploitation of older people and people with disability?
2. What is the evidence of good practice of effective interventions and prevention strategies that target carers as the perpetrators of abuse, neglect and exploitation of older people and people with disabilities?

This REA focused on:

1. The abuse, neglect, and exploitation of adults with disability and/or older people by carers,
2. Support for carers of adults with disability and/or older people, and
3. Carer stress relating to caring for adults.

In addition to the REA, unpublished data from the Carers NSW 2020 National Carer Survey regarding carer distress and wellbeing, relationships, and access to support was analysed to supplement the review of published literature.

3.1 Literature search

The literature search involved a scan of academic literature, and identification of the state of knowledge on the factors associated with abuse, neglect, and exploitation by carers. The following databases were used for the literature search:

- Social Sciences Citation Index
- Medline
- PsycINFO
- CINAHL
- Scopus

The database search was limited to the last 10 years of literature, published between 2012 and 2021.

Key words searches were conducted using combinations of the following:

- Abuse
- Neglect
- Exploitation
- Carers
- Caregivers
- Older people
- Adults with disability

The initial search of the databases yielded 587 articles. Articles were selected if they focused on carers, however, definitions of 'carers' varied between studies (see Table 1 for an example of some of the definitions from included articles). Initially the articles were screened on the basis of title and then abstract. Articles were excluded if they concerned paid carers or volunteers and were not in English. The selection process produced 53 studies which were included in the review. Studies were not assessed for quality prior to their inclusion in the review, however, individual study limitations have been highlighted in the following sections where relevant.

These articles predominantly related to abuse of older people with limited research identified on abuse of adults with disabilities by carers. Additional searches on Google, government websites and other organizational websites yielded additional reports and research papers, the majority of which were not specifically focused on abuse by carers and included abuse by paid carers, service providers, and staff in residential settings. However, these reports and research papers have been included to provide contextual information and an overview of the factors associated with abuse, neglect and exploitation of older people and adults with disability.

In the studies reviewed, the term 'carer' (or 'caregiver') referred to different types of carers, in different caring contexts and providing varying levels of support. Table 1 provides some examples of the varying definitions of carers and different types of carers in the literature reviewed.

Table 1: Example of definitions and types of carers

Study	Description of type of carer included in research study
Ezalina, et al, 2019	Families who were the primary caregivers of an elderly person (60+ years) who was not bedridden, either living with the elderly person or living within the same city
Lin, 2018	Aged 18 years and older and who cared for a family member aged 65 years or older
Mahmoudian et al., 2021	Caring for an older adult under hemodialysis, being a relative of that person and not have other caring responsibilities and no self-reported physical or mental illnesses
Orfila et al. 2018	Family caregivers that, for at least the past 3 years, had taken care in their own homes of individuals aged over 65 years of age with moderate to total dependency
Pickering et al., 2020	Family caregivers who lived with a care recipient with Alzheimer's disease and related dementia

3.2 Carers NSW 2020 National Carer Survey Method

This survey was conducted nationally for the first time in 2020. Sampling for the survey was based on self-identification as a carer who is, or has been, providing unpaid care. Participants were recruited via the websites and social media accounts of Carers NSW and other state and territory Carer Associations. The survey contained questions about the caring relationship, services and support, paid work, health and wellbeing and demographics. The survey was conducted online, and a paper version was also available. A total of 7,735 valid responses were received from carers in every state and territory of Australia. South Australia, New South Wales, Victoria and Tasmania had the highest response rates. The sample contained 92.8% current carers and 7.2% former carers. As the sample was predominantly recruited through Carer Associations communication channels, it is likely that the sample over-represents carers in contact with services and those who identify as a carer. The survey sample is not statistically representative of the broader population of Australian carers (Carers NSW, 2020).

4 Findings from the review of literature

This section reviews research identified in the REA in relation to abuse by carers of older people and people with disability. The research identified through the database search predominately focused on abuse of older people, with less specifically focused on adults with disability. Another gap identified in the REA was research on the prevalence of abuse of older and people with disability by carers, both in Australia and internationally. Rapid assessment of international literature identified in the searches suggests that cultural issues are likely to impact abusive situations in caring relationships. For example, Nguyen et al. (2016) compared English- and Spanish-speaking carers in the USA and found that Spanish-speaking carers defined abuse more broadly than English-speaking carers (including issues of disrespect for the elderly) and were more likely to acknowledge that abuse could occur in the home, rather than primarily in institutional contexts. Within a sample of 1,002 caring dyads in China, 40% of those who experienced abuse were related to carer neglect, 33% related to financial exploitation, while significantly smaller proportions were related to psychological or physical abuse (10% and 1%, respectively) (Fang et al., 2019).

Below, the carer characteristics associated with abuse are outlined, followed by research examining the characteristics of care recipients associated with abuse, and broader contextual factors. The final section reviews evidence of good practice to support carers and the prevention of abuse.

4.1 Factors associated with abuse, neglect and exploitation by carers

While caring relationships between carers and family members or friends are typically based on trust and empathy, it is acknowledged that some carers do perpetrate abuse, neglect, and exploitation. It is therefore important to understand risk factors involved in these situations to assist in identifying and preventing abuse from occurring. A recent systematic review found that abuse within caring relationships is a broad and more complex phenomenon than has previously been understood (Valimaki et al., 2020). The characteristics associated with abuse of older people can differ according to the type of abuse in question and by the operational definition used (Dong et al., 2014). Overall, the literature points to a number of risk and protective characteristics associated with carers, care recipients, and broader cultural or systemic issues, many of which are common across different international settings (Melchiorre et al., 2017). Furthermore, several theoretical approaches to understanding this abuse were described in the reviewed literature.

4.1.1 Theoretical approaches

The theoretical approaches reported in the reviewed literature typically identified broad categories of risk or protective factors related to abuse within caring relationships. For example, Valimaki et al. (2020) describe a dyadic approach to understanding abuse of older people by their carers that makes a key distinction between 'risk' factors (connected to the

role of carer) and 'vulnerability' factors (associated with care recipients). These factors are broadly categorized into 'personal', 'physical and psychological', and 'social' domains, each of which are argued to hold potential for increasing the likelihood of abuse or preventing it. A risk and vulnerability framework suggests that the 'vulnerabilities' that are characteristic of care recipients interact with risk factors in the wider environment (including carer characteristics and broader social contexts) to result in abuse and/or neglect (Ernst, 2019). The concept of vulnerability on the part of care recipients within caring relationships is also a key component of sociocultural conceptual frameworks (Dong et al., 2014), attributional conceptualisations of abuse (Ostaszkievicz, 2018), ecological models (von Heydrich et al., 2012) and power-based frameworks (Lin & Giles, 2013).

An alternative theoretical approach to understanding abusive behaviour among carers draws on a stress-process model (e.g., Pickering et al., 2020; Serra et al., 2019). According to this model, abuse is an outcome, which is a response to stressors experienced in a caring role (e.g., high levels of carer burden, care recipient behavioural difficulties). While some situational factors can increase the risk of abuse and neglect, others may act in a protective manner, mitigating the effect of stress or preventing risk factors for abuse developing. Variations in day-to-day living (and caring) therefore play an important role in whether or not a carer behaves in an abusive or neglectful manner at any particular time (Pickering et al., 2020). In addition, carers' individual characteristics (e.g., coping strategies, mental health, personality) can potentially mediate relationships between stressors and abuse of care recipients (Serra et al., 2019).

4.1.2 Carer characteristics

Demographics and personality

Literature has identified a range of demographic variables that have been associated with increased risk of perpetrating abuse or as protective factors against it. For example, lower levels of carers' formal education and less knowledge about care recipients' disabilities and/or health conditions have been shown to be risk factors for abuse occurring within caring relationships (Valimaki et al., 2020). Similarly, lower socioeconomic status among both carers and care recipients has been identified as a risk factor for abuse of older people, particularly not being able to afford housing, medical care/medication, and food (Burnett et al., 2020; Mercier et al., 2020). Older people's inability to afford living expenses has been specifically associated with their financial exploitation (Burnett et al., 2020), while family poverty has been specifically associated with psychological abuse of older people by carers, and younger carers and co-residence have been associated with financial exploitation (Fang et al., 2019). Carers' low income has been associated with the risk of perpetrating both physical and psychological abuse towards people living with dementia (Kim et al., 2018).

In a study utilising data from the National Health and Aging Trends Study and the National Study of Caregiving (USA; n=1,366 older adults with disabilities and n=1,996 carers), younger carers, sons as carers, not living with care recipients, and having paid care workers to supplement care needs were all associated with unmet needs and risk of neglect among adults with disabilities (Beach & Schulz, 2017). The analyses undertaken for this study were

cross-sectional, therefore causal relationships could not be inferred. For example, it should not be assumed that supplemental paid care is a risk factor for unmet need, as those with unmet needs in relation to instrumental activities of daily living may be more likely to seek additional paid care support.

In a sample of 800 Chinese carers, higher levels of neuroticism (as measured by the neuroticism subscale of the NEO Five-Factor Inventory; Costa & McCrae, 1992) were found to be associated with an increased level of physical and psychological abuse over a two-year period (Fang et al., 2021). It is worth noting that this study utilised a convenience sampling approach from geriatric and neurologic departments of three hospitals in China, so findings may not be generalisable to broader carer populations. This study further found that changes in carers' perceived burden changed the relationship between neuroticism and risk of abuse (see 'Carer burden' section below). Neuroticism was also associated with increased likelihood of neglect, though this was independent of changes in perceived burden (Fang et al., 2021). In a qualitative study comparing English-speaking (n=8) and Spanish-speaking (n=8) carers, Nguyen et al. (2016) found that most English-speaking carers considered factors such as temperament and emotional detachment to be the main cause of abuse by carers, while Spanish-speakers suggested abuse would result from caring for the 'wrong reasons' or lack of knowledge of the older person being cared for.

The reviewed literature identified a range of demographic and personal characteristics that have been associated with abuse by carers. It is important to note, however, that these studies were typically cross-sectional in nature, so it should not be assumed that these factors are direct causes of abuse. Rather, they provide some insight into certain contexts where abuse may be more likely to occur.

Carer burden

Literature widely suggests that higher levels of care burden experienced by carers is associated with increased risk of abuse of older people (Johannesen & LoGiudice, 2013; Kohn and Verhoek-Oftedahl, 2011; Mahmoudian et al., 2021; Orfila et al., 2018; Perez-Rojo et al., 2015; Touza & Prado, 2019; Twomey, 2018; Yan, 2020). Severe carer burden has been associated with the risk of both physical and psychological abuse from carers of people with dementia in Korea (Kim et al., 2018). Similarly, high levels of carer burden have been associated with substandard care for adults with disabilities and a risk for neglect (Beach & Schulz, 2017). The clear association between carer burden and risk of abuse should be considered in light of the self-reported data collection methodologies utilized in most of these studies. This approach may result in some under-reporting of abusive behaviour, but nonetheless, still highlights the significance of carer burden as a risk factor for abuse.

The association between carer burden and risk of abuse of older people is particularly pertinent when considering the substantive role undertaken by many carers on a daily basis. Unpublished data from the Carers NSW 2020 National Carer Survey indicate that 28% of carers of older people and 31% of carers of adults with disability reported being unable to leave their care recipient alone for more than one hour (Carers NSW, 2020). Additionally,

44% of carers of older people and 49% of carers of adults with disability reported that they provided more than 60 hours of care per week (Carers NSW, 2020).

As well as experiences of burden, carers' willingness to take on caring responsibilities and their ability to cope with difficult situations can affect the likelihood of abuse of older people occurring, with abuse more common among carers who perceive their caring role as an unwanted burden (Touza & Prado, 2019). This is particularly noteworthy, given that 70% of Australian primary carers report family responsibility as a reason they took on their caring role, 47% felt an emotional obligation, and 22% felt they had no other choice (ABS, 2018). As noted above, carer neuroticism has been associated with increased likelihood of physical and psychological abuse in a longitudinal study of Chinese carers recruited through three hospitals. Decreases in carers' perceived burden, however, prevented any increase in abuse over a two-year period (Fang, et al., 2021). While the sampling approach of this study means results are not necessarily generalisable to wider carer populations, they do support the hypothesis that reducing carer burden is a protective factor for preventing the abuse of older people.

Potentially harmful behaviour from carers has been independently associated with scores on the Zarit Caregiver Burden Interview when controlling for a range of other factors, including care recipients' behavioural and psychological symptoms, and the relationship between carer and care recipient (specifically, daughter-in-law carers) (Toda et al., 2018). Alongside increased subjective reports of burden, spending more hours per week caring has been associated with risk of abuse in a Spanish sample of carers (Serra et al., 2018). Physical and emotional exhaustion, along with frustration associated with an inability to manage health-related symptoms and resentment due to lifestyle limitations imposed by caring roles are theorized to contribute to abuse in caring relationships (Ostaszkiwicz, 2018). Results from Carers NSW 2020 Carer Survey show that carers of people with disability spend significantly more time providing care than those providing care for other reasons (e.g., mental illness, chronic health conditions, or frail aged; 81 hours per week vs. 62 hours per week) (Carers NSW, 2020). The high level of care provided by all carers in this national sample highlights the potential for considerable stress that can impact all carers, especially in situations of caring for a person with disability.

Only one study identified in this literature review explicitly found no correlation between caring burden and mistreatment of older people (Rekawati et al., 2018). However, this study was based on a relatively small sample (n=135), the majority of whom indicated that they experienced no burden in caring for their elderly relative. On balance, the reviewed literature overwhelmingly indicated that carer burden is a significant risk factor for the abuse of older people.

While burden has been widely associated with instances of abuse by carers, research has also shown that there are multiple factors associated with the burden experienced by carers in their roles. These associations suggest that carer burden should not be considered a primary cause of abuse of older people (Chow & Tiwari, 2014). The significance of carer burden in relation to abuse of care recipients highlights that abusive or neglectful behaviour

should not be assumed to be malicious but should be considered in the stressful and often distressing contexts of high intensity caring (Brown, 2012).

Physical and mental health

“It truly has become almost overwhelming mentally and emotionally and in recent years has become extremely difficult physically.”

(Carers NSW 2020 National Carer Survey participant)

Issues of carer burden are closely related to both physical and mental health outcomes. In general, the reviewed literature referred to burden in the context of the amount of time per week spent caring or carers’ subjective experiences of feeling overworked. These experiences of burden can therefore relate to carers’ health, both physical and mental. It has widely been shown that carers experience poorer physical and mental health outcomes than their non-caring peers. According to the Carers NSW 2020 National Carer Survey, 41% of carers of older people and 47% of carers of adults with disability report high or very high levels of psychological distress (Carers NSW, 2020). This supports findings from the 2018 SDAC, where primary carers were significantly more likely to report high or very high levels of distress than people who were not identified as carers (27% vs. 19%) (ABS, 2018).

Poor carer physical health has been associated with neglect of their care recipients (Beach & Schulz, 2017; Fang et al., 2019) and has also been found to be consistently correlated with psychological abuse and neglect by carers across various definitions of those types of abuse (Dong et al., 2014). Carer physical and mental health have both been identified as prominent features related to carers’ difficulties in their caring roles within Adult Protective Services case records in the USA (Ernst, 2019). While the results of these studies are not able to infer that poor physical health is a causal factor for abuse, these associations across multiple studies suggest that health-related services may be an important consideration in supporting carers both generally and in the specific context of preventing abuse.

Issues of carers’ mental health are commonly reported in relation to situations of abuse, particularly anxiety and depression (Kohn and Verhoek-Oftedahl, 2011; Orfila, et al., 2018; Perez-Rojo et al., 2015; Twomey, 2018). A number of studies have reported that increased anxiety and depressive symptoms among carers have been associated with mistreatment of older people (Orfila et al., 2018; Twomey, 2018), though no causal relationships were reported in the reviewed literature. In the context of dementia, a recent systematic review of 81 original studies found that carer distress was commonly associated with worsening behavioural and psychological symptoms, and the presence of abuse of older people (Stall et al., 2019). Another systematic review found that carers’ psychological issues (including quality of life, distress, anxiety, and depression) are a key factor influencing abuse in caring relationships between older people with memory disorders and their family carers within the home (Valimaki et al., 2020). A scoping review of research conducted in emergency department settings found that psychiatric and substance use disorders are more prevalent among both carers and older people who are victims of abuse (Mercier et al., 2020). Carers’

substance use has been specifically associated with neglect of older people (Fang et al., 2019), with some studies reporting upwards of 1 in 4 alleged perpetrators having substance use problems (Conrad et al., 2019). Substance abuse among perpetrators has been associated with financial exploitation, physical abuse, and emotional abuse, but not neglect, however, perpetrators with substance abuse issues tended not to be carers (Conrad et al., 2019). In an analysis of individuals registered with Protection and Specialized Care Service to Family and Individuals in Brazil, more than half were suspected of having a mental health disorder and almost 40% reported suicidal ideation (Estevam et al., 2021). Negative psychosocial impacts of caring may contribute to the provision of substandard care and therefore be a risk factor for neglect of adults with disabilities (Beach & Schulz, 2017). Each of these studies has been limited to a specific context of care. While the results of each may not be generalisable to wider carer populations, there is some consistency in findings that suggest mental health concerns are associated with situations of abuse. Approaches to supporting carers should therefore consider the associated mental health factors as one possible avenue of contributing to the prevention of abuse, as well as more generalised support for carers.

While mental health issues have been identified as risk factors, resilience (i.e., the abilities and personal resources of individuals that allows them to successfully deal with adverse situations) has been identified as a particularly strong protective factor, remaining significant even after controlling for the effect of caring burden (Serra et al., 2018). Resilience was conceptualised at an individual level in this study, however, broader social contexts can significantly affect resilience among individuals and therefore act as either a protective or risk factor for abuse.

“Even the most resilient person who may seem to be coping, cannot go through this without profound emotional and psychological stress and impact.”

(Carers NSW 2020 National Carer Survey participant)

Social factors

Alongside individual factors, carers' social environments can be important contextual factors in relation to abuse. Social isolation is associated with caring responsibilities, and this isolation contributes to complex situations where abuse may occur (Valimaki et al., 2020). Having fewer social contacts and increased social isolation have been correlated with increased likelihood of abuse of older people (Johannesen & LoGiudice, 2013; Mercier et al., 2020; Twomey, 2018). The Carers NSW 2020 National Carer Survey found that approximately 1 in 3 carers of people with disability reported high levels of social isolation and 1 in 4 reported low levels of social support (Carers NSW, 2020). Similarly, 1 in 4 carers of older people reported high levels of social isolation (Carers NSW, 2020). Given the potential for social factors such as these to contribute to instances of abuse, the high prevalence of social isolation and low levels of social support reported among these sample of carers highlight a need for preventative action. Other social factors, such as the

stigmatised nature of some conditions or disabilities can also contribute to situations where abuse exists (Ostaszkiwicz, 2018).

Summary

Overall, the reviewed research shows that mental health is a key factor in abuse by carers. High levels of carer burden and carer stress and poor physical health were also commonly identified factors in the literature sourced for this review. The studies identified for this review predominantly utilised cross-sectional designs, meaning causality cannot be inferred. Therefore, while each of these factors have been associated with abuse, they should not be perceived as direct causes of abuse. Access to social support provides a protective effect on abuse, even when controlling for other covariates (Serra et al., 2018). Notwithstanding the limitations of individual studies, the findings outlined above suggest a range of areas where carers may be supported, and which may also contribute to the prevention of abuse. The next section outlines the characteristics of care recipients that are associated with abuse by carers.

4.1.3 Care recipients

Functional level

As noted above, carers' perceived burden in their caring role has been identified as a risk factor for abuse. Similarly, care recipients who demonstrate more impaired levels of functioning have been found to be at higher risk of abuse (Johannesen & LoGiudice, 2013; Mahmoudian et al., 2021; Valimaki et al., 2020; Sathya & Premkumar, 2020). A recent review of the literature emphasized that functional disability, frailty, and cognitive impairment have all been found to relate to risk of abuse (Mercier et al., 2020). Cognitive decline has been associated with abuse from carers (Touza & Prado, 2019) and older Iranian people who have greater need for a carer have been found to be more likely to experience abuse (Rohani et al., 2019). Neuropsychiatric symptoms and cognitive impairments among older people are prominent risk factors for experiencing abuse (Fang et al., 2019), and poor physical health in general appears to leave older people more susceptible to being abused (Dasbas & Isikhan, 2019; Dong et al., 2012). Results from the Chicago Health and Aging Project suggest that older people recording the lowest levels of physical performance were the most at risk for psychological abuse, financial exploitation, and neglect by their carers (Dong et al., 2014). In addition, the mental health of older people (particularly depression) has been identified as a risk factor for experiencing abuse (Rohani et al., 2019). The context of each of these studies was varied, however, there was a consistent theme running through whereby care recipients with lower levels of functioning were found to be more vulnerable to abuse by their carers. As with the carer-related factors outlined previously, the evidence does not imply that functional level is a causal factor for abuse, however, it does highlight an important contextual factor that has widely been associated with abusive and/or neglectful behaviour.

Behaviour

Carers' reactions to care recipients' problem behaviours have also been identified as relating to abuse of older people (Johannesen & LoGiudice, 2013; Orfila et al., 2018; Perez-Rojo et al., 2015; Yan, 2014, Yan 2020). Adult Protective Services data from the USA suggest that victim suicidal ideation and threatening behaviours are both significant factors in differentiating financial exploitation from other forms of mistreatment (Burnett et al., 2020). Specifically, these behaviours were more strongly associated with other forms of mistreatment (i.e., emotional/verbal abuse, physical abuse, or neglect) than with financial exploitation. Behavioural symptoms are particularly relevant in the context of dementia. When older people with dementia exhibit more challenging behaviour, carers may be more likely to justify various forms of maltreatment (Rivera-Navarro & Contador, 2019). Physical or psychological aggression from care recipients, including in the forms of agitations and irritability, puts them at greater risk for experiencing abuse (Orfila et al., 2018; Twomey, 2018). dyads

It has been theorized that behavioural issues trigger feelings of powerlessness and loss of control among carers, which may contribute to their use of abusive behaviours, including physical abuse, verbal abuse, or neglect, in order to facilitate compliance from the care recipient (Lin & Giles, 2013). According to this model, abusive behaviour from carers should be understood in the context of power and control within the caring relationship, and the fact that carers may feel they have no control over their circumstances. The main theoretical approaches identified in the reviewed literature refer to risk and vulnerability factors related to carers, care recipients, and their broader context (e.g., Ernst, 2019; Valimaki et al., 2020), and also the potential influence of stressors on abusive behaviour (e.g., Pickering et al., 2020; Serra et al., 2018). The various theoretical approaches highlight the complexities of the many situations that result in abuse of older people and adults with disabilities.

The impact of care recipient behaviour on abuse by carers is particularly significant, as situations can also arise where carers are the victims of abuse. Literature is inconsistent in terms of definitions and measures of abuse directed towards carers, and it is a topic often hidden within the broader caring context (Isham et al., 2019). Some research has suggested that rates of abuse of older people by carers and rates of carer abuse by older people are similar. For example, Ozcan et al. (2017) conducted a descriptive, cross-sectional study of older people and their carers, with 69% of older people reporting exposure to any form of abuse by their carer and 73% of carers reporting exposure to any form of abuse by the older person they cared for. It should be noted, however, that this research involved a relatively small sample (n=186 older people and n=136 carers) recruited via a convenience sampling approach at a single medical centre. Therefore, the rates of abuse self-reported by this group may not be generalisable to broader caring contexts. Carers who experience abuse from those they care for face particular challenges in sharing their experiences and accessing appropriate support. Carers may be sensitive to anticipating stigma or feel reluctant to reveal these issues of abuse due to perceptions of the private aspects of caring relationships (Isham et al., 2020). Challenges can also exist for carers of adult children with disability or mental illness who experience abuse as they consider their own need to avoid abuse alongside their adult child's need for care and support (Band-Winterstein et al., 2014).

Additional research is warranted to investigate abuse experienced by carers, any associated factors, and the implications for abuse of care recipients.

“Caring for my person with disability has affected my physical and mental health. I now have chronic pain and health issues due to stress and physical assaults by one of the persons I care for.”

(Carers NSW 2020 National Carer Survey participant)

4.1.4 Relationships

Instances of abuse, neglect, or exploitation involving carers occur within the context of a relationship. Relationship dynamics therefore play a major role, particularly in long-term caring situations. Carers’ self-reported perceptions of relationship quality over time (including prior to caring responsibilities) has been shown to be a factor contributing to likelihood of abuse, with less relationship satisfaction on the part of carers being associated with increased risk of abuse and more positive past relationship reducing the risk of abuse of older people by carers (Johannesen & LoGiudice, 2013; Orfila et al., 2018; Serra et al., 2018; Touza & Prado, 2019; Valimaki et al., 2020). In a systematic review, Johannesen and LoGiudice (2013) found that relationship quality (specifically family disharmony and poor or conflictual relationships) was among the risk factors with the highest odds ratios for predicting abuse by carers in studies of older people requiring assistance with activities of daily living, older people with dementia, and general populations.

Relationship quality and satisfaction can be particularly complex in situations where a carer takes on caring responsibilities for a family member who was abusive towards them earlier in life (Isham et al., 2019). Shifting dynamics of power within these relationships and increasing vulnerability of a previous perpetrator of abuse can impact the likelihood of a carer perpetrating abuse or neglect. The quality of relationship between carers and their elderly parents has been shown to mediate relationship between other risk factors and the enacting of abuse (e.g., health, social isolation) (von Heydrich et al., 2012). Alongside positive relationship experiences, a stronger sense of familism has also been identified as a protective factor for abuse of older people (Fang et al., 2019). Similarly, recent conflict within the relationship has been identified as a key factor in differentiating financial exploitation from other forms of abuse (Burnett et al., 2020).

“My relationship with the person I care for broke down over time and it became extremely stressful and slowly my life became focused on caring with inadequate external supports available to help.”

(Carers NSW 2020 National Carer Survey participant)

Not only does previous relationship history play a role, recent research from the USA has identified the importance of ongoing investment in a positive caring relationship. Specifically,

participating in meaningful activities with care recipients was identified as a significant protective factor against neglectful behaviour, though not necessarily abusive behaviour (Pickering et al., 2020). Conversely, increased levels of verbal abuse have been associated with more days of co-residency between carers and people with dementia (Yan, 2014).

4.1.5 Cultural/Systemic issues

The complexity of caring relationships in which abuse may occur can be further compounded by broader contexts, including service systems and culture. For example, it has been suggested that the social isolation and perceived carer burden that may contribute to instances of abuse could be mitigated through community-based long-term care (Valimaki et al., 2020). However, families and carers often feel pressure to avoid long-term or institutional-based care arrangements. This pressure may result from care recipient preferences to receive informal care from family members (rather than formal care providers) or could be enacted by other family members and cultural groups, or from systems based on a preference to allow older people to remain in their own homes. Cultural norms can also dictate a privacy element to care, thereby limiting access to various supports and contributing to a context where abuse may be more likely to occur (Ostaszewicz, 2018). Current practices such as these add further to the complexity of caring relationships and may indirectly contribute to situations where abuse can eventuate (Valimaki et al., 2020). A lack of support from formal services (whether due to accessibility issues or refusal to accept services) is a predominant theme in Adult Protective Services case records (Ernst, 2019).

4.1.6 Summary

Overall, the research shows that several care recipient characteristics are associated with abuse by carers, most notably high levels of impaired functioning and behavioural problems and the quality of relationship (including relationship history) between care recipients and carers. However, these characteristics should not be considered in isolation as they impact on the caring role and can contribute to increased carer burden. Also, a lack of access to support services in turn can add to carer burden.

4.2 Good practice

Australian and international research evaluating the effectiveness of interventions that target carers as the perpetrators of abuse, neglect and exploitation is lacking (Ayalon et al., 2016). A systematic review of interventions for abuse of older people that were implemented in a variety of settings and aimed to address prevention in multiple ways found that the evidence regarding the effectiveness of these interventions in reducing or preventing abuse was weak and insufficient (Marshall et al., 2020). However, some promising practices were identified. For example, education-based interventions were associated with increased knowledge and recognition of abuse among older adults, and increased reports of abuse (Alt et al., 2011; Day et al., 2017; Marshall et al., 2020). Australian research has also suggested that family mediation can effectively resolve issues of abuse by identifying core problems related to abuse, empowering older people to make decisions, and resolving underlying conflict (Bagshaw et al., 2015; Dow & Brijnath, 2019). Helplines that offer information, advice, or assistance regarding adult abuse have also been argued to show promise (Twomey, 2018).

A Cochrane Review on preventing abuse of older people identified the following categories of studies: 1) education; 2) programs to reduce risk factors; 3) policies related to abuse of older people; 4) legislation related to abuse of older people; 5) programs to improve the detection of abuse of older people; 6) programs for elderly victims of abuse; 7) rehabilitation programs for perpetrators of abuse of older people (Baker et al., 2016). Due to a range of methodological issues and constraints, the review could not determine whether the studied interventions were effective in reducing the occurrence of abuse of older people. In particular, it was unclear how effective education programs were in increasing carers' knowledge related to abuse of older people due to the low quality of the evidence reviewed (Baker et al., 2016).

4.2.1 Carer focused research

Much of the existing research recommends that preventative measures to support carers are likely to be the most effective in reducing incidents of abuse (Yan, 2014), however, empirical evidence is lacking. For example, an evaluation of the START initiative (StrAtegies for RelaTives) found a positive effect on carer anxiety and depression, but no evidence of reducing carer abusive behaviour (Cooper et al., 2016). The authors noted, however, that there are difficulties in conducting an evaluation of such a program, such as the ethical ramifications of excluding a control group from needed support. Therefore, it is difficult to identify intervention effects.

Practical supports and interventions to relieve caring burden and support carers' mental health have been suggested, particularly nursing and medical care, homecare assistance, respite, and carer support groups (Twomey, 2018). Findings from the Carers NSW 2020 National Carer Survey further highlight specific areas of support where carers report significant unmet need (see Table 2). Across each support type listed, significantly more carers of older people and carers of adults with disability reported that they need more access than reported they currently used the support. Addressing these unmet support needs may therefore be an important factor in reducing the risk of abuse occurring.

Table 2. Carers' use of different types of support and unmet need (Carers NSW, 2020)

Support type	Carers of older people		Carers of adults with disability	
	Currently use	Need more	Currently use	Need more
Face-to-face peer support	19%	30%	19%	35%
Online peer support	14%	20%	17%	22%
In-person counselling	11%	33%	10%	37%
Phone counselling	14%	25%	10%	27%
Emergency respite	9%	38%	7%	39%
Planned respite	16%	38%	15%	39%

Addressing the range of risk factors associated with abuse, neglect, and exploitation, such as those identified in this literature review, in relation to both carers and victims of abuse may be a useful preventive approach (Chow & Tiwari, 2014). Carers' use of emotion-focused and solution-focused coping strategies has been identified as a protective factor for abuse within caring dyads in China (Fang et al., 2019) and there is some evidence that teaching coping skills to carers has beneficial outcomes in terms of preventing abuse (Baker et al., 2017). Providing psychological counselling for carers has also been argued to alleviate carer burden and therefore impact on the likelihood of abuse occurring (Mahmoudian et al., 2021). Participants of one particular training program designed to reduce depression and anxiety among dementia carers reported less potentially abusive behaviour towards care recipients (as measured by the modified conflict tactics scale) when compared with carers who did not receive the training (Twomey, 2018).

Literature suggests that there is a need to assist carers to improve their coping strategies, as well as improve home-based care services for older people living at home (Valimaki et al., 2020). Other approaches to providing preventative measures for abuse included: multidisciplinary case management (Yan, 2014; Khanassov & Vedel, 2016), education and training, financial assistance, social support, and respite (Orfila et al., 2018; Valimaki et al., 2020). It is suggested that these approaches could significantly assist in improving the wellbeing of both carers and care recipients. Other interventions suggested to reduce the incidence of abuse by carers include addressing mental health issues, providing respite services, caregiver training about disease progression and the way in which care can change over time (Kohn and Verhoek-Oftedahl, 2011).

Given the range of carer characteristics that have been identified as potential risk factors for abuse, literature has recommended implementing carer-focused prevention and intervention strategies that specifically target those traits (e.g., neurotic personality characteristics and cognitive appraisal of caring burden; Fang et al., 2021). Education-based interventions also

need to be targeted to specific groups of carers, accounting for cultural factors. Nguyen et al. (2016) found that English-speaking carers in their study were receptive to education that developed their advocacy skills, while Spanish-speaking carers were more likely to prefer education that developed skills in keeping their elderly relatives safe and able to live with dignity. Community-based services should be designed to align with the specific needs of carers who may be at increased risk of abuse (Valimaki et al., 2020). Health care professionals also require adequate targeted training to ensure they are equipped to appropriately care for older people who may experience abuse, while also providing appropriate support and referrals to carers (Mercier et al., 2020).

Not only is there a need for preventative services, carers must also be appropriately encouraged to share their experiences and seek support for both themselves and those they care for when needed (Ernst, 2019; Valimaki et al., 2020). This is particularly the case when considering that service providers are well placed to recognise abuse by carers and initiate referral pathways for appropriate support. For such an intervention to occur, systemic factors such as legislative protection and adequate sector resourcing are essential to ensure service providers can respond appropriately and effectively (Adams et al., 2014).

Some of the reviewed literature suggested that valid risk measurement tools are needed to enable systematic screening early on in caring roles and assist in identifying carers and families at increased risk of abuse (Valimaki et al., 2020). The database search undertaken for this review identified a small number of specific tools reported in the literature, though it is likely that others exist. The literature also suggested that few of the instruments that have been developed have been validated and many are impractical for routine implementation due to their length or the need for training (Orfila et al., 2018). Some small studies described measurement tools such as the Caregiver Abuse Screen (CASE; Perez-Rojo et al., 2015; Melchiorre et al., 2017) or the Potentials and Risk Factors of Family Caregiving for Older People (PURFAM; Heidenblut et al., 2013). These studies focused predominantly on the psychometric properties of the screening tools in question, as opposed to how practical and useful they would be in real-life settings where abuse may occur. While these studies indicated that these particular tools demonstrated strong psychometric properties, they also reported significant limitations in terms of the representativeness of their study samples and the inability to screen for all forms of abuse (e.g., financial abuse). More broadly, a recent systematic review found that the validation of screening tools and clear assessment of their effectiveness in screening for outcomes are lacking (Mercier et al., 2020). Furthermore, a recent Australian study identified five separate screening tools (Vulnerability to Abuse Screening Scale, Elder Abuse Suspicion Index, Elder Assessment Instrument, Caregiver Abuse Screen, Brief Abuse Screen for the Elderly) found that health professionals did not consider any of them to be suitable for use in routine practice. This was due to a range of factors, including: outdated language, reliance on binary questions, multiple questions being asked at once, lack of consideration for older people's cognitive state, no consideration of cultural issues related to abuse of older people, and no clear referral pathway after administering the tools (Brijnath et al., 2020). Participants in this study also raised concerns regarding the ethics of screening for the abuse of older people, particularly when screening may involve the presence of a potential perpetrator of abuse.

Considering the gaps in research literature regarding effective practice in this area, substantial investment in high-quality research is warranted and service providers supported to undertake or commission meaningful evaluations of their services (Baker et al., 2016; 2017). Future research regarding interventions for the abuse of older people should include high-quality trials, and should include elements of cost-effectiveness analysis, equity assessment, and implementation measurements (Baker et al., 2016).

5 Conclusion

This rapid evidence assessment found a complex array of factors that are associated with the neglect, abuse and exploitation of older people and people with disabilities. For carers, high levels of burden, stress, and social isolation, which impact on both physical and mental health, appeared to be key factors associated with abuse. In addition, care recipient characteristics such as high levels of functional impairment and behavior management problems can contribute to increased vulnerability for abuse. These factors were consistently reported across a range of studies, utilising different research methods and in a range of international jurisdictions. However, the predominance of cross-sectional research design means that causality cannot be assumed from these findings. Rather than suggest these factors directly cause abusive situations, this review has highlighted various personal, interpersonal, and contextual factors that are more likely to be characteristic of these situations. Drawing on the theoretical approaches outlined in the literature, this review suggests that there are important factors to consider at a microsystem level (e.g., carer characteristics, care recipient characteristics), a mesosystem level (e.g., socioeconomic status, existing support structures), and a macrosystem level (e.g., carer support policies, cultural factors). These factors create complex social and interpersonal situations where care takes place and abuse may occur. The substantial stress and burden that many carers experience in their daily provision of care for an older person or adult with disability can further be seen as a contributing factor to abusive or neglectful behaviour.

Research on good practice to support carers and prevent neglect, abuse and exploitation is limited. However, some approaches have been argued to show promise. In particular, intervention and support initiatives that target the risk and vulnerability factors outlined in the literature are suggested to be most likely to demonstrate effectiveness in meaningfully supporting carers and preventing the abuse of older people or adults with disability. Once identified, carers need access appropriate support such as respite services, training to assist with managing caring tasks and education about disease progression. The provision of information and education about abuse and available support through helplines may mitigate risk and adequate funding of support services to alleviate carer burden is also required to help reduce, abuse of older people and people with disability.

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