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## **Title page**

### **Title:**

**When older people are violent or abusive toward their family caregiver: A review of mixed-methods research**

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## **Abstract**

What happens when family caregivers experience violence and abuse from the older person for whom they care? Though this issue has received little global attention, it is of relevance to researchers, practitioners and policy-makers working across the intersecting fields of older age care and medicine, adult protection and safeguarding, and domestic and intimate partner violence (IPV). To date, these fields have generated diverse explanations of what violence and abuse in older age illness is (and is not) and how to respond to it. This paper reports the findings of a systematic literature review of eighteen quantitative, qualitative and mixed-methods studies that investigated violent and abusive behavior by older people towards their family caregivers. The review identified three central themes in the literature: 1) There are inconsistent definitions and measurements used to research harmful, violent and abusive behavior towards family caregivers. 2) Violent and abusive behavior towards caregivers is a sensitive and hidden topic across. 3) There is some evidence to suggest that people who were violent and abusive in their earlier life - or who had a poor relationship with their family member in the past - are more likely to continue to experience violence and abusive behavior in later life. There were two central ways in which violence and abuse were conceptualised and investigated: as a 'symptom of illness' or as an 'act of abuse'. We present a visual map of the relationship between these two conceptualisations, drawn from our analysis of the literature. We conclude by discussing the implications of the findings and recommend future directions for practice, research and policy to support affected families.

# **When older people are violent or abusive towards their family caregiver: A review of mixed-method research**

## **Introduction**

In the last fifty years the age of mortality has risen steadily and the proportion of older people relative to younger adults and children continues to increase year-on-year (World Health Organization, 2015). Within these ageing populations, many people are experiencing chronic and complex health conditions in later life and living at home until they need end-of-life care (Pin & Spini, 2016). Families are the single largest group of caregivers for older people, with elder spouses and adult children being the family members most likely to take on the role of caregiver (Pinquart & Sörensen, 2011). For some families, the challenges of illness and caregiving are particularly intense and complex and that ‘caregiver burden’ can increase the risk of poor care developing into elder abuse (Momtaz, Hamid & Ibrahim, 2013). This involves caregivers acting in an abusive, neglectful manner towards older family members: exploiting their position of vulnerability and/ or failing (by omission or commission) to meet the health and welfare needs of someone who is dependent on them in a significant if not total way (Cooper, Seelwood & Livingston 2008). Research has played a critical role in mapping the prevalence and impact of elder abuse. In turn, this has shaped an increasing concern in health and social care practice to identify, prevent and intervene in cases of elder abuse in families (Pillemer, Burnes, Riffin & Lachs, 2016).

However, there has been much less consideration of what happens when it is the family caregiver who is adversely affected by the violent or abusive behavior of the older person for whom they care. This can arise from the following types of behavior: when caregivers experience frequent and extreme verbal, physical and sexual violence; when caregivers feel manipulated and controlled by their family member; and when families live in unpredictable,

often chaotic circumstances in which the dynamics of power, love and duty are complex and closely intertwined (Daniel & Bowes, 2010; Probst, Di Gregorio & Marks, 2013). This in turn gives rise to a number of key questions: How do caregivers respond to violent and abusive behavior and how do they make sense of it? What is the impact of such behavior on both the caregiver and older person? To what extent is it an extension of ‘caregiver burden’ and is it a form of domestic abuse or harm? These questions highlight the importance of giving careful consideration to how we talk about and identify harmful behavior when issues of vulnerability, need and risk are blurred. Examination of these issues is important for practitioners working in adult protection, health and domestic abuse services and to researchers in applied and theoretical fields, if they are to investigate and respond to them sensitively and meaningfully. To address these questions, we set out to explore the research landscape by conducting a systematic review of research conducted in this area. The focus was on studies that investigated the phenomenon of informal, family caregivers of older people experiencing violence and/or abusive behavior by the person for whom they care.

## **Background**

### Older age violence and abuse in illness and disease

One of the most prevalent and disabling diseases affecting older people is dementia. Prince, Bryce, Albanese, Wilmo, Ribeiro & Ferri (2013) estimated that the number of people affected by dementia would double every twenty years, reaching a total of 115.4 million by 2050 (Prince et al., 2013). There is an association between increased rates of violent and abusive behavior - often referred to as ‘behavioral disturbance’ or ‘challenging behavior’ – and dementia type illnesses. The intensity and frequency of somatic symptoms (such as pain, tiredness and hunger) can result in the person affected finding personal care feel invasive and unwanted. This, in turn, can make some caregiving situations sites of tension and conflict

(Enmarker, Olsen & Hellen, 2011). Additionally, day-to-day social activities and conversations can lead to feelings of stress, anxiety and frustration if communication and memory are impaired. This can lead to physical and verbal violence as forms of alternative albeit distressed communication (Duxbury, Pulsford, Hadi & Sykes, 2013). People with dementia can also experience emotional dysregulation, which is manifested in limited impulse control and an impaired ability to anticipate and address emotional cues (Gormley, Lyons, & Howard, 2001). This may result in aggressive behavior, physical and verbal violence and sexual disinhibition (Rosen, Lachs & Pillemer, 2010).

However most of the research about violence towards caregivers by dementia patients investigates the experiences of formal caregivers working in nursing home and hospital settings, rather than those of family caregivers (Wharton & Ford, 2014). There may be some common elements found in formal and informal caregiving situations, however, there are also significant differences. For example, a review of studies that had investigated violence by adults with a serious mental illness (SMI) towards their family members found limited research suggested that one of the central reasons may be hesitancy on the part of researchers and practitioners to further stigmatize a population with complex needs (Solomon, Cavanagh & Gelles, 2005). They also found prevalence rates of violence towards family members by people with SMI between 10-40% and concluded that there are multiple and complex reasons why people may become violent, including how their caregivers recognize and respond to signs of illness and distress (Solomon et al., 2005). Family caregivers are likely to have less training and education in recognizing and responding to distress than professional caregivers. This may increase the likelihood of violence and/ or inhibit opportunities for prevention and de-escalation. Research with families affected by violence in adults with mental ill health

finds that the emotional impact of such harm is particularly acute for family caregivers (Hsu & Tu, 2014).

Coming to terms with the loss of physical and cognitive function is often a difficult and emotionally demanding experience for older adults with dementia and for their families (Desai, Schawrtz and Grossberg, 2012). Illness can also bring with it loss of role, status and profound changes to a person's identity and relationships with others. In dementia, as with other illnesses, such existential challenges may cause some people to find new ways of exerting power or influence within their intimate relationships by taking on new roles and responsibilities, or by requiring high levels of attention and emotional support (McDonald & Thomas, 2013). The dynamics of care and dependency are often complex in intimate relationships in later life and the causes and nature of violence or 'dysfunctional' behavior can take on new meanings, particularly in illness (Roberto, 2016). In extreme cases, lethal violence is a way of alleviating suffering, as in the case of mercy killing or homicide-suicide 'pacts' between couples when one or both people are affected by a terminal disease (Cohen, 2004). More commonly, patterns or incidents of difficult and abusive behaviour are shaped by expectations and obligations to care and to tolerate changes in behavior and to changing circumstances of a long-term relationship, infused with personal meaning and social implications.

#### Older age IPV and long-term patterns of conflict and abuse

One of the most developed areas of research and practice with regard to violent and abusive behavior in older age is the field of intimate partner violence (IPV). In a seminal study, Bonomi et al.. (2007) questioned 370 older women about their experiences of IPV and found that incidents of severe (e.g. forced sexual contact) and moderate (e.g. threats) behavior was

similar between older adult and younger adult groups (Bonomi et al., 2007). Although older age IPV is characterized by a decrease in episodes of physical and sexual violence, relative to non-contact, psychological forms of control and coercion (Roberto, McPherson & Brossoie, 2014). Such abuse is associated with complex and enduring negative health outcomes for those affected (Beaulaurier, Seff, Newman & Dunlop, 2006). IPV in older age is a particularly sensitive and mainly 'hidden' issue. In a qualitative literature review of studies investigating IPV towards older women, Fingfeld-Connet (2014) found that generational and gendered norms about the privacy and sanctity of family life inhibited disclosure and help-seeking by older women and normalised patterns of abuse and violence (Fingfeld-Connett, 2014). In addition, feelings of moral obligation, social shame and concerns about the emotional and practical upheaval of re-building a life after decades of married and family life affect decisions about remaining in abusive relationships (Policastro & Finn, 2015). The limited visibility and lack of awareness of the needs of older victims of IPV and the paucity of tailored domestic abuse services for this population are also areas of emerging concern (Lundy & Grossman, 2004; McGarry & Simpson, 2011).

## **Methods**

### A review of mixed methods research

In order to explore the evidence concerning these issues we conducted a literature review of papers reporting the findings of qualitative, quantitative and mixed-methods studies that investigated violent and abusive behavior by older people towards their family caregivers. The aim of the review was to identify, synthesize and examine critically the available empirical and theoretical literature relating to family caregivers' experiences of violent and abusive behavior from the older person for whom they care. A literature review is a useful exercise in the initial stages of developing knowledge about a topic. By systematically



identifying literature from a wide range of sources, the review process can map areas of consensus and difference in the field and identify areas of limited development that need further work. This can direct and focus future research activity. We used a mixed-methods research synthesis approach for this review (Joanna Briggs Institute, 2014). The term ‘mixed-methods’ has different definitions in the context of reviewing literature (Harden, 2010), so for the purpose of this paper, we use the term to reflect that the review encompassed studies which used a range of methodological designs. This approach is increasingly used in the study of complex topic areas that are multi-dimensional and difficult to capture using only one theoretical or technical approach (Grant & Booth, 2009). It has been also used to explore new or developing areas of study, particularly those where there is limited empirical evidence or a lack of clarity concerning the central concepts and definitions of the phenomena in question (Pluye & Hong, 2014) which can involve the comparison, contrast and integration of different types of evidence. In this review, the mixed-methods approach enabled us to explore and critically engage with the range of literature necessary to examine a sensitive and under-researched issue.

### Identification of studies

The first phase took place between October and November 2015 and involved a systematic search for relevant papers. Following this, in December 2015, we carried out additional ‘hand-searching’ of journals. We used four electronic databases: Web of Science, ProQuest Nursing and Allied Health, Medline and Cinahl Plus. The databases covered a range of clinical, practice and research interests and specialisms, which gave the review breadth. However, for the most part, these databases include medical, health and social science studies. As a result, studies from the psychological and philosophical disciplines may have been under-represented in the review. During the stage of identifying papers, we did not set a

time period for publication as a criterion for inclusion. The studies included in our final sample were published between the years 1992 and 2014. We only included papers published in the English language as we did not have the resources (or linguistic skills) to review papers in other languages. This may have limited the number of studies included in our analysis and the range of cultural and social perspectives encompassed in the review process.

Table 1 shows the inclusion criteria used to identify papers for review. In order to identify the maximum number of potential papers, we used a range of paired search terms in conjunction with Boolean operators in the search strategy. To identify literature relating to family caregivers, the terms ‘caregivers’, ‘informal caregivers’, ‘family members’ and ‘caregiver burden’ were used. These synonyms were combined with a group of terms to identify older people. The phrases ‘older people’, ‘elderly’ and ‘geriatric’ were used to identify studies relating to this population. For some databases, it was appropriate to select the relevant ‘population’ group (people aged over 65 years old) if this option was available. In order to capture papers relating to violence and abuse, the terms ‘violence’, ‘patient aggression’, ‘patient initiated assault’, ‘family violence’, ‘IPV’, ‘patient-initiated violence’ and ‘caregiver assault’ were used as synonyms.

#### Quality appraisal and methods of analysis

We used three tools to assess the quality of the different papers. We did not use a scoring system but rather made detailed assessments of each paper as appropriate to the standards and expectations of their methodological approach taken. For the observational quantitative research we used the National Institute for Clinical Excellence assessment tool (NICE, 2012); for the qualitative studies we used the Critical Appraisal Study Program tool (CASP, 2013) and for the mixed-methods papers we used guidance set out by Pluye, Gagon, Griffiths &

Johnson-Lafleur (2009). Following this, the findings from each study were synthesized using a thematic approach (Pluye et al., 2009). This is a common feature of literature reviews of papers incorporating mixed-methods literature because the quantitative data being reviewed cannot be aggregated and analyzed using statistical methods. This is often because the studies employ different measurement tools and/ or the study populations are too dissimilar and therefore results cannot be compared on a 'like-for-like' basis (Thomas & Harden, 2008). Because this review included studies of varying design and quality, a thematic approach was considered the most appropriate for making sense of this heterogeneity.

Thematic analysis involves three steps which were set out in a systematic protocol developed by the review team. Initially, the texts (in this case, the papers) were read and coded in small text segments. At this stage, codes reflecting the descriptive meaning of the text were assigned. The second step involved grouping the codes and interpreting how they related to one another. Finally, the overarching themes were drawn out and a 'narrative' or framework for understanding was developed (Hannes & Macaitis, 2012). This process was carried out by the primary researcher, whose coding and thematic categories were then checked and discussed with the other two members of the team. Codes were refined and developed through a process of discussion and reflection. We developed three central themes in the course of the analysis: 1) There are inconsistent definitions and measurements used to research harmful, violent and abusive behavior towards family caregivers. 2) Violent and abusive behavior towards caregivers is a sensitive and hidden topic across the different studies. 3) There is some evidence to suggest that people who were violent and abusive in their earlier life are more likely to continue to be so in older age and that family members with poor relationship quality are more likely to experience violence and abusive behavior in later life. These three themes are discussed in detail in the following section.

## **Findings**

Eighteen studies were reviewed and their findings and methods are summarized in Table 2. The review was international in scope with the work reported conducted in North America, Europe, Australia and Asian countries. Nine employed cross-sectional study designs, six qualitative and three adopted a mixed-methods approach. Most of the studies reflected a largely health and medical science perspective although several (mainly qualitative) papers adopted a sociological and feminist theoretical perspective. The studies employing a cross-sectional design (and two of the mixed-methods papers) reported on investigations of the experience of caregivers of older people with dementia. Most of the qualitative studies did not specify the illness or health condition that gave rise to the need for care and caregiving. Instead, they focused on women affected by violence throughout their lives, either from their partners or parents. These papers explored how past experience and relationship histories affected the nature of harm they experienced as caregivers as well as their responses to continuing and changing violence. The analysis of the papers revealed three central themes:

1. Inconsistent definitions and measurements

The studies used different terms to describe violent and abusive behavior. Furthermore, amongst the nine cross-sectional and three mixed-methods studies, investigators adopted different models to measure the nature, severity and extent of the behavior. At times, this made it difficult to be clear whether different studies meant the same thing when employing these terms. Estimates of the extent and nature of violence towards caregivers reported in the cross-sectional and mixed-methods studies varied. For example, in a study of 220 family caregivers of people diagnosed with dementia in the previous three months, Cooper, Selwood, Blanchard & Livingston (2010) found that 82 caregivers (37.3%) reported abuse from their family member 'at least sometimes' (Cooper et al., 2010). Similarly, in a study of

198 caregivers of people with Alzheimer's disease, O'Leary, Jyringi & Sedler (2005) found that 25% of this caregiver population had also experienced violence from their family member (O'Leary et al., 2005). Also, of Coyne, Reichman & Berbig, (1993) 33.1% of caregivers reported abusive behavior from the person with dementia they cared for and 33 caregivers (11.9% of the total population) reported that they had 'retaliated' towards the older person and acted in a violent or abusive manner (Coyne et al., 1993). These studies indicate the broad spectrum of harmful behavior that affects family caregivers. However, estimating the extent, nature and impact of this behavior accurately is not yet possible mainly because of the limited and diverse nature of current empirical research.

The cross-sectional studies (and survey data from the mixed methods studies) examined the patient and caregiver factors that may be associated with violence towards caregivers. In these studies, data were collected using a series of structured questionnaires and psychometric measures which required used yes/ no (dichotomous) responses and the completion of rating scales (Likert). Many of these measures were drawn from the medical and psychiatric fields and operationalized definitions of violence, health and relationships that reflected these disciplinary perspectives. However, despite this common approach there are some significant differences in the findings. For example, some studies found that the greater the level of cognitive impairment, the greater the severity and duration of violence towards the caregiver (Pillemer & Sutor, 1992) whereas others found no evidence for such an association (Hame et a., 1990; Phillips, de Ardon & Briones, 2001; O'Leary, 2005). The studies also report different findings concerning the extent to which people's physical impairments and intensity of care needs affected levels of violence. Cooper et al. (2010) found an association between higher levels of violence and higher physical impairment (and care needs), although this association was less clear in other cross-sectional studies. In

addition, several studies reported that higher levels of depression in caregivers and care recipients correlated with more frequent reports of violence towards caregivers (Hughes, 1997; Paveza, et al., 1992; VandeWeerd & Paveza, 2006).

In the majority of the qualitative studies (and qualitative data from the mixed methods studies), violence and abuse were conceptualized primarily as patterns of behavior that could include physical, psychological, emotional and sexual dimensions of harm. This incorporated patterns of interaction and behavior that play out over time, often across the 'life-course' of the family relationship. The qualitative studies tended to focus on psychological and emotional harm and the importance of recognizing the ways that violence and abuse affect different people. There was a lack of discussion in these papers about how and in what ways different types of physical, psychological and cognitive illness might affect the nature of abuse, violence and care in families. As with the cross-sectional studies, there was a lack of specific terminology to delineate what was different about the context of violence towards caregivers from other types of violence and abuse. In addition, the term 'caregiver' was not always used or used consistently throughout the studies in question. Instead, people were referred to according to their status as family members or intimate partners. Nevertheless, they did describe relationships between family members in which care, caring and ill health played a significant role.

## 2. A 'hidden' and sensitive topic to research

All the papers reported the considerable methodological challenges involved in recruiting and engaging with families with experience of violent and abusive behavior by older people towards their family caregiver. The small and unrepresentative nature of the sample populations reported in the cross-sectional studies indicates this problem affected the number

of participants taking part. In the six qualitative studies and qualitative components of the mixed methods studies, the sensitive and complex nature of the topic – and its potential social taboos and emotive nature – was identified as a central rationale for using in-depth, exploratory techniques and analysis methods. Several studies suggested that caregivers would be reluctant to speak out against their family member for fear this would place the individual at risk of being taken into state care or that the caregiver would be seen in a negative light (Cahill & Shaprio, 1993; Pillemer & Suito, 1993). Hughes (1997) and Coyne et al. (1993) suggested that some caregivers worried that violent or abusive behavior could be interpreted as a ‘failure’ to protect and care for their family member and this inhibited discussion of the issue (Hughes, 1997; Coyne et al., 1993).

Several of the qualitative studies also identified that caregivers may not recognise their situation as one of violence or abuse. Instead, they may regard challenging behavior or unequal power relationships as part of the normal practice of care (and love) in their relationship (Band-Winterstein, 2012). This may be more common for women habituated to living in long-term relationships involving IPV (Zink, Regan, Jacobson & Pabst, 2003).

Whereas in other studies it was suggested that caregivers may over-estimate and misattribute violence and harm because they do not properly understand its aetiological causes and/or lack the skills to de-escalate and prevent conflict. For example, in two of the cross-sectional studies, it was found that caregivers often ‘over-estimated’ the severity and level of violence they experienced (O’Leary et al., 2005; Cooper et al., 2010). This was considered an issue of (subjective) bias when using self-report measures that complicated attempts to estimate the prevalence and type of violence and abuse experienced by caregivers. Unsurprisingly, bias was not identified as a concern in the qualitative studies, which did not question the veracity

of participants' accounts but rather sought to explore individuals' experiences, views, and beliefs.

The sensitivity of language and its role in maintaining secrecy and inducing feelings of shame about unusual or distressing experiences was evident in the qualitative studies. For example, the Band-Winterstien (2012) and Band-Winterstein & Eisikovits (2009) found that the process of creating narratives about care and illness were central to how couples accepted the challenge of old age and in some cases the end of life. For some couples, caring and illness provided an opportunity to become closer and to re-frame their relationship, and minimize the significance of past violence in the context of newly found respect or appreciation of care and vulnerability. In other cases, one partner being identified as a victim of violence offered a way of making sense of difficult experiences and conflicting, often painful feelings. In this way, a 'narrative of suffering' provided a coherent way of codifying and explaining feelings of powerlessness brought about by long-term IPV (Band-Winterstein & Eisikovits, 2009; Band-Winterstein, 2012). Reflection and talk were also important for female survivors of IPV to use to reclaim power in the context of caregiving in older age (Koeing, Rinfrette & Lutz, 2006). This was demonstrated in two case studies of women who were better able to engage with the ethical dilemmas and complex life choices they faced as caregivers and victims of domestic abuse following therapy and rehabilitation (Koien et al., 2006).

Although some of the paper highlighted the potential overlap of IPV and abuse/ violence to caregivers (Copper et al., 2010; Pillemer et al., 1992), only one paper engaged critically with the vocabulary and concepts of 'abuse' by means of a systematic concept analysis (Ayres & Woodtli, 2001). One of its central findings was that caregivers were unlikely to identify with the terms 'abuse' and 'victim' as they were too emotive, simple and associated with



perceptions of IPV. As a result, Ayres & Woodtli (2001) suggested that researchers and practitioners need to be sensitive to this and develop nuanced ways of discussing the issue with families. In turn, this could help families disclose and discuss the issue in a more timely and meaningful way (Ayres & Woodtli, 2001).

### 3. Relationships and interactions

The nature, quality and life-course trajectory of family relationships were identified as significant in understanding the nature of violence and abuse towards caregivers. This was a finding in all of the studies irrespective of design or disciplinary perspective. Within the cross-sectional studies, low quality or 'dysfunctional' relationships were consistently associated with more severe and more frequent aggression towards caregivers (Cooper et al., 2010; Paveza et al., 1992; Hamel et al., 1992). Those caregivers reporting exposure to, and experience of violence prior to diagnosis of dementia in the person being cared for, were exposed to more severe forms of violence following its onset (Cahill & Shapiro, 1993; O'Leary et al., 2005). In addition, how caregivers 'coped with' and responded to their family member's violence correlated with the quality and stability of their relationship prior to illness and care (Phillips et al., 2001; Hamel et al., 1990; Coyne et al., 1993). Those caregivers found to be less emotion-focused in their care and who identified the causes of aggression as a personality trait or deliberate act of challenging or disruptive behavior on the part of the family member were also found to have poorer quality relationship histories (Wilks, Little, Gough & Spurlock, 2011; Vande Weerd et al., 2006; Huang, Shyu, Chen & Hsu, 2009). However, there was limited evidence that this group of caregivers reported experiencing higher levels of violence from their family member (Hughes, 1997; Cooper et al., 2010).

Collectively, these findings highlight that people's understanding of and responses to their family member in illness and in violence were shaped by their experiences with them over their life-course. This was particularly the case in long-term relationships between spouses who married decades earlier, or between adult children and elderly parents. For some family relationships, there appeared to be a risk that caregivers would become less caring and potentially violent in retaliation towards their family member, leading to a situation of 'bi-directional' or mutual harm. O'Leary et al. (2005) suggest this could lead to the premature ending or 'relinquishing' of the care relationship as people with dementia were placed in institutional care. However, although this seems a plausible consequence of violence towards caregivers, Hamel et al. (1990) found that this is supported by limited evidence.

In the qualitative studies, understanding the relationships of family members was central to interpreting people's experiences of care and violence. Individuals with a history of conflict, violence or abuse with their parent or spouse found different ways to cope and find meaning from becoming their caregiver later in life. This ranged from a turning away and 'relinquishing' the caregiver role and its expectations and demands, committing to the role as an opportunity to reshape and re-order memories of powerlessness and abuse. Relationships were the primary context in which power (and its abuse) played out and in which decisions and responses to violence were understood. For example, it was identified that relationships shaped by violence and abuse in child and adulthood shaped how people responded to experiences of being cared for and providing care later in life (Pickering, Moon, Pieters, Menten & Phillips, 2014; Phillips et al., 2001). Illness appeared to complicate and compound dysfunctional and harmful dynamics already present in violent relationships. This was the case, for example, in Pickering's (2014) study of daughters who engaged in 'spiteful aggression' and retaliatory violence towards older mothers who were neglectful or abusive

towards them in childhood. Caring needs and caring roles could also heighten feelings of obligation and duty to family members. This was more often an issue for older women caring for husbands and partners who had strong views about the unconditional nature of family duty and marriage in particular (Zink et al., 2003; Band-Winterstien, 2012). In some cases, caregiving for a physically ill or disabled partner altered the status and increased the power of the carer in a long-term intimate and often difficult, relationship (Koeing et al., 2006; Band-Winterstein & Eisikovits, 2009).

## **Discussion**

There is limited research examining violence and abuse towards family caregivers of older people and the research that does exist is fragmented and lacks inter-disciplinary perspectives. There is a body of research that focuses on family caregivers for people with dementia illnesses which, in the main, adopted cross-sectional or mixed-method designs and sought to establish the nature and prevalence of violence and abuse towards caregivers.

There was a smaller body of qualitative studies (and mixed methods studies using qualitative methods) that focused on the experiences of families involved in violent and abusive relationships prior to the onset of older age and illness. These studies explored how violence and abuse continues or changes. Figure 1 presents a conceptual map characterizing these two categories and it identifies some of the conceptual differences between the studies and how these may have contributed to other aspects of the phenomenon remaining hidden.

The aim in developing this map is to highlight the conceptual and linguistic resources that are necessary to define and engage with the issue of violence and abuse towards caregivers. This is important, not only for the purpose of definitional clarity and research measurements but also for practice in this area. There is a need to move beyond understanding harm to

caregivers either as a ‘symptom of illness’ or as an ‘act of abuse’ and to investigate and consider how it can be both. This involves exploring aspects of current legal, medical and social practice that are (unintentionally) creating the circumstances in which the issue hidden from view. Developing theory and analysing evidence about the nature of violence and harm towards caregivers will help practitioners from a range of disciplines identify and support affected families. This is important because we know that discussing violence and abuse is something that many practitioners find difficult (Tower, 2006; Bradbury-Jones, 2015) and encouraging more discussion of the issues involved may provide opportunities for them to develop their confidence to ask difficult but important questions of caregivers and the cared-for, and to do so before situations escalate or become entrenched. Raising the profile of the issue and suggesting new ways to talk about it sensitively and honestly by identifying how it has been characterised in research also provides a ‘language’ that can be used to address some of the shame, fear and ethical tension that may be currently preventing some affected caregivers from speaking out about their experiences.

Another line of inquiry is to explore some of the reasons that illness has been the primary and central lens through which violence and abuse towards caregivers is examined in health and medical-focused studies. Reflecting on our findings and drawing on work in the field of elder abuse and adult protection, clear links between the concept of illness and patient-hood: a state of vulnerability and/ or the inability or impaired ability to cause violence or abuse intentionally (Dixon, Biggs, Stevens, Manthroe & Tinker, 2013) can be discerned. With this comes a release from responsibility for individual action in most legal or moral understandings of these terms. This shifts attention from the person carrying out the violence or abusive behavior to a critical focus being directed onto the caregiver. For example: are they caring in the best or right way, do they understand the illness well enough, how will this

affect the way they care in the future? These implicit and explicit questions in many of the dementia-focused studies in the review reflect how in focusing on the caregiver, the issue of their potential harm from the person being cared for can be overlooked. The issue of violence and abusive behavior towards caregivers was ‘lost’ in concerns about medication regimes, the adequacy of training and education of caregivers and the potential need for tailored emotional and social support for affected families. The focus was on the risks to the older person of receiving poor care or being the future ‘recipient of violence’, rather than the needs of the caregiver.

In light of our synthesis we question whether it is appropriate to assume that behavior on the part of an ill or disabled older person be understood as occurring without intention.

Similarly, we question assumptions that the older person/ ill person is in a static and constant state of vulnerability in relation to the person caring for them (Daniel & Bowes, 2010).

Practices of power in adult relationships are complex and subtle and people do not necessarily hold power ‘over’ or ‘against’ another person in an absolute way. More often, power is developed through action and inaction and is constantly negotiated and mediated.

Disrupted power relationships are more likely during times of transition and loss, crisis and change in long-term intimate and family adult relationship (Biggs & Haapala, 2010).

Moreover, even when illness appears to be an appropriate and valid way of understanding violent and abusive behavior, the impact on the family caregiver should not be obscured or minimized, as is the case in several of the studies included in this review. There is evidence to suggest that some caregivers experience extreme, regular violence and life with their family member is characterized by its unpredictable and volatile nature. Moreover, they lack agency or the resources needed to change this situation, often feeling that ‘leaving’ is not an option and that learning to ‘cope with’ violence and/ or distress is the only central moral and

pragmatic option. We suggest there is a need to explore the overlap between harmful behavior as a ‘symptom of illness’ and as an ‘act of abuse’ in a more critical and sustained way. Examining caregiver responses to violence and illness through the lens of trauma and social context - as responses to IPV often are – would be helpful in understanding the different ways caregivers cope and why some families may be at much greater risk of increased violence and/or a deterioration of the caring relationship than others.

Turning to the qualitative literature, we reflect on further future directions for empirical and theoretical work. This small group of studies has made an important contribution in developing knowledge about this complex and hidden subject but the topic would benefit considerably from further empirical study. For example, there is minimal reference to, or engagement with, the (neuro)-biological nature of illness and how this may shape what violence and abuse ‘looks like’ and ‘feels like’ as compared to behavior taking place when illness is not a dominant dimension of an intimate relationship. In addition, most of the sample populations were made up exclusively of women and there is limited discussion of ut the particular or different needs of men experiencing violence and abuse as caregivers. More starkly, perhaps, there is little qualitative research either with families in which violence and abuse did not precede illness, or with families where violence and abuse is more fluid, complex and ambiguous when it does occur.

The qualitative literature is also limited in terms of its theoretical and conceptual scope. As noted earlier, the concepts of gender inequality and structural models of violence and ‘power and control’ (and the attendant division of roles into ‘perpetrator’ and ‘abuser’) are central in the analysis and discussion of findings in the small number of papers included. This reflects dominant paradigms in IPV and gender violence work over the past thirty (and more) years as

well as the more recent shift to conceptualising these issues of public health and legal concern. However, there may be other factors that are helpful in explaining people's understanding of care and violence, such as how and when they set limits and when they feel this is not possible.

### **Limitations**

This review has three principal methodological limitations. Firstly, studies were included based on specific inclusion criteria (see Table One) and none were excluded on the grounds of methodological quality. Consequently, the quality of evidence reviewed is not consistent or sufficiently robust to underpin a definitive explanatory conceptual or theoretical model. However, the review was guided by decisions about how best to examine an area in which there is limited empirical work and little conceptual development, so inclusion of studies irrespective of quality was deemed appropriate. Moreover, given that we reviewed studies using a variety of methods, we were able to draw evidence from different paradigms thus ensuring the breadth, if not quality of the included studies. Secondly, the concepts and evidence discussed in the background literature and discussion sections of the paper reflect choices about what is relevant and useful based on professional and personal worldviews of our research group. Arguably, it would be equally legitimate to synthesize the studies with reference to alternative literature and concepts given the 'under developed' nature of theorizing and research concerning this phenomenon. However, by adopting a systematic approach to the identification, appraisal and analysis of the studies we have sought to make it clear how the decisions taken, techniques used and wider influences shaped the synthesis of the evidence and the subsequent discussion and recommendations. The review included only English-language papers and so did not engage with all the available international literature. This reduces the scope of the paper as well as the transferability of its findings. It is also

likely to minimize or obscure comparison of how cultural and geographical differences shape the rate and nature of violent and harmful behavior towards family caregivers. A further significant limitation of this review is that we searched for studies using predominately social science, applied health and clinical databases. The gaps in the literature that we have identified will, of course, reflect gaps specifically within these disciplinary areas and their associated methodological fields. However, the review does set out some key questions and identify important lines of inquiry in this area.

## **Conclusions**

This paper is the first systematic literature review that focuses specifically on identifying and integrating knowledge about family caregivers who experience violent, abusive or harmful behavior from the older person for whom they care. It is a complex and multi-dimensional phenomenon and defining when difficult and harmful behavior is and is not abusive is problematic. Identifying what causes it and in what ways it affects individuals and families is also empirically and conceptually challenging. The topic raises uncomfortable questions about how culpability, inter-dependency and psychological abuse are understood in family relationships. We suggest that developing a clearer and more sophisticated understanding of what harmful behavior towards family caregivers looks like, feels like and means, is the cornerstone of any future work in developing knowledge and increasing understanding. Exploring how it differs in a range of social and cultural contexts is also necessary. Approaching the issue using recommendations of the review as a basis for exploration has the potential to uncover dimensions of the phenomena that have been hidden in research and social terms until now. This review is a critical and initial first step in working out how to identify and help affected families.



**Table 1: Inclusion criteria**

Inclusion criteria	<ul style="list-style-type: none"><li>• The care recipient is as an older person. Age is identified by any appropriate synonym (i.e. elderly, aged, geriatric) rather than an age range.</li><li>• The care recipient has health needs that require care giving (e.g. they have a physical and/ or mental health illness that is either diagnosed or recognised as such). Care-giving is not defined by number of hours caring per week or by the nature of the family member’s health condition. The paper may not use the term ‘caregiver’ but the experience of caring and violence within illness is a major theme/ finding.</li><li>• The care-givers are family members of the care-recipient (spouse, adult child, sibling, etc) and the care relationship takes place in a domestic setting.</li><li>• The research explores care-giver experiences of violence and abuse from the care recipient towards the care-giver. Violence and abuse can be identified by an appropriate synonym (i.e. aggression, power and control, attack). Violence and abusive behavior encompasses physical, psychological, sexual and financial acts/ patterns of behavior.</li></ul>
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**Table 2: Included studies**

No	Author, publication year, country	Aim	Design and study type	Analysis methods	Participants
Quantitative studies					
1	Cooper, C et al (2010), UK	To investigate levels of dysfunctional CG coping and likelihood that CG experiences abuse from CR.	Quantitative-observational, cross-sectional	Spearman r, Mann-Whitney U and Pearson correlation for analysis	220 family carers of patients with dementia
2	Coyne et al, A. (1993)	To explore if CG who experience abuse are more likely to abuse.	Quantitative, cross-sectional	Multi-variate analysis of variance statistical tests.	342 caregivers
3	Hamel, M. et al. (199), USA	To estimate the prevalence of aggression and responses of family caregivers.	Quantitative, cross-sectional	Multiple regression and discriminant function analysis	213 care receiver-giver dyads
4	Huang, H. et al (2009), Taiwan	To explore association between care receiver aggression and caregiver resilience	Quantitative, cross-sectional	Descriptive statistics	80 care receiver-giver dyads,
5	O’Leary, D. et al (2005), USA	To explore whether behavior patterns in early life are associated with greater prevalence of aggressive behavior.	Quantitative, cross-sectional	Chi-square tests	198 care receiver-giver dyads
6	Paveza, G. et al (1992), USA	To identify risk factors for ‘severe’ violence in family care receiver and care giver dyads	Quantitative, cross-sectional	Logistic and stepwise regression	184 care receiver-giver dyads,
7	Phillips, L et al. (2001), USA	To analyse correlates of abuse amongst older women who provide care for a family member.	Quantitative, cross-sectional	Analysis of variance and hierarchical regression	93 older female care givers
8	Weerd C. et al (2006), USA	To identify risk of verbal aggression towards caregivers for people affected by Alzheimer’s Disease.	Quantitative, cross-sectional	Logistic regression analysis	254 care givers and 76 care receivers
9	Wilks, S. et al (2008), USA	To investigate the association between aggression in Alzheimer’s Disease and caregiver coping skills and styles.	Quantitative, cross-sectional	Logistic regression analysis	419 care givers,

Mixed method studies					
10	Cahill, S. et al (1993), Australia	To identify experiences of female caregiver affected by aggression from older family members	Mixed methods (interviews and questionnaire/ survey)	Descriptive statistics and narrative interview data	39 caregivers recruited from services
11	Hughes, M. (1997), Australia	To investigate factors associated with higher rates of abuse and violence during the caring relationship.	Interviews and survey instrument for statistical analysis	Descriptive statistics and narrative presentation of qualitative data	47 care receiver-giver dyads
12	Pillemer, K. et al J. (1992) USA	To explore care givers' feelings and fear of violence with the experience of acting out violently.	Semi-structured interviews and validated questionnaire	Logistic regression and narrative presentation of qualitative interview data	236 care givers, referred by medical practitioners
Qualitative studies					
13	Ayres, M. (2001), USA	Concept analysis of abuse of ageing carers by elderly CRs	Qualitative, theoretical/ conceptual study	Concept analysis	NA
14	Band-Winterstein, T. et al. (2009), Israel	To explore intimate partner violence in older age/ life-span perspective.	Qualitative, semi-structured interviews	Phenomenological analysis of interview transcripts	40 (20 couples) from social services
15	Band-Winterstein, T. (2012), Israel	To explore how long term intimate partner violence shapes people's relationships and experience of abuse.	Qualitative, semi-structured interviews	Categorical-content analysis of interview transcripts	30 individuals (15 couples) from social services
16	Koenig, T. et al (2006), USA	To explore experiences of caregiving women who continue to experience intimate partner violence in older age	Qualitative, case studies	Empowerment model to discuss cases	Two female caregivers
17	Pickering, C. et al. (2014), USA	To explore the dynamics and nature of conflict between adult daughters who care for their mothers.	Qualitative, semi-structured interviews	Grounded theory and constant comparison analysis	13 daughters
18	Zink, T. et al. (2003), USA	To understand women's reasons for continuing in long-term abusive relationships in older age.	Qualitative, semi-structured interviews	Thematic analysis	36 older women,

**Table 3: Critical findings**

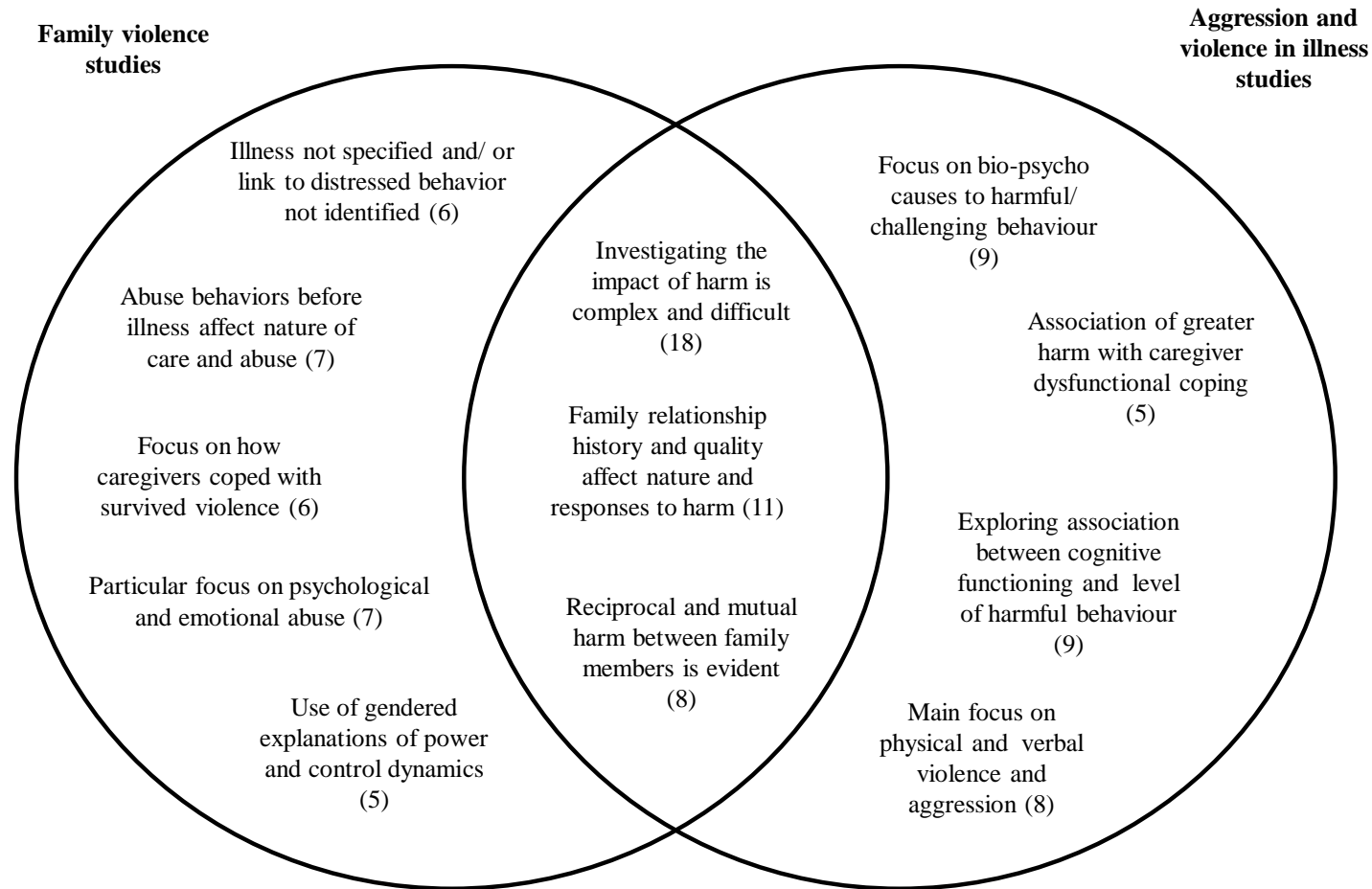
<b>Finding</b>	<b>Description</b>
Limited evidence	There is limited empirical, conceptual and theoretical work that focuses clearly or specifically on the experiences and needs of family members affected by violent, harmful and abusive behavior from the older person for whom they care.
Terminology and concepts	The majority of the studies conceptualized the issue as either a symptom of illness or as an act of abuse. This resulted in significant differences in how studies framed the causes, contexts and consequences of harmful behavior.
Hidden issue	Almost all of the studies reported difficulties recruiting participants. They identified many potential and commonly perceived barriers to people discussing and sharing their experiences of harmful behavior. Several of the social and psychological studies identified barriers specific to relationships in older age and long-term intimate partner violence.
Family and intimate relationships over the life-course	Many of the cross-sectional studies found that for families reporting previous violence and/ or poor relationships prior to caring/ health diagnosis were more likely to report violence and abuse, and that this behaviour was more extreme when it did occur. Caring was framed both as an opportunity to 'recalibrate power' as well as complicating the entrenched dynamics of power and control between family members within the qualitative studies.

**Table 4: Findings and recommendations for practice, policy and research**

<b>Recommendation</b>	<b>Details</b>
Conceptual development	It is suggested that a more complex and nuanced perspective on the practice and meaning of ‘intentionality’ and ‘vulnerability’ within harmful behavior may be useful in understanding power, control and autonomy within affected families.
Empirical research	This review identified limited empirical work focusing on families affected primarily or exclusively by physical illness and disease. We also identified no research that explored the experience of affected families over time. Longitudinal studies may help build understanding about how patterns of caring, conflict and harm develop within families.
Potential signs of risk and concern	There is some evidence to suggest that when there is a history of violence and/or negative coping and dysfunction between family members, the risk for violent and abusive behavior towards the caring family member is higher and more severe. There is also evidence that reciprocal or bi-directional takes place in some families.
Inter-disciplinary and reflective working	Identifying and addressing this problem may be challenging and complex. It is likely to raise difficult questions about the different rights and needs of family members and how they can be reconciled. Reflective supervision and team discussions may be helpful in thinking through these issues. Inter-disciplinary working may also be useful.

**Figure 1: Conceptual map of the review literature**

Note: The numbers in brackets identify the number of studies that make the given finding and/ or use of a concept.



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