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What is Known About Dementia Care Recipient Violence & Aggression Against Caregivers?

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Abstract

While agitation is a known behavioral manifestation in advancing dementia, there is little in the literature about the risk to home-based caregivers, particularly in situations where severe aggression is present. This review article examines this issue with a focus on what is known and where further research is needed. Although consistent definitions failed to emerge from the literature, rates of violence by dementia care recipients against caregivers are estimated at greater than 20%, and may be the strongest predictor of nursing home placement. A review of available literature suggests that there is a need for interventions aimed at strategies to educate and protect the informal caregivers of dementia patients living at home, while advancing understanding of the communicative properties of behavior. With high rates of violence by care recipients against their caregivers, and low success rates of chemical restraints, there is substantial risk to the safety and well-being of caregivers. Several pilot interventions for nursing home settings have shown promise in reducing care recipient violence, and these may be adaptable for informal caregivers in home-based settings. Alternative delivery platforms using technology may be appropriate to consider, for real-time, flexible targeted intervention and support.

Keywords

dementia; violence; assaultive behavior; aggression; caregiving

Physical aggression is a known behavioral manifestation in dementia patients, and is usually related to identifiable triggers, or communication challenges. Despite this well documented fact, there is not much in the literature about the impact and experience for caregivers (Enmarker et al., 2011; Kunik, 2010a; Mega et al., 1996; Orengo et al., 2008; Shah, 1995). While there has been some investigation of intervention models in nursing home settings for disruption of violent behavior by care recipients against nursing home staff, home-based caregiving remains largely outside of the purview of the current state of knowledge on this topic. The majority of dementia caregivers are spousal and have a median age of 63, making this a particularly salient issue for older adults who may be nearly as vulnerable as the

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people that they care for (Family Caregiving Alliance, 2011). While there may be a range of triggers for aggression in care recipients, evidence suggests that caregivers are given little information about causes and triggers, about disruption of the behavior itself, or validation about the ongoing traumatic experiences that the caregiving individual may be faced with as they endeavor to keep their loved one at home. Risk to safety and well-being of caregivers is high in these situations, and the implications for ongoing care of the care recipient are substantial.

Ryden (1988) explains that “better empirical information regarding the phenomenon is essential as a basis for development of strategies for prevention and management” (p.343). This appears to remain an issue, as one systematic review published in 2011 (Enmarker, Olsen, & Hellzen), found only 21 published papers on the topic that met medium or high levels of scientific rigor. Injury and violence prevention are goals included in the Healthy People 2020 initiative, with specific focus on the impact on families and on provision of services; furthermore, violence against the elderly is highlighted as an emerging topic of concern (U.S. Dept of Health and Human Services, 2010). Since the majority of dementia caregivers are spouses who themselves tend to be elderly, this violence would meet the criteria for intimate or domestic partner violence, if not for the dementia, and although caregivers are likely to understand that the underlying reasons for the behavior are nothing like domestic violence, the resulting injuries and potential for trauma remain valid. While there are developing evidence-based models of practice with community dwelling dementia patients, disruptive and dangerous behaviors can confound the successful implementation of these models. It is imperative that we seek to understand the behaviors and processes occurring in caregiving situations involving violence; the NIH has determined that these are key variables for the sustainable adoption and implementation of evidence-based practices (NIH, 2010).

This paper examines the current state of the literature about home-based dementia caregiving and care-recipient violence, identifying the gaps in knowledge, and making suggestions as to the next steps for research. Three databases: PubMed, EBSCOhost, and PsychInfo, were searched using keywords related to dementia, aggression, and caregiving. Reference lists of articles were also hand-searched. Recent and seminal articles were included, to provide a comprehensive view of the literature.

Definitions, incidence, and correlations to premorbid personality traits

A universally accepted definition of violence by dementia care-recipients has not yet emerged, and the language that we use to discuss the issue can be problematic. “Aggression” and “violence” are value-laden terms, and reliable definitions that recognize the unique situation of dementia sufferers who are responding to stimuli have not been agreed upon in the literature. Previous studies have enumerated a number of items which should be included in any such definition, however. For the purposes of this review, violence is defined as physical aggression or hostile action with physical contact or attempts at physical contact, or threats of physical contact and aggression. This includes assault that may result in major or minor injuries, or that may result in no injury. Assault may include being hit, kicked, pinched, shoved, grabbed, or bitten. Assaults in this context may also include believable

threats to the caregiver(s), or physical aggression against property which could induce fear of assault or danger to the caregiver (Galinsky et al., 2010; Shah, 1995; Ryden, 1988; Enmarker, Olsen, & Hellzen, 2011; Kunik et al., 2010). Note that “agitation” is not necessarily “aggression.” These two concepts are not always clearly separated in the literature, but while agitation generally implies verbal or physical behaviors related to discomfort or confusion, aggression clearly implies hostile physical motion, regardless of the trigger or intent. Aggression, in general, usually does not persist through the entire course of the disease, although some analyses have found that physical aggression tends to persist through advanced stages (Brodaty & Low, 2003).

Behavior is communicative for cognitively impaired individuals who may have lost other means of expressing needs. Violent or aggressive behavior, however, can have substantial consequences on the quality of care received, the use of chemical or physical restraints, increased caregiving burden and potential for trauma, and increased healthcare costs, as well as the safety and health of the caregiver (Kunik et al., 2010a; Matsumoto et al., 2008; Orengo et al., 2008). For these reasons, more information and interventions to effectively manage violent and aggressive behaviors while preserving the communicative properties of these expressions are needed.

In the case of military veterans, there may be exceptional risks. In a study of newly dementia-diagnosed veterans in 2008, Orengo et al. found that 20% of all participating veterans exhibited aggressive behavior at the baseline screening, somewhat higher than estimates of early stage aggression in the general public (13%). However, Kunik states, “There is no aggression gene. There are no absolute indicators in a person’s history that they will develop aggression. It is not directly connected to combat duty or PTSD” (Petersen, 2010). Despite this caution, a recent study led by his team found a tenfold increase in injury rates related to violence by veterans with dementia being cared for in their homes (Kunik et al., 2010a). Further study with this population is clearly warranted.

In 2006, the incidence of death by Alzheimer's disease was 177 per 100,000, with rates for all dementias estimated to be slightly higher, if harder to track (Older Americans, 2010). There is a distinct population of dementia patients who are physically violent: Shah (1995) estimated between 18-35%; Kunik et al. (2010b) reported 35-64% in community dwelling persons, and 37% in male Veterans; O'Leary, Jyringi and Sedler (2005) report one study of community dwelling elders where aggression occurred in 24% of dementia patients, but in only 3% of participants without dementia; they also cite a study in which a standardized instrument measuring violence was used, indicating that 15% of the participants were rated as severely violent, and report findings from their study of institutionalized dementia patients where 25% had been violent against their caregiver in the past year and 33% had been aggressive against another individual (not necessarily the caregiver) in the past two weeks. Cooper, Selwood, Blanchard & Livingston (2010) report on two studies, one in the US and one in the UK, where greater than 20% of people with dementia in each country were reported to exhibit aggressive behaviors (p.592). They also report that their study (N=220) found that over 1/3 of family caregivers reported being abused by their care-recipient.

There is some evidence of correlation in the literature between premorbid aggressiveness and violent behavior in advanced dementia patients. Ryden (1988) found 65% (N=183) of study care-recipients showed aggression of some kind (46.4% physical aggression, and 17.5% sexual aggression); 40.4% of these showed premorbid aggressive behaviors. Hamel (1990) found 34% (N=175) of care-recipients showed physical aggression, and 10% of these had premorbid aggression. Chen, Ryden, Feldt, & Savik (2000) hypothesize that the high correlation between aggressive behavior and alienation from family members found in their study may be related to premorbid personality characteristics. Kunik et al. (2010b) found that in a study of 215 newly diagnosed dementia patients who had never exhibited aggression or violence previously, 41% developed aggressive behaviors over the course of the two year study (0.37 cases per year at risk, or 40% of newly diagnosed pts per year; p. 1150 and 1153). Additionally, there have been several studies linking testosterone and estrogen levels to aggression levels in elderly men, and research seems to suggest that this correlation is both strong and worthy of continued study (Kyomen, Nobel, & Wei, 1991; Orengo et al., 2002).

There appears to be no empirical evidence to indicate any predictors related to caregiver demographics or qualities. Evidence suggests that prevalence of aggression and violence does not differ by gender or by type of dementia (O'Leary, Jyringi, & Sedler, 2005, p.403).

Triggers to violence & issues of homecare and healthcare services

There are a number of things which have been correlated in the literature as triggers for violence, including: pain, reduced vision and/or hearing, changes in the environment, excessive noise or activity, locked doors, limited privacy or space, and quality of relationship with caregivers (Enmarker, Olsen, & Hellzen, 2011; Kunik et al., 2010). Depression and premorbid aggressive personality traits may also be related to aggressive or violent behavior (Enmarker, Olsen, & Hellzen, 2011; Kunik et al., 2010; O'leary, Jyringi & Sedler, 2005). O'Leary, Jyringi & Sedler (2005) found a significant correlation between depression and physical aggression against the caregiver ($p<0.05$; p.403), and some evidence suggests that testosterone levels may be related to aggression in dementia patients, although not agitation (Orenga et al., 2002).

To complicate matters, although physical or chemical restraints are frequently used to try to manage behaviors, there is little evidence that restraint of any kind is either an effective or safe method, although some medications have been found to have more impact than others (Brodaty and Low, 2003; Chrzescijanski et al., 2007; Enmarker, Olsen, & Hellzen, 2011; Kunik et al., 2010b; Rayner, O'Brien, & Schoenbachler, 2006). Questions have been raised about the ethical implications of medication and restraint use, noting that such methods are the antithesis of person-centered care (Chrzescijanski et al., 2007), and some additional cautions in the literature note that some classes of medications may actually increase behavioral disruptions (Desai & Grossberg, 2001; Rayner, O'Brien, & Schoenbachler, 2006). Desai and Grossberg (2001) note that "Many patients ... are often inappropriately prescribed psychotropic medications, which are then inadequately monitored and reviewed, with the potential for serious detrimental consequences" (p.93).

In home care settings, the impact of violence on caregiving can be significant (Geiger-Brown et al., 2007). Violent behaviors are sometimes seen in patients who have few other life-threatening or immobilizing illnesses and may be living in the community with caregivers. There is substantial evidence supporting aggression as a significant predictor of institutionalization (Brodaty and Low, 2003; Chrzescijanski, Moyle, & Creedy, 2007; Matsumoto et al., 2007; Orengo et al., 2008). O'Leary, Jyringi and Sedler (2005) state that "abuse of caregivers is one of the key factors leading to placement of Alzheimer's patients in residential care facilities" (p.401). Additionally, there is anecdotal evidence suggesting that although rates of desired placement by caregivers may be high as a result of these challenging or dangerous behaviors, these patients are difficult to place in long-term care (LTC), since they may not need skilled nursing care, despite behavioral problems. As a result, they may have poor quality of life and poor end-of-life care in home environments (Wagner-Felkey, 2011; Malone, 2011). Chrzescijanski and colleagues (2007) discuss the salience of this issue, noting that "managers of nursing home facilities, including some 'dementia specific' units, are often apprehensive about admitting people with challenging behaviours such as aggression" (p.272). Aggression towards caregivers in home environments can result in injury or trauma to the caregiver and may impact health outcomes for caregivers (Cahill & Shapiro, 2008). There is some evidence that home healthcare workers are four times more likely to experience assault if they have one or more patients with dementia (Galinsky et al., 2010), and this led to significantly shortened home care visits (impact on quality of care). In LTC environments: "Being subjected to abuse ... may compromise a workforce's ability to provide person-centered care" (Scott, Ryan & Mitchell, 2011, p.111). Evidence suggests that "a majority of providers actually experience acts of violence" (Enmarker et al., p.154; Irvine et al, 2011).

Matsumoto et al. (2007) report that care-recipient behaviors "may be the most important care recipient variable in terms of their adverse impact on caregiver burden" (p.220). Caregivers receive little information about dealing with challenging behaviors, and while healthcare personnel are trained to ask about elder abuse of vulnerable care-recipients, there is infrequent inquiry into abusive behavior towards the caregiver (Cooper, Selwood, Blanchard, & Livingston, 2010). Ryden (1988) suggests that need for assistance by caregivers motivates participation in interventions (i.e., the more violent the care-recipient, the more need for assistance by the caregiver); for this reason, support and training groups may hold promise as an intervention for caregivers, both professional and informal. Although interventions of this type seem to offer the most optimistic path forward, there are a few cautions to be noted. It is perhaps worthy of consideration that caregivers may inadvertently be given the message that 'if only you could identify the triggers,' this would not be as problematic or dangerous; in giving such a message, we not only fail to validate the experience of the individual on the receiving end of the aggression, but set up a dynamic where they may self-perceive that they are at fault for their own trauma.

Existing interventions & previous related work

Ryden (1988) found that only 38.3% of caregivers had received suggestions from healthcare personnel, although 70% of caregivers with a severely aggressive care-recipient had found strategies to avoid conflict. Some of these included: distraction, ignoring, positive nurturing,

and maintaining routines. Enmarker et al. (2011) reported on several strategies for reducing conflict that showed promise in the literature, including person-centered care planning, personalized and respectful bathing and toileting routines, personalization of patient's bedrooms, respect for privacy and dignity, and person-centered interactions outside of ADL management. Effects of these types of interventions were reported to reduce aggression by as much as 60% (p.159). Indeed, Whall et al. (2008) found strong evidence relating bathing and aggressive behavior in nursing home settings, implying that this is one of the most challenging aspects of care, and that attention to adaptation this task could substantially reduce behavioral disruption.

There is some evidence that interventions focused on coping strategies for the caregiver may increase the sense of personal reward and decrease the overall subjective burden of caregiving in this type of situation, although these strategies remain theoretical for caregiving situations with violence present. Cooper et al. (2010) report that "emotion based coping strategies can mitigate the impact of burden on dementia carers' mental health" (p. 592). The REACH studies promoted a problem-focused approach to behavioral management, and some success with agitation and distressing behavioral problems was evidenced, as well as increased caregiver self-satisfaction, although violence was not a specific focus of that intervention (Gallagher-Thompson et al., 2003).

Desai and Grossberg (2001) discuss the Progressively Lowered Stress Threshold Model (PLST), which aims to decrease behavioral disturbance by adjusting and adapting environmental stressors. They identify six areas where disruptive behavior may be triggered: fatigue (in the patient); overwhelming stimuli; changes of environment, routine, or caregiver; excessive demand; perception of loss (by the patient); and delirium. They note that there are a range of behavioral interventions that may be helpful in decreasing aggressive behaviors, and that psychopharmacological interventions should be reserved until after these have been tried, since evidence suggests low rates of medication success. Some of the suggestions include music, pet therapy, simple activities like sorting or folding, and regular exercise. They also suggest a focus on "humanizing" the environment to reduce patient stress and return as much control as possible to the care recipient. Although their focus is primarily on institutional settings, there is the suggestion that such techniques would work equally as well in a home-care setting. This is consistent with other recommendations in the literature, particularly where cautions about the "start low, go slow" approach to chemical interventions are noted, and nonpharmacological interventions recommended as the first line of approach (Reyner, O'Brien, & Schoenbachler, 2006).

There have been several interventions designed for formal (professional) caregivers, primarily those in LTC settings. Chrzescijanski, Moyle, & Creedy (2007) describe a number of promising educational interventions that they used as a basis for the design of an emotion-based, active-learning oriented staff educational program for addressing aggression. These authors found a direct relationship between staff attitude and management of aggression, and while intensity of aggression did not reduce, frequencies of episodes did. Irvine et al. (2011) found that an internet-based dementia aggression training for nursing assistants demonstrated a viable approach that was manageable for workloads, administered with little supervision and high fidelity, using a series of short, interactive modules. This study was a

redesign of a prototype used in a previous study (Irvine et al., 2007), and was an expansion of previous attempts at internet-based trainings for dementia care for nursing assistants (Hobday et al., 2010; McDonald, Stodel, & Casimiro, 2006; Rosen et al., 2002).

Impact

Further research is needed to gain insight into the lived experience of caregivers and healthcare providers taking care of care-recipients with dementia who are violent, and to develop a theoretical model for how violence and aggression in care-recipients impacts on the health outcomes of both care-recipient and caregiver. Such research could be used to inform consideration as to what points of intervention might exist, and what types of interventions might be feasible, effective, and cost-effective with these families. There seems to be support for both case management types of programs and internet-based models of training delivery (Family Caregiver Alliance, 2011; Vickrey et al., 2006). One study found that technology guided care management programs were both successful and cost-effective, noting that “Improvements were noted in all domains, including caregiver education and support, where there is evidence linking provision of such services to delays in institutionalization, and safety, which is particularly important because appropriate care could prevent rare but severe adverse outcomes” (Vickrey et al., 2006, p.719). Such models could potentially be adapted for use with informal caregivers, using either home computers or potentially through apps for smart phones or tablet computers, once specific needs are identified. These kinds of technology based models are effective and lower costs not only for training but also for interventions, and hold great promise for further development.

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