Older adults neglected by their caregivers: vulnerabilities and risks identified in an adult protective services sample

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Abstract

Purpose – Using a risk and vulnerability framework, the purpose of this paper is to describe the characteristics of older adults that Adult Protective Services (APS) substantiated for neglect by caregivers, their caregivers and the interrelationships between them.

Design/methodology/approach – The paper uses a qualitative study of 21 APS case record narratives using a template analysis.

Findings – Neglect related to withholding or refusing medical care was the most common. The older adults had multiple health conditions and geriatric syndromes. Caregivers had difficulties in carrying out caregiving role due to health and mental health issues, work responsibilities and lack of insight into older adults’ needs. The refusal to access or accept services by both the older adults and the caregivers was a predominant theme.

Research limitations/implications – The sample size was small, limited to one geographical area, and non-representative of all neglect cases. The data were extracted from written case narratives and not directly from the older adults and their family members. Case records varied in the case detail provided.

Practical implications – To protect vulnerable older adults and improve quality of life, APS involvement in cases of caregiver neglect needs strategies to get people to accept help and access services to address multiple health and psychosocial problems for both older adult victims and their caregivers.

Originality/value – This study provides in-depth information on APS cases involving caregiver neglect that add to understanding of this complex problem and points to areas for further study.

Keywords Older people, Safeguarding, Neglect, Risk factors, Elder mistreatment, Caregiving, Adult Protective Services

Paper type Research paper

Elder mistreatment is a serious social problem that affects an estimated one in ten older adults each year (Acierno et al., 2010). Elder neglect is the “failure by a caregiver or other person in a trust relationship to protect an elder from harm or the failure to meet needs for essential medical care, nutrition, hydration, hygiene, clothing, basic activities of daily living or shelter, which results in a serious risk of compromised health and/or safety, relative to age, health status, and cultural norms” (Hall et al., 2016, p. 34). In the USA, caregiver neglect is the second to self-neglect as the most common type of mistreatment reported to and substantiated by Adult Protective Services (APS) (Acker et al., 2018).

Despite the serious risks to well-being of frail older adults, neglect by caregivers is difficult to study, characterize and understand (Strasser and Fulmer, 2007). Evidence on risk factors and for the effectiveness of interventions (including APS) that target elder neglect is lacking (Ayalon et al., 2016). Indeed, “the number and type of services needed by type of elder abuse, or by victim-offender relationship, has not been assessed in the elder abuse field” (Jackson, 2017, p. 221).

Research on elder mistreatment including neglect presents ethical and practical challenges (Dresser, 2003). The research subjects are often vulnerable older adults who may be cognitively impaired. Participation in research may have negative legal, social and financial repercussions for older adults and their caregivers. Research on neglect assessment in emergency departments

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underscores the practical challenges; the researchers screened over 3,500 older adults to identify 86 cases of neglect to analyze (Fulmer et al., 2005b).

Given these challenges and need for knowledge related to neglect and to APS practices, this qualitative study used case record narratives from a large department of social services in a suburban county in the USA. It aimed to describe and categorize the demographic, health, and mental health characteristics of older adults that APS confirmed for caregiver neglect. This study also sought to describe characteristics of caregivers and to examine the interrelationships between victim and caregiver characteristics. In spite of their limitations as a data source, agency records offer descriptions of the life situations of older adults and their caregivers, which are necessary to understand neglect.

Theoretical framework

This study used a risk and vulnerability framework, which has been used in studies focusing specifically on elder neglect by Fulmer and colleagues (2005a). The framework focuses on the vulnerabilities of the older person, the risks or presence of potentially stressful factors, in the environment, including the caregiver, and the interaction between the caregiver/care recipient dyad (Fulmer et al., 2005a). It posits that the characteristics internal to the older adult (vulnerabilities) and the characteristics of the environment, including caregiver health and social support, interact to result in the neglect of the older adult.

There are differences in risk factors for caregiver neglect when compared with other types of mistreatment (Acierno et al., 2010; Jackson and Hafemeister, 2011; DeLiema et al., 2018). However, most studies “do not separate neglect from overall mistreatment sufficiently, do not look at the caregiver side of neglect, and do not sufficiently assess the older person’s overall functional and health status for the purpose of understanding vulnerabilities for neglect” (Strasser and Fulmer, 2007, p. 342). Studies also exclude neglected individuals with cognitive impairment (Acierno et al., 2010). Understanding the events and circumstances of elder neglect confirmed by APS will help identify ways in which intervention could occur and neglect prevented.

Literature review

This review focuses on agency-, hospital- and population-based studies that examined characteristics of neglected older adults and their caregivers. While the research on risk factors for elder abuse or mistreatment defined more generally is extensive, fewer studies examine neglect by caregivers separately or solely (see e.g. Dong, 2015).

Characteristics of neglected older adults

Demographics. The National Elder Mistreatment Study (Acierno et al., 2010) revealed that the overall prevalence of neglect, characterized as unmet needs, is 5.1 percent, and found that “risk of potential neglect was predicted by minority racial status, low income, poor health, and low social support” (p. 294). These findings were consistent with those of a study of mistreatment of persons with dementia; neglected individuals were more likely to have lower income and education than those who were physically abused (Wiglesworth et al., 2010). Some studies of cases confirmed by APS show that neglected older adults are more likely to be non-white, female and older than other mistreated older adults (Lachs et al., 1997; National Center on Elder Abuse, 1998). In contrast, a study of APS cases in Virginia found that neglected individuals were more likely to be younger than those confirmed for physical abuse or financial exploitation (Roberto et al., 2004). A study of 781 hospitalized older adults in Israel found that the 14.1 percent identified as neglected were significantly more likely to be female, older and poorer, and to have less education than non-neglected patients (Cohen, 2008).

Cognitive impairment. A study of neglect uncovered in hospital emergency departments found that the neglect group had significantly lower scores on the Mini Mental Status Exam than the non-neglected older adults (Fulmer et al., 2005a). Other studies also have found that poor
cognitive status is associated with neglect (Jackson and Hafemeister, 2011; Heath et al., 2005; Iecovich, 2005).

Health problems/geriatric syndromes. Studies of older individuals involved in APS reveal their vulnerability to physical and mental illnesses and injuries (Heath et al., 2005; Wiglesworth et al., 2009), likelihood of institutional placement (Lachs et al., 2002) and increased risk of mortality (Lachs et al., 1998).

As they age, many people experience common health conditions, known as geriatric syndromes, such as frailty, pressure ulcers, falls, incontinence, delirium and declining functional status. Geriatric syndromes have multiple causes and affect quality of life and disability status. Risk factors include older age, cognitive impairment, functional impairment and impaired mobility (Inouye et al., 2007). Although they are frequently present in adults who are mistreated, they do not alone confer special vulnerability status in terms of elder neglect. While care must be taken not to over- or under-diagnose neglect on the basis of these syndromes, neglect status is associated with certain syndromes (Collins and Presnell, 2007).

Frailty is identified by the presence of three or more of the following: unintentional weight loss, weakness, poor endurance and energy, slowness and low activity level (Baker, 2007). Frailty was significantly associated with neglect in a sample of community-dwelling hospitalized older adults in Israel (Cohen, 2008). Incontinence was significantly associated with neglect identified through screening in a hospital or emergency room (Cohen, 2008; Fulmer et al., 2004) and in older persons confirmed as neglected by APS (Heath et al., 2005).

Poor nutritional status was associated with neglect uncovered in hospital settings (Cohen, 2008; Fulmer et al., 2004). Neglected older adults had lower albumin levels (a measure that signaled poor nutritional status) than non-neglected older adults (Cohen, 2008). Older adults who screened positive for neglect in hospital emergency departments were more likely than those non-neglected to have evidence for dehydration, and to have decubiti and urine burns (Fulmer et al., 2004). Eight autopsies of neglected older adults revealed five had sepsis from severe decubiti and three had experienced severe dehydration, underscoring the seriousness of these risks (Collins and Presnell, 2007).

Several studies have found an association between neglect status and functional status, the older person’s ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Older adults identified as neglected during emergency department visits had higher instrumental unmet needs for care than non-neglected adults (Fulmer et al., 2005a; Fulmer et al., 2004). In a sample of 95 APS cases, neglected older women had poorer self-care abilities and were more likely than physically abused women to be mistreated by female caregivers (Roberto et al., 2004). ADL impairments were most prevalent in those identified with medical neglect/self-neglect when compared with cases where other types of neglect were present and non-substantiated cases (Choi et al., 2009).

Characteristics of caregivers

Relationship to older adult. While research does not tell us whether the specific relationship of the victim to the perpetrator is predictive of neglect, living with others has been documented as a risk factor for mistreatment (Johannesen and LoGiudice, 2013). When compared to self-neglecting older adults, those abused and neglected by others are more likely to live with their spouse, children or others (Choi and Mayer, 2000). Cohen (2008) found that deteriorated health conditions and personal neglect “were predicted by patients’ higher functional disability and children being their main caregivers” (p. 707). However, other types of neglect, such as delay in seeking medical care or missing appointments, were predicted by low levels of caregiver education but not by the relationship between the older adult and his or her caregiver (Cohen, 2008).

Mental illness and/or substance abuse by caregivers are risk factors for elder mistreatment (Johannesen and LoGiudice, 2013). One study found that nine caregivers who admitted neglect had significantly higher anxiety scores than abusers; the researchers hypothesized that these caregivers coped with their anxiety and distress by avoiding the caregiving role (Reay and
Browne, 2001). Another study of caregiver/care recipient dyads found that caregiver IADL/ADL impairments and physical symptoms were predictive of the caregiver provision of lower quality care, which could lead to neglect (Beach et al., 2005).

Many studies of caregivers have increased the understanding of “self-perceived caregiver skills, and constructs such as self-efficacy, caregiver mastery, competence, preparedness, and quality,” in addition to their attributes with “respect to perceived burden and quality of care” (Strasser and Fulmer, 2007, p. 342). A study of elder mistreatment among 129 caregiver/care recipient dyads revealed that caregivers who neglected their older care recipients tended to be socially isolated and to have higher perceived burden than non-neglectful caregivers (Wiglesworth et al., 2010).

**Risks in the environment**

Research with health care providers and social workers highlights risks that arise from the context and nature of relationships between older adults, caregivers, other family members, and the wider social network, including how decisions about care are negotiated. Individual and focus group interviews with health care providers regarding the recognition of older adult maltreatment in hospital settings noted the “complicated dependency issues surrounding family and carer perpetrators of abuse” that included the patient’s desire to go back to an abusive situation and remain independent and the family’s desire to preserve assets rather than investing more in providing optimal care for the older adult (Joubert and Posenelli, 2009, p. 710). The health professionals saw the potential for non-deliberate neglect where caregivers’ intentions and actions were misguided due to difficulties in coping with the strain of caregiving. This study also concluded that the “complexity of family relationships and the dependency issues surrounding suspected abuse of the aged are subtle and can make detection and referral difficult” (Joubert and Posenelli, 2009, p. 711). Indeed, social workers recognize the difficult choice between removing an unwilling victim against his or her wishes and leaving the older adult in an unsafe situation (Band-Winterstein et al., 2014).

The role of the caregiver’s dependency on the victim differs by the type of elder mistreatment. A study of cases reported to APS found that physical abuse cases were more likely to involve perpetrators who were characterized as “parasitic” in their dependence on the victim. In contrast, the neglectful caregivers were more likely to be overburdened in the provision of support (Jackson and Hafemeister, 2011); a study of perpetrators revealed that caregivers substantiated for neglect by APS were less likely to exhibit negative characteristics associated with elder abuse such as dependency on the victim and problems with alcohol (Deliema et al., 2018).

The review of research on neglect by caregivers reveals inconsistencies in findings of studies using different data sources, definitions, and methodologies. However, the research reveals that neglected individuals are more likely to be poor, female and cognitively impaired, and to have multiple health problems. Neglect is associated with frailty, pressure ulcers, incontinence, and low functional status, highlighting the need for care that requires time, attention, and the ability to deal with complex health needs. Caregivers have challenges related to mental illness, substance abuse, and the nature of their relationship with the older adult. Relationships between older adults and the caregivers who neglect them are characterized by their complexity, making it difficult to address in ways that guarantee the older adult’s safety. Even though research identified characteristics uniquely associated with caregiver neglect, more knowledge development is needed. This qualitative study sought to uncover details about the characteristics of neglect as addressed by APS that would provide insight and direction for future research.

**Method**

**Setting and sample**

This is a qualitative content analysis of the referral narratives, risk assessment reports, and closing narratives drawn from the records of 21 non-institutionalized community-dwelling older individuals (aged 65 and older) who were confirmed for caregiver neglect by APS between 2005 and 2007. An APS program in a large suburban county in a Mid-Atlantic state provided the records. During the time period studied, approximately 500 cases of maltreatment were
investigated per year with over half confirmed. The majority of the cases were for self-neglect; an average of 49 cases of caregiver neglect were confirmed per year (Ernst, 2009). Identifying information was deleted from the records prior to the analysis by a research assistant who had signed a confidentiality agreement. The study was approved by the Hood College Institutional Review Board.

**Study procedures**

Each file consisted of opening and closing narratives, a psychosocial assessment, a risk assessment and a health/psychosocial assessment completed by a nurse and a social worker who performed the initial investigation. The records also contained contact logs that were either typed or handwritten, and copies of forms, correspondence and miscellaneous items such as directions to the client’s home.

The author employed a template analysis (Crabtree and Miller, 1993; Miles and Huberman, 1994) and, using Microsoft Access, developed a list of code families and codes a priori. The codebook specified code definitions and examples (MacQueen et al., 1998). The code families related to vulnerabilities of older adults, and risk factors at the level of caregiver, the family context, and the social and physical environments, the characteristics of the mistreatment and APS services. It was developed using the risk and vulnerability framework and the literature on elder neglect. For example, the “Caregiver” (CG) code family included codes for caregiver’s health and mental status, substance abuse, and capabilities. The latter was used to code text that referred to the extent to which the caregiver was capable of caring for the older adult.

Using Atlas.ti software, which allows for the researcher to create a “hermeneutic unit” that contains primary documents (in this research, the case file contents), codes and memos, a trained research assistant coded the referral narratives, risk assessment reports and closing summaries for each case and created memos and tables summarizing themes. The author reviewed the coded narratives, and differences were resolved through discussion. The coded passages were categorized, grouped, and summarized to provide a picture of risks and vulnerabilities and service characteristics. For example, passages in the record that referred to any health conditions that the client had were given a label of “CR-HS” (care recipient-health status). All coded passages were then examined and further grouped into specific types of health conditions or health-related concerns (e.g. diabetes or multiple morbidities), which allowed for the development of themes related to the vulnerabilities of the older adult.

**Findings**

The age range of the sample of twelve women and nine men was 69–97, with a mean age of 82.1 (SD = 6.9). In total, 16 (73.9 percent) were white, 2 were Hispanic, 2 were African American and 1 was Asian. Five had immigrated to the USA as adults. Also, 11 were widowed, 8 were married and 2 were single (never married). Eight (38.1 percent) were classified as low income and twelve had incomes defined as middle or upper middle class; one case had no information on income. Eight caregivers were spouses: seven wives and one husband. Seven caregivers were adult children, one was a sibling, four were other relatives and one was unrelated to the older person.

Following the discussion of case characteristics, findings are discussed related to the vulnerabilities of the neglected older adults, followed by the findings related to risk factors at the level of caregiver, the family context and the wider social context.

**Case characteristics**

The majority of referrals came from health care providers. Caregiver neglect was the sole reason for the first referral in 11 of the 21 cases (52 percent). Seven (33 percent) had a second referral; in three cases, neglect was not confirmed until the second time the case was investigated; in one case, caregiver neglect was not reported the first time that the case was investigated. The most common types of neglect involved the refusal to access medical or home health services or withholding medical care (eleven cases), or misuse or withholding of medication (eight cases).
Other neglectful conduct by caregivers included the older person being left alone (seven cases), the older person locked in a room or house (two), older persons whose nutritional needs were neglected (two) and an older person who was ignored, failing to provide personal care such as bathing and toileting, and the failure to change wound dressing (one case each). The majority of the older adults lived with their caregivers; however, in two cases, the reason for the report was the older adult was left alone in her own home without adequate supervision either overnight or while the caregiver was at work. In these two cases, the older adults had dementia and could not provide for their own nutritional or safety needs (e.g. the older adult left the stove on).

The length of service provision ranged from 1 to 40 weeks (mean = 14.4, median = 10). APS workers averaged 3.3 face to face contacts with clients and provided services primarily via telephone and contacts with collaterals.

Vulnerabilities of the older person

Many of the victims had multiple chronic illnesses and conditions. The vulnerabilities can be categorized in terms of specific health conditions, multimorbidities, geriatric syndromes and the adults’ functional abilities.

The older adults experienced chronic and acute health problems. Conditions related to the cardiovascular system were the most common. Ten records mentioned heart disease, congestive heart failure or various types of cardiac arrhythmias (e.g. tachycardia, atrial fibrillation), while nine noted high blood pressure. Eight of the individuals were recovering from a stroke, and six had diabetes. Less frequently mentioned conditions were lung problems/COPD (five), Parkinson’s disease (two) and cancer (three).

Multiple morbidities were common. Six had combinations of heart disease, lung disease and/or diabetes. Nine individuals had two or more of the following conditions: heart disease, lung problems/COPD, diabetes, cancer and Parkinson’s disease. A total of 13 had dementia plus one other chronic illness. There were no differences by gender or age in having multiple conditions.

Of the 21 cases, 20 mentioned at least one geriatric syndrome (e.g. falls, incontinence, delirium or a declining functional status). Nine cases mentioned incontinence, nine mentioned malnutrition or dehydration and two mentioned pressure sores. The case record mentioned cognitive impairment or Alzheimer’s disease in sixteen cases. Of the 21 individuals, 15 had limited or no ambulation.

While six cases explicitly mentioned “functional decline,” the records indicate that most of the older adults had reduced functional ability. Each case record contained a 15-item rating form for ADLs and IADLs. Each item was scored 0 = needs complete assistance; 1 = needs some assistance; or 2 = needs no assistance. The highest score possible is 30; scores ranged from 0 to 18 (mean (SD) = 8.8 (5.7)).

Risks in the environment

Several themes around the health, mental health and capabilities of the caregivers emerged. Some case narratives offered a detailed picture of caregiver characteristics and what the caregivers did and did not do for the older adult. Others provided fewer details about the caregivers’ abilities to provide the care needed.

Caregiver health status. Of the 21 caregivers, most of them spouses, 8 had chronic health conditions, physical limitations or illnesses. The health problems included arthritis, COPD, cancer, diabetes, bronchitis and obesity. Other conditions included poor eyesight and mobility limitations. One daughter, the oldest of several siblings, had multiple health problems including lupus, diabetes, morbid obesity and arthritis. She was described as too ill to care for either her mother or herself even though she insisted on providing care. A hospitalized husband left his wife, who had dementia, alone in their home. Two other caregivers were also described as having physical health problems that interfered with their ability to care.

Mental health/substance abuse. While no formal diagnoses were recorded, several narratives mentioned caregivers’ psychiatric symptoms such as mania, paranoia, agoraphobia or delusions.
An elderly sibling, described as “paranoid and suspicious,” refused to let hospice personnel have access to the client, which likely resulted in a worsening pressure ulcer and hygiene for a dying woman. The record noted that “sister has not allowed aide to provide personal care to her sister” and “was blocking their entry into the house to provide services for the client.”

A son hindered the attempts of hospital and community-based health care providers to treat his mother for psychiatric and physical health problems. The record described his behavior during his mother’s hospitalization as “disruptive and obstructive” and noted mania, delusions and grandiosity. Another record indicated that a caregiving wife had not left her home for two years; she was described as forgetting to cook for or feed her husband while at the same time refusing help from her children and home health services. One caregiver was described as an “acknowledged drug addict.”

Capabilities of the caregiver. Records also described behaviors that were not attributed to any particular mental or physical health condition. Caregivers were described as overwhelmed by their responsibilities, as lacking insight into the needs of the older adults, or in denial of those needs. For example, one wife was described as “having limitations with comprehension of situation, care planning, and judgments” because she did not seem to understand the extent of her husband’s cognitive impairment. Three caregivers left the older adult alone because they needed to go to work. One woman left her ailing husband alone for the entire workday because she feared she would lose her job. Another caregiver returned his aunt, who had severe dementia, to her own apartment because she was up most the night and she wandered and her behavior was distressing to his wife, who was also caring for an infant. A third caregiver left his relative unsupervised while he worked; she had lived in psychiatric institutions while younger and the caregiver felt strongly that she should not be institutionalized.

Family involvement. Of the 21 records, 16 mentioned family or household members in addition to the caregiver. The involvement of family and other network members varied. In some cases, the involvement harmed the older adult, while in others, family members advocated to improve situations where the caregiver refused assistance. In four cases, family members such as adult children were described as distant or estranged from the older person. In five situations, the case record mentioned neither contributions to nor interference with care by other family members in the household. In three cases, the caregiver and older person refused assistance offered by family members; in two cases, adult daughters made the report to APS. In four cases, the case narrative revealed family discord over the care of the older person. In one case of alleged medical neglect, the adult children considered APS to be harassing their family.

Home environment. Of the 21 case records, 5 noted concerns about the home environment, which included single-family homes, town homes and apartments. The conditions in one apartment were “abominable,” with the smell of old food and urine and clutter including syringes found throughout. Two homes were described as dangerous due to hoarding by caregivers or others.

Use of services. Several records indicated that the decision to accept or reject services was either jointly made by the caregiver and older person, or that the caregiver reported that the client did not want services. Sometimes the rejection of services provided the impetus for the referral. In other cases, caregivers and/or the older person refused to implement suggestions made by APS or declined to follow through with referrals to other resources. In five cases, the caregivers or the older person (or both) refused to consider placement in a nursing home or assisted living facility. In nine cases, caregivers did not want to initiate or increase services from a home health agency, with one caregiver refusing “county” services. In other cases, the intervention by APS led to increased use of home health services or placement in a nursing home.

Discussion

This study revealed vulnerabilities in the older person and risks present in the caregiver, and suggested issues related to the interactions between older persons and their caregivers that contributed to substantiation by APS for caregiver neglect. Many of the neglected older adults were medically frail and cognitively impaired and had complex health needs because of multiple
chronic and acute health problems. Older adults with multiple morbidities may require more and more complex care, and treatment of one condition can exacerbate another condition. Over one-third of the caregivers had physical health problems or limitations that may have interfered with their ability to care or their insight about what was needed. The caregivers engaged in behaviors such as withholding medication and refusal to engage home health services. Many lacked financial and other resources and were overwhelmed. The study results highlight the need for more systematic information about caregivers that can be connected to the reasons why older adults do not use needed services, even when they possess resources to do so.

This study amplifies ways in which caregiver neglect is tied to the older adult’s dependence on caregivers who also have needs, creating an environment where neglect is more likely to occur. The opportunities for frustrating, confusing and annoying a caregiver who must manage multiple prescription medications, dietary needs and physical care regimes are plentiful. Geriatric syndromes, which result from an accumulation of impairments, create needs and can exacerbate the impact of neglect. For example, incontinence can lead to urine burns and other consequences; unchanged or infrequently changed linens or clothing lead to worsened pressure ulcers and create an unpleasant environment for both the older adult and the caregiver. The presence of nutritional deficits can result from deliberate withholding of food or poor oversight of an older adult’s nutritional needs.

The circumstances and characteristics of the caregiver/care recipient dyads in this study are consistent with research findings and practice experience that shows that the family relationships and the dependency issues surrounding suspected elder abuse and neglect care are very complex (Band-Winterstein et al., 2014). A skilful APS worker must be able to tease out complex family dynamics in order to determine risk of further neglect and to provide support and referrals that older adults and their families will accept.

The literature on gerontological social work and health care amplifies concerns about elder mistreatment due to the growing number of older adults and their greater longevity. Life expectancy has increased due to improvements in health care technology and delivery, but many people live longer with chronic diseases and limited functional status, which increases their need for potentially difficult, intensive and expensive caregiving for long periods of time (Berkman et al., 2006). The older adults in this study, both the neglected older individuals and in many cases their caregivers, fit this description.

Increased understanding of the dynamics of caregiver neglect is important in developing interventions to address it. This study cannot tease out the reasons for the behavior but it does identify some areas for further exploration and suggests areas where intervention could be developed. Particularly challenging are situations where caregivers left medically frail and cognitively impaired individuals alone for many hours and entire days. The finding that both victims and caregivers refused help in a number of cases highlights the need to find ways to intervene that are acceptable and that will increase safety while helping older adults maintain self-determination. While the records reveal the types of referrals that were made and the services that were offered, they do not reveal what occurred in the interactions. The challenge of getting individuals to accept services remains (Jackson, 2017).

Research has revealed that, unlike in physical abuse or financial exploitation cases, caregivers in cases reported for neglect are not likely to be “parasitic abusers” who are dependent upon the older adult for housing and material support (Jackson and Hafemeister, 2011). The cases analyzed for this study suggest that many caregivers are overwhelmed by their caregiving duties and compromised by physical, mental or other challenges. Other potential explanations, such as caregivers who do not keep up with the changing needs of the older person due to denial or lack of insight, need to be further explored in research.

Limitations

Multiple perspectives aid in understanding the complexities of elder neglect and the situations that APS must investigate (Eisikovits et al., 2013). Using case records as a source for information on elder neglect is an imperfect solution to the challenges of building knowledge on caregiver neglect. Records are “secondhand knowledge” from professionals and “may distort the actual dynamics of mistreatment by failing to present the problems and their effects as actual
participants perceive them” (Bonnie and Wallace, 2003, p. 22). Some records were far more detailed than others. While in most cases detailed information on the older person was uniformly available, information on caregivers was much less consistent. Although the cases examined are more than ten years old, practice in the agency where the data was collected with respect to neglect by caregivers has not changed significantly (personal communication, Smith, September 14, 2018).

Efforts to include both older adults and their caregivers in research on elder neglect must continue. Larger scale studies of intervention in APS funded by the US Administration for Community Living will help (Administration for Community Living, 2017), and recent studies have highlighted characteristics of perpetrators (e.g. DeLiema et al., 2018).

Conclusion

The safety and well-being of vulnerable older adults would be improved with the right combination of assistance either from family, friends and a network of agencies and resources. APS agencies need to continue to collect and analyze systematically information related to the health and functional status of clients and of their caregivers, environmental stressors and interventions offered. The analysis of this information should then shape the development of intervention strategies that will lead to greater safety and well-being of the APS clients and their families.

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