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Elder Abuse at End of Life

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ABSTRACT

***Context*: Advances in health care and changing demographics have led to an aging population whose care at the end of life has become complex. Patients at the end of life, by the nature of their clinical and social circumstances, are at high risk for elder abuse. Underreporting of elder abuse is a growing concern. The clinical presentation of abuse may overlap with the natural dying process, further compounding the problem.**

***Evidence acquisition*: Articles were obtained through a PubMed search using the terms "elder abuse" and "elder mistreatment" and from the University of California, Irvine's Elder Abuse Forensic Center library. Additional references were followed through these first set of articles and also from colleagues expert in this field.**

***Evidence synthesis*: Multidisciplinary teams have been shown to be the most effective intervention for the assessment and prevention of abuse. Most abuse occurs at home by family members; the hospice team may be the only outside professionals coming into the home. Caregiver stress and victim dependency increase the risk for abuse. Although physical abuse is the most commonly envisioned, neglect is the most common form of abuse. Financial abuse is often the underlying motivation for other forms of abuse.**

***Conclusions*: Health professionals have an ethical and legal responsibility to both report and work to prevent suspected abuse. The interdisciplinary team can make a significant impact on elder abuse, a major detriment on quality of life.**

INTRODUCTION

ALTHOUGH THE THOUGHT of a dying elderly patient being abused is almost unconscionable, abuse of the elderly at the last phase of their lives occurs everyday in the United States. In fact, seniors are at much higher risk for being abused at the end of life (EOL) because they acquire many of the risk factors for abuse as they decline. With the elderly being the fastest growing segment of the U.S. population, the problem of elder abuse can only be expected to escalate.[1] Because underreporting of abuse is a significant problem, the current picture of elder abuse at the EOL is likely the "tip of the iceberg."[2] If the palliative care team is to address this mounting problem adequately, then its team members must become capable of identifying and acknowledging abuse, report it, and put into place interventions that will reduce or eliminate the risk for future abuse.

The palliative care team (including the hospice team) is in an ideal position to identify and prevent abuse in this vulnerable group of patients. Multidisciplinary teams are the best approach to

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address the problem of elder abuse, because no single discipline has all the resources or expertise needed to effectively address all the aspects of abuse and neglect.[3,4] Elder abuse is often, by its nature, a hidden offense.[5] Victims of elder mistreatment are often isolated and may have few contacts with individuals other than the perpetrators of mistreatment.[6] The hospice professional coming into the home may be the only other contact an abused elder has with the outside world.[7]

Elder abuse is not only a social problem, but a medical problem as well. Physicians caring for patients at EOL have an ethical and professional obligation to take the leadership in addressing this issue and to develop the necessary skills in detecting active abuse and patients at risk. This review article will therefore discuss the knowledge necessary for an American palliative care professional to address this issue. While the authors have attempted to provide as comprehensive a discussion on the state of the art as possible, the intent of this paper is to provide concise, practical information rather than a theoretical discussion or a complete review of the available literature.

DEFINITIONS

The professionals involved in elder abuse cases must have a common understanding of the definitions of abuse. This common understanding facilitates communication within the palliative care team and with other agencies such as Adult Protective Services (APS).

Standard definitions for the forms of abuse exist. The American Medical Association's guidelines on elder mistreatment in 1987 define elder abuse as "acts of commission or omission that result in harm or threatened harm to the health or welfare of an older adult. . . . Mistreatment of the elderly person may include physical, psychological, or financial abuse or neglect, and it may be intentional or unintentional."[8] The National Center on Elder Abuse divides elder abuse into seven categories: physical, emotional, and sexual abuse, financial exploitation, neglect, self-neglect, and miscellaneous.[9]

Neglect is defined as the withholding of necessary food, clothing and medical care to meet the physical and mental needs of an elderly person.[2] Neglect is further separated into self-neglect and neglect by others. Self-neglect is behavior conduct by the patient themselves that threatens his or her health or safety.[10] Neglect by others is often separated into intentional and unintentional neglect. While the intention of the perpetration is not part of the determination of neglect itself, the differentiation of intent is important to prosecution and successful intervention. Unintentional neglect may stem from either ignorance or from the genuine inability to provide care.[11] Intentional neglect occurs when a caregiver deliberately fails to fulfill care-taking responsibilities, causing harm to the elderly person.[12]

Many people think of physical abuse when the term elder abuse is used, while not thinking of the other forms of abuse. Physical abuse includes pushing, striking, or causing bodily injury, force feeding, or improper use of physical restraints.[13] The withholding of pain relief is as much abuse as the infliction of pain, ethically and legally.[14] Psychological or emotional abuse includes verbal or nonverbal insults, humiliation, infantilization or threats, including institutionalization or abandonment.[15] Financial abuse includes theft, misappropriation of funds, and coercion or undue influence (such as changing of wills or deeds).[16] Sexual abuse is nonconsensual intimate contact, including with victims who do not have the capacity to give consent.

EPIDEMIOLOGY

The problem of elder abuse is steadily increasing, and palliative care professionals should appreciate the magnitude of the problem. Published studies estimate that two million older adults are being mistreated each year in the United States.[17] With an estimated 84% of elder abuse cases going unreported (or 5 of 6 cases not reported) the problem is not being adequately addressed.[2]

Neglect is the most prevalent form of mistreatment. The National Elder Abuse Incidence Study showed that 49% of reported mistreatment was neglect.[2] Of the forms of neglect, self-neglect is as common, if not more common than neglect by others. Neglect has been shown to be an independent risk factor for increased mortality.[18] The other forms of mistreatment in order of frequency are emotional (35%), physical (30%), financial (26%), abandonment (4%), and sexual abuse (1%).[2] Different forms of abuse often occur

simultaneously. One study found that 73% of elder abuse cases involved more than one type of victimization.[19] To date, no data on the demographics of elder abuse at the end of life or in the hospice population are available.

Contrary to popular belief, family members are the most frequent perpetrators and abuse occurs mostly at home. A large scale random sample study by Pillemer et al.[20] identified the spouse as the perpetrator in more than half (58%) of the cases. The National Elder Abuse Incidence Study revealed that 47% of abusers are the children of the elderly victims and that compared to the 50,000 cases of abuse reported in nursing homes, 236,000 cases of abuse were reported as occurring in the home.[2] One large survey of staff working in nursing homes found that 36% had observed physical abuse and 81% witnessed psychological abuse.[21] Recent data from a California-based study documented an incidence rate of 0.03 per nursing home beds per year.[22] Sixty percent of the cases arose from incidents of assault, battery, and neglect.

Studies have also shown that elders of all socioeconomic classes are equally vulnerable to abuse, and it is an issue that crosses all racial and ethnic groups.[23] Both men and women are equally likely to be mistreated.[3] Elder abuse transcends all social and economic boundaries. All elders at the end of life are potential victims of mistreatment, and therefore, all elderly patients and their families should be screened.

RISK FACTORS

Identifying risk factors for abuse is important for palliative care professionals in order to recognize possible victims and intervene at an early stage to prevent or stop abuse. This proactive approach is consistent with good palliative care (i.e., to anticipate the needs of the patient and family and address the problem preventatively). Because the risk factors are complex, a multidisciplinary, comprehensive approach is necessary to identify the risk factors.

The risk factors for the complex nature of elder abuse are related to the victim, the perpetrator, and the social/cultural contexts. These factors interact to precipitate abuse.[24] Therefore, not all individuals with social, physical or emotional problems become abusers, and not all abusers are so readily identifiable. Elder abuse is the outcome of a complex and troubled situation in which a wide range of medical, psychosocial, economic, and interpersonal factors converge.

The caregiver's perception of his/her own stresses appears to be one of the main risk factors for abuse, and therefore, caregiver stress should be the focus of the team's assessment. This perception is more important than the actual burden of caregiving. Studies have failed to find a direct relationship between abuse and the poor health and functional impairment of the patient or his/her dependence on the abuser,[25,26] although increasing frailty does play at least some part.[24,27] Cognitive impairment and the need for assistance with activities of daily living have been cited as important risk factors for elder mistreatment.[28] Elders who exhibit abusive or provocative behavior themselves have also been found to be at risk for abuse.[29] All of these risk factors are increasingly likely in EOL patients as they decline.

Patients at higher risk for abuse are also more likely to have a brittle or poor social support system and experience more conflicts with family and friends.[30] Perpetrators of abuse may feel that the inadequate social support means no one knows or cares about their abusive behavior. Abusers of those with a limited prognosis may fear less legal retaliation, believing their victim will not be capable to testify against them or that others (family, the legal system, and government agencies) will drop the issue once the victim is dead. Family members who financially abuse a dying patient often express the attitude, "it's all going to be mine soon anyway."

Homer and Gilleard[26] suggested that greater importance be attached to the characteristics of the abuser. Research has found that the dependency of the abuser on the elder, especially if the abuser is an adult child of the elder, may be more important than the elder's dependence on the abuser.[31,32] Elder abuse and neglect are both significantly related to poor premorbid relationships.[33] Substance abuse by the caregiver, especially abuse of alcohol, significantly increases the risk of physical violence and neglect.[27,34] Other studies have shown that abusers scored higher on depression rating scales.[35] In the home hospice setting, caregiver burnout and frustration can lead to elder mistreatment. A stressed caregiver may become abusive when overwhelmed, or exhausted. Depletion of resources or lack of skills needed to adequately care for the dependent el-

der add to the risk for abuse.[36] Family members who refuse or do not follow up with offers of respite care are at risk for neglecting the patient.

RECOGNIZING ELDER ABUSE

A comprehensive history and physical examination is critical to gathering clues suggestive of elder abuse.[37,38] Physicians are encouraged to inquire about domestic relationships between patient and caregiver as a part of the routine social history.[39] This domestic relationship history should include the exact nature and duration of the relationship, how the relationship started, and the amount of caregiving responsibility. The history should focus on the risk factors discussed above with an emphasis on coping skills, stresses, and social support systems. The interviewer should probe for the existence of one person's control over another within the relationship and for any recent changes or shifts in the power struggle. Questions should be asked about financial resources, how decisions are made, and the durable power of attorney status for both healthcare and finances. Discrepancies, such as failure to administer prescribed medications, should elicit a further evaluation of the care situation.[40] During routine visits, the palliative care team must evaluate patient and caregiver's cognitive, physical, and functional status. Questions ought to be asked in plain language and framed in a nonjudgmental way. The setting should be private and comfortable, and the patient interview should occur with and without the caregiver present. Interviewing the caregiver and the patient separately is important, not only to protect the victim from undue influence, but to also allow for comparison of the stories.

The physical examination can provide clues or "red flags" relating to abuse. Focused physical findings may confirm or alleviate the concerns that arose from the history. The clinician should carefully observe the patient's behaviors toward the family member or companion and their interaction, and be suspicious of patients who seek delayed medical attention, especially after an injury or fall.[41,42] Caregivers who refuse to leave the room during an interview may be concerned that the patient will complain of abuse.[20] Suspicions should be raised, for instance, if an elder's story appears rehearsed or the individual appears fearful, tentative, or excessively cautious in presenting information.[38] Indicators of abuse include undertreatment of pain and other nonpain symptoms, oversedation, and social isolation.[43] The psychiatric manifestations of elder abuse include resignation, ambivalence, fear, anxiety, anger, cognitive change, depression, insomnia, and substance abuse.[44] Suspicion of intentional neglect should be aroused when caregivers are not invested in the care of the patient. For instance, caregivers continue to provide shoddy care, even after being educated about the patient's needs and limitations.

The challenge in the physical assessment is distinguishing the normal dying and aging processes from abuse. The patient's general appearance may give clues to common signs of abuse and neglect including dehydration, poor nutrition, and decubitus ulcers. Aging skin undergoes changes that predispose the skin to tear with minimal trauma. These changes can be further exacerbated by nutritional deficits, use of steroids, immobilization and decreases in pain perception that are common among EOL patients. Thus, even with the best of care, elders in palliative care settings may still develop pressure ulcers. These ulcers are usually discovered in the early stages and are located mainly on the coccyx or sacrum; therefore while pressure ulcers are not avoidable in end-stage patients, severe lesions in multiple sites do suggest neglect.[45] Other factors that indicate unnatural or nonspontaneous lesions, such as burns and bruises, include circumferential lesions, signs of serial or repeated trauma, linear demarcations or patterns, and lesions in skin folds (breast folds, axilla, popliteal fossa). Failure to draw the correct etiologic distinctions could result in either false allegations of abuse or attributing the problem to age or end-stage decline. Patients with dementia and delirium may have difficultly answering questions about suspicious injuries. Therefore, the history should be corroborated and all inconsistencies investigated. When in doubt, all suspicious cases must be reported so that further evaluation may be performed by those with more expertise in elder abuse.

Financial abuse leaves telltale signs (Table 1).[46] Warning signs include the signing of legal documents[47] (wills, deeds, trusts) by a cognitively impaired individual, missing financial records such as bank statements, or evidence of undue influence (coercion or threats).[48,49] Determination of the patient's capacity to make complex decisions is often the key in financial abuse cases and re-

Table 1. Elements of Financial Abuse

Element	*Factors or action*
Vulnerable adult	Combination of medical, pharmacologic, psychological, or social problems
A trusted other	Exploits vulnerability (undue influence) Establishes trusting relationship
Transfer of assets—real, negotiable or of future value	Disproportional to benefit or wishes of victim Made during time of vulnerability Kept secret or keeps control
Lack of informed consent	Victim's capacity to make decision not determined or victim does not have full understanding Not in writing or no verification Deceit or lack of full disclosure Conflict of interest

Adapted with permission from Kemp and Mosqueda.[49]

quires an evaluation by the physician. Romantic involvement of a relative newcomer (especially of a much younger age) into a bereaved spouse's life after a death should raise concern.[50] Inability or unwillingness to provide adequate basic care or medical care, such as filling prescriptions, may be financially motivated. Thus, financial abuse is often the underlying cause of other forms of abuse and is a precursor to more gross forms of abuse.[51,52] The financial abuser and victim are typically codependent because of the financial relationship.[53] A family member's motivation for neglecting an elder at home, yet refusing placement, may be financial.[54]

REPORTING

Underreporting is a significant problem for elder abuse. A U.S. congressional report estimated that only one in six cases is reported to the agencies charged with dealing with the problem.[55] Multiple interrelated factors are responsible for poor reporting, and health care providers have identified several barriers for reporting of elder abuse.[56] These barriers include the lack of awareness of the prevalence of abuse and insufficient understanding of proper reporting procedures.[57] As a leader of the health care team, the physician should lead the decision to report abuse and not delegate this responsibility to the social worker, who may not have the medical background to reach a conclusion. Considering the many barriers and fears that discourage elderly patients from mentioning and reporting abuse, physicians can better serve their patients by becoming proactive in identify and reporting abuse.

Similar to the denial of death and dying issues by American society, denial also exists regarding elder abuse. In the case of dying patients, the clinician may have the misconception that talking about abuse will "make things worse."[58] Physicians may equate talking about family violence to "opening a Pandora's box" and fear the issue will take up too much time.[59] Reporting elder abuse is not an admission of failure by the palliative care (or hospice) team. The team members should be reassured that they have provided good care and are now taking the appropriate action by reporting the abuse.

Because the philosophy of the family as a unit of care underpins the practice of palliative care, the health care team member may be torn between loyalty to the caregiver versus patient.[60] This conflict of interest raises unique issues of reporting elder abuse in palliative care. Concerns regarding the violation of trust and the confidentiality of the therapeutic relationship between the clinician and the caregiver may impede the palliative care professional from reporting. Our society has already decided that the ethical imperative to protect the vulnerable outweighs the violation of confidentiality. This societal decision has been codified into law mandating health professionals to report.[61]

Health care professionals have expressed a sense of futility about reporting because they think no action will be taken by the receiving agency. This sense of futility may be due to a lack of understanding of the function and role of APS. While health care professionals are mandated to report, APS is ethically and legally required to maintain confidentiality. This confidentiality limits the communication APS can give to the re-

porting party, which means that the palliative care team may never find out the results of the investigation. Hospice teams are sometimes frustrated that the information flow is a one-way street.

As long as the patient has the capacity to choose, an elder does have the right to refuse abuse interventions.[62] APS cannot force placement or resources on the senior. The palliative care team may also feel helpless about their inability to "fix" the situation or influence a patient's decision.[63] Frustration, by the professionals involved, over not immediately solving the problem frequently leads to anger, guilt, and blame toward themselves or others. For complex or persistent cases, multiple reports may be needed before the social or legal system can take action. However, if the first report is never made, no action can ever be initiated.

Concerns about making a "bad situation worse" may prevent elder abuse reporting. The team may raise concerns about the patient's safety in the event that no intervention is performed and the victim stays in the abusive environment. While in some cases reporting may accelerate the inevitable outcomes, not reporting is more likely to ensure the abuse will persist and potentially worsen. When in doubt, the health care professional should err on the side of his/her ethical and legal obligation to report. Fear that the patient or family may sign-off hospice when they find out about the abuse report should not prevent the reporting. While APS protects the anonymity of the reporting party, ideally the hospice or palliative care team should inform the patient, family, and caregiver that a report is being made. This disclosure gives the team the opportunity to frame the reporting process in a positive, constructive manner and educate all involved.

Physicians should be alert to family dynamics and cultural issues that are deterrents to the reporting of elder abuse.[64] The elder might experience feelings of embarrassment, shame and guilt, especially if a family member is the abuser.[65] Additionally, in some cultures abuse may be considered a private family problem, and perceived interference by outsiders is not welcomed. Most elders want the abuse to end, but their families to remain intact, and to feel safe at home for their remaining years. The victim may not be willing to take legal action against a family member. Similar to child abuse and domestic violence victims, elder abuse victims often want to change or recant their stories as they become aware of the consequences of their accusations on the perpetrator or on their family. Such recants should not dissuade reporting.

The isolation of the victim is an additional barrier to the reporting and detection of mistreatment.[66] The abuser often prevents contact with outsiders through threatening behavior or by creating conflict in order to make visitors feel uncomfortable. Often the abuser is the only person the patient can rely on for assistance with the activities of daily living. Thus the elder may fear that institutionalization, such as nursing home placement, is the only alternative solution, and the abuser may utilize this fear.[67] The concerns of staff members for their own safety may be another factor hindering willingness to uncover abuse. Health care providers themselves may feel frightened or even threatened by an abuser. Safety measures need to be considered, to decrease possible harm to both health care providers and patients, including if necessary, involving law enforcement or the facility security.

Once elder abuse is suspected, a report should be made to the appropriate authorities. In most instances, the report should be made to local adult protective services or in the case of long-term care institutions to the ombudsman. If a potential criminal component is suspected, such as evidence of gross intent, an immediate report should be made to law enforcement. Although all 50 states have APS programs, each state has its own unique laws for reporting elder mistreatment. The reports are anonymous, and health care providers are mandated reporters in 37 states. While suspected physical abuse must be reported, the mandate for reporting other types of abuse varies.[68] Failure to comply with mandatory reporting is a crime and may result in allegations of both negligence and medical malpractice.[69] Health care providers are only required to be suspicious of abuse to file a report, and need not prove it. Most states provide reporters of abuse with immunity from criminal or civil litigation, and the reporting is not deemed a breach of patient confidentiality. This immunity applies even if the subsequent investigation determines that no abuse has occurred as long as the report is made in good faith. Because reporting requirements vary from state to state, health professionals need to know their own state reporting laws.

MANAGEMENT

The multidisciplinary team approach used by hospice and palliative care is well suited for the management of elder abuse patients. This approach can address risk factors for elder abuse including dependency and caregiver stress, and can also educate the elder and the caregiver. Prevention-oriented interventions in high-risk situations should be implemented, ideally prior to the initiation of abusive behavior.[70] In other words, the best time to intervene in abuse and neglect is before it happens.

Caregivers should be educated about what to expect during the approach to the end of life and also their role as caregivers. Ignorance of the dying process itself can be a very stressful situation. Discussion of how to handle anticipated difficult situations should also be initiated. This includes difficult medical and behavioral issues at end of life, such as abusive or provocative behavior by the patient.[71] These discussions should be individualized to each family and situation. Education can also reduce the feelings of embarrassment and shame at being a victim. Both the patient and the family should be made aware of what constitutes abuse and the resources available to them. Knowledge of the laws and regulations might deter some caregivers from abusing victims.

Anticipating the needs of the patient/family unit is not only good palliative care planning—it is also elder abuse prevention. Because dependency is one of the potential triggers of abuse interventions, reducing dependency will likely reduce the occurrence of abuse. Reducing caregiver stress and encouraging the patient's autonomy are consistent with good palliative care. The initial step should be optimal alleviation of all physical and emotional symptoms, including pain. The benefits of being maximally functional are both physical and emotional and will help maintain the dignity of elders in the final days of their lives. This increased independence and good symptom control will also benefit the caregiver by reducing the caregiving burden. Measures to decrease the burden and increase coping skills are an essential part of care at end of life.

Dispersing the caregiving responsibilities by utilizing more resources may reduce the likelihood of abuse. This distribution of responsibility will prevent one person from getting overwhelmed by the physical and emotional demands of caring for a dying elder. It also provides additional accountability, which in and of itself may prevent abuse.

Hospice programs should develop a protocol for the detection and assessment of elder mistreatment. In these situations, interdisciplinary communication and good documentation are essential. Such a practice should enable all providers in that practice setting to rapidly assess the elder and document the situation.

The responsibility of the hospice or palliative care team does not end at the filing of an abuse report. The collaboration of the palliative care professional is essential to the APS investigation and intervention. Because one third of victims refuse to even see APS, the palliative care team can serve as the major in-road to the patient and prepare the patient for the APS visit. A competent older adult may choose to stay in an abusive situation. The physician should provide to the investigating party their determination of the patient's capacity to make decisions and an estimate of prognosis.[72] Such key information is critical to the central goal of APS to balance the patient's autonomy and their need for protection. The hospice team also serves as a monitor in the home for abuse. Monitoring of the situation with the abuser knowing that someone is "looking over their shoulder" may in and of itself be a deterrent. At the time of death and the completion of the death certificate, the physician should indicate to law enforcement and the coroner the likelihood, if any, that abuse contributed to the cause of death.

For severe, acute, or persistent elder abuse situations, removal of the victim from the current care situation may be the best option. If the abuser can be removed, continuous care at home may be an option. However, all too often, the factors associated with the patient, caregiver, and family are not amenable to immediate change. The only variable subject to change is the care setting. Depending upon the goals of care, placement options include admission to an acute palliative care unit, admission under General Inpatient Status (for which abuse or neglect is an appropriate justification), or respite care at a nursing home.

CONCLUSION

Elder abuse is a growing and an under-recognized problem in the United States. Because pa-

tients at the end of life have many of the risk factors for elder abuse they are a highly vulnerable group. Palliative care specialists already have the essential skills to make a difference in elder abuse and are in a position to detect, manage, and prevent elder mistreatment. Improvements in these complex medical situations can be rewarding to an interdisciplinary team as patients are better protected and their dignity preserved. Increased collaboration between EOL professionals and those investigating abuse is needed.

There is a need for future research to examine elder abuse issues at the end of life. Examples of such research topics include

- Examining the incidence and prevalence of abuse of elderly patients at the end of life.
- Identifying and reducing barriers to reporting by palliative care and hospice professionals, including an assessment of their attitudes, knowledge, and training on elder abuse.
- Identifying the characteristics and patterns of pressure ulcer development that would distinguish ulcers from neglect and those from the natural effects of the dying process.

In the meantime, there is already sufficient information for physicians to take the lead in educating patients, families, and other health professionals and to make a difference regarding elder abuse at the end of life.

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