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Authors

Ma, Hannah
Matos, Eliana
Lee, Matteo
et al.

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Illuminating Elder Abuse in Hospice Centers: Bringing Awareness and Policy Reform to An Overlooked Crisis

Authors: Matteo Lee, Leslie Luna, Hannah Ma, Eliana Matos, Tenzing Sherpa

ABSTRACT

Hospice care amongst the elderly is not uncommon, as it specifically focuses on improving and supporting the lives of those who are either terminally ill or unable to support themselves. Over one million individuals are admitted into hospice care centers every year, and the numbers have only increased with time. However, this increase in patient quantity is accompanied with a higher risk of elder abuse within the hospice industry as a whole, as demonstrated by the five million older Americans who are abused every year.[1] Elder abuse within hospice settings is a public health issue that is not widely discussed. The abuse can appear in many forms and in all locations of patient care, from the home environment to hospice facilities. Elder abuse is wide ranging and includes physical, emotional, and sexual abuse, as well as neglect and abandonment. Older individuals, especially those who depend on care from others, are especially vulnerable to such abuse. In this literature review, we aim to uncover the truth about elder abuse in various healthcare settings. We begin with current research findings and general knowledge about elder abuse. Next, we address nonprofit versus for-profit hospice centers, as well as the responsibilities of the healthcare team to speak out against abuse. In doing so, we then propose direct, actionable solutions that are in the process or being implemented or should be implemented in order to prevent further abuse of the elderly.

[1] (February 23, 2021). Get the Facts on Elder Abuse. Accessed April 5, 2023, from https://www.ncoa.org/article/get-the-facts-on-elder-abuse

INTRODUCTION

Palliative and hospice care in Western, industrialized nations are situated at the intersections of healthcare, mortality, family, geriatrics, and politics. It presents as a valuable alternative to curative medical treatment in hospitals. Palliative and hospice care emphasize patient comfort and include psychosocial support from non-medical professionals to allow patients at the end of their lives or those living with chronic illnesses to live comfortably and happily. Hospice care discontinues life-saving treatment, while palliative care may or may not discontinue cures. However, both types of care models frequently serve a unique demographic: the elderly population. For some elderly, hospice centers are an alternate solution to aggressive treatment of disease in hospitals, but is it truly a better choice than standardized hospitalizations?

In order to answer our inquiry, we analyze several articles and papers to determine whether elder abuse plays a role in the selection of hospice care and hospice centers themselves. First, we compare the advantages and disadvantages of hospice and allopathic care. We summarize findings from observational studies on the elderly and elevated risk factors. Then we examine the financial motives of hospice centers within the overarching regulations and rules of insurance reimbursements in the American healthcare system. Finally, we enter hospice centers themselves and study the role of healthcare workers in reporting and preventing elder abuse. Through this examination, we hope to illuminate important, little-known information about hospice care.

DISCUSSION

Though misconceptions and stereotypes surround patients who choose hospice end-of-life care, it can be distilled to an individual's own choice in healthcare. Rather than pursuing aggressive allopathic treatments to prolong life at the expense of debilitating side effects, patients who choose hospice prefer to relieve pain and live their remaining days surrounded by family and friends in their home. Hospice is only offered to patients who have six

or less months to live.[2] With access to a majority of their medical team, from doctors to nurses to social workers, hospice presents as a comforting alternative to the sterile, institutionalized walls of a hospital. However, hospice as a care option is not well understood by the general public, due to societal avoidance in discussing topics surrounding death and mortality. There are a multitude of rules and regulations which dictate how each hospice center is run, the degree to which health insurance covers hospice costs, and the level of involvement of the family in the patient's health needs. For example, patients who expect to live longer than 6 months must receive approval from their medical provider before hospice care can continue.[2] The patient, who is usually elderly, is placed in a vulnerable position, in relation to both their medical team and family members. Financial incentives, familial obligations, and neglect are serious considerations about the hospice system that requires deeper analysis.

Research studies have been conducted to analyze the extent of elder abuse, and their findings are concerning. Interviews from observational studies provide data that reveal elderly mistreatment is wide-ranged, encompassing emotional to financial abuse. In "Prevalence and Correlates of Emotional, Physical, Sexual, and Financial Abuse and Potential Neglect in the United States: The National Elder Mistreatment Study," Ron Acierno et al. analyzed data that has been previously collected about the mistreatment of the elderly in the United States. The research team discovered a scarcity of existing information, as well as limitations present in previous experiments. For example, many experiments transpired more than two decades ago, and they did not have a broad population of participants.[3] In addition, studies did not include a variety of types of abuse and neglect. Acierno, a clinical psychologist, decided to conduct his own experiments in order to address these limitations. The research team created a stratified random sample by using random digit-dialing in an area throughout the United States. They designated the person in the household with the most recent birthday to be the respondent for each household and conducted interviews in English or Spanish.[3] To keep the participants protected and to limit wording biases, they asked if the participant was in a safe space to speak and formulated questions in a way that wouldn't make the participant uncomfortable or trigger strong

[2] Smith, D.G. (February 22, 2023). How Does Hospice Care Work? Accessed April 1, 2023, from https://www.nytimes.com/2023/02/22/well/live/hospice-care.html?searchResultPosition=1

[3] (2010). Prevalence and correlates of emotional, physical, sexual, and financial abuse and potential neglect in the United States: the National Elder Mistreatment Study. Accessed March 1, 2023, from https://doi.org/10.2105/AJPH.2009.163089

emotions. It is also important to note that they screened the individuals so that they could make sure that they had the cognitive capacity to consent to participation.[3] They addressed mistreatment variables of potential neglect, as well as emotional, financial, sexual, and physical abuse. What they found was that a little more than 1 in 10 of their participants experienced at least one of the forms of abuse and/or neglect and that very few incidents were reported to authorities.

There are several reasons why the elderly are an especially vulnerable population. Unique risk factors surround their situation, and many victims themselves may be unaware of their abuse. In a paper published in the Journal of Elder Abuse & Neglect, the authors conducted a meta-analysis of previous studies that aimed to prevent or stop elder abuse and neglect. The study mentions that abuse of elders can result from various factors including caregiver burden, social isolation, and financial dependency.[4] The risk factors can vary depending on the type of abuse physical, mental, or financial. The authors were able to find 21 high-quality review articles which encompassed 128 individual studies. According to the study, there is still an absence of proven intervention methods to curb elder abuse that can be implemented on a wider scale.[4] Educational intervention improves awareness of abuse and neglect in the elderly population. However, simple didactic education lacks any impact on reducing the incidence of abuse and neglect.[4] The article suggests targeting risk factors for caregivers. Taking care of older family members can require a large commitment of time and effort from caregivers. This can negatively affect their mental health and their job performance which can lead to financial hardships. As a result, it causes them to lash out at their older family members. Providing financial help for families addresses this risk factor, and there is some evidence that shows it prevents multiple forms of violence against the older population.[4] Financial assistance can be provided through increased subsidies through tax credits or in the form of government assistance to families taking care of older members at home.

Hospice centers were created to be a safe haven for elderly patients in their last stages of life. However, individual institutions vary greatly in their missions and goals and are not exempt

[4] (2020). Do interventions to prevent or stop abuse and neglect among older adults work? A systematic review of reviews. Accessed March 1, 2023, from https://doi.org/10.1080/08946566.2020.1819926

from elderly abuse. As in the majority of fields, profit often creates dishonest motivations for corporations and incentivizes individuals to only perform the bare minimum requirements to receive said profit. This is no different in the hospice industry, as demonstrated in "Differences in Care at For-Profit Hospices" by Paula Span, an article detailing how Medicare reimbursements to hospices very clearly resulted in differences in their procedures and priorities. Medicare reimburses hospices at a fixed daily rate, regardless of the length of care of the patient, meaning the more patients hospices acquire, and the faster they cycle them out of care when they become too costly, the greater the profit they would receive from those reimbursements.[5] As a result, for-profits are much less likely to train their employees in end-of-life care practices, often discharging their patients while they are still alive, about twice as often as nonprofits, demonstrated by a 2008-2009 representative national survey of nearly 600 hospice organizations.[5]

A Mount Sinai and Yale study, unfortunately, showed that cancer patients who are discharged from hospice care died within an average 24 days, actually costing Medicare more money due to their tendency to wind up in emergency rooms and ICUs afterward.[5] Although there are clearly few upsides for the patient regarding for-profit facilities, the need for these hospices to rapidly recruit new patients means that they do more outreach in low-income and minority communities than nonprofits, ironically.[5] However, this one incidental upside does little to make up for the many disservices done to hospice patients due to dishonest monetary motivations in for-profit organizations.

Within hospice centers themselves, the healthcare team and staff may not be professionally trained in working with the elderly population. The lack of education manifests in elderly abuse from healthcare providers who are supposed to be caring for their patients. In "Elder Abuse and Neglect: An Overlooked Patient Safety Issue," Janne Myhre analyzes factors that play a significant role in elder abuse in healthcare-like settings, primarily hospice care. Nursing home leaders' perspectives and personal opinions on elder abuse and neglect are the primary focus of this article since their knowledge on this phenomenon ultimately influences the

[5] (March 3, 2014). Differences in Care at For-Profit Hospices. Accessed March 1, 2023, from https://archive.nytimes.com/newoldage.blogs.nytimes.com/2014/03/03/differences-in-care-at-for-profit-hospices/?searchResultPosition=4

staff along with their willingness to dive into investigations relating to elder abuse. Surveys of sixteen hospice homes conducted in countries of both Norway and Ireland demonstrated that "91% of staff had observed a colleague engaging in some form of inadequate care, and 87% of staff reported that they themselves had perpetrated some form of inadequate care in the past."[6] Each elderly patient that entered those hospice homes hoping to be cared for had been at extremely high risk for inadequate care.[6]

This risk could further increase especially if the residents displayed any sort of aggressive behavior towards staff, even if it was by accident. When the direct-care staff were prompted to discuss staff-to-resident abuse, they primarily focused on the verbal and physical aggression that they received themselves.[7] They also noted that "We have the opposite focus in our units. We focus on staff being subjected to abuse by residents."[6] They also expressed that elder abuse was not something they took time to talk about in their daily work at the hospice. Their opinions on possible abuse from the staff revolved around whether or not it could have been an accident, and that it was all from good intentions. This scarcity of knowledge regarding possible elder abuse in the hospices is a severe issue. Although this was just one part of the study, the rest of the study also came to the conclusion that most of the care managers were not actually aware of elder abuse in their hospices or were providing possible excuses for the behavior if it was noted.[6] Overall, the findings pointed to the fact that nursing home care managers lacked awareness of elder abuse that they either heard about or saw for themselves.

CONCLUDING REMARKS

Reviewing data collected, it is clear that exploitation of elders is a widespread and common issue globally and in America. Historically, there has been legislation passed on the federal level to combat elder abuse. The Elder Justice Act, enacted March 23, 2010, was included as part of the Patient Protection and Affordable Care Act. This act of federal legislation authorized the release of federal funds to address elder abuse, neglect, and exploitation. It

[6] (March 12, 2020). Elder abuse and neglect: an overlooked patient safety issue….Accessd March 1, 2023, from https://doi.org/10.1186/s12913-020-5047-4

authorized grants for a variety of programs and resources to help gather more information about elder abuse.[7] Notable examples include strengthening long-term care staffing and designating funding to forensic centers to gather expertise about the extent of elder abuse.[7] It also allocated resources for proper training to surveyors of nursing facilities so that they recognize signs of abuse within facilities and are able to offer suitable remedies.[7] The act expired in 2014 and very little of the funding, less than 10%, was actually distributed.[8]

However, Congress has continued to slowly provide funding for both the Elder Justice Act and Adult Protective Services combined. The amount of funding for both the Elder Justice Act and Adult Protective Services has steadily increased each fiscal year. From 2018-2020, 12 million dollars were provided in funding. This funding has been used to implement programs to train employees about signs of elder abuse as well as create the National Adult Maltreatment Reporting System (NAMRS).[9] However, a majority of other programs and activities have not received funding because the expiration of the act doesn't allow for congressional appropriations. The Elder Justice Reauthorization and Modernization Act of 2021 has been introduced into the Senate and if passed, will reauthorize the Elder Justice Act and provide funding through the 2025 fiscal year.[10] This renewed bill would add onto existing programs.

Providing financial assistance to caregivers is a possible solution that can reduce multiple risk factors for elder abuse. It relieves caregiver burden and improves financial dependencies for elderly people. Financial relief can be provided as state tax credits. In 2019, the California Earned Income Tax Credit was expanded to include older adult dependents, in addition to children.[11] Using this income tax credit, caregivers are eligible to receive financial help of up to 2,000 USD. Family caregiver programs also help target other risk factors for elder abuse. Family

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[7] (n.d.). Current Federal Elder Justice Laws, National Center on Elder Abuse. Accessed April 1, 2023, from https://ncea.acl.gov/What-We-Do/Policy/Federal-Laws.aspx

[8] (August 14, 2019). It's Time to Make the Justice Elder Act More Effective. Accessed April 1, 2023, from https://www.forbes.com/sites/nextavenue/2019/08/14/its-time-to-make-the-elder-justice-act-more-effective/?sh=1bc793c05605

[9] (n.d.) National Adult Maltreatment Reporting System (NAMRS). Accessed April 1, 2023, from https://acl.gov/programs/elder-justice/national-adult-maltreatment-reporting-system-namrs

[10] (August 6, 2021). H.R.4969-Elder Justice Reauthorization and Modernization Act of 2021. Accessed April 1, 2023, from https://www.congress.gov/bill/117th-congress/house-bill/4969/text

[11] (n.d.). Eligibility and credit information CalEITC. Accessed April 1, 2023, from https://www.ftb.ca.gov/about-ftb/newsroom/caleitc/eligibility-and-credit-information.html

caregiver support programs are administered by the state or local agencies and can provide direct financial assistance, counseling, or education programs. However, these programs are often underfunded and have strict eligibility criteria that prevent many people in need of help from getting assistance. Expansion of such programs can greatly curtail many of the risk factors associated with elder abuse.

Individual hospice centers have different structural organization and mission goals. Thus, it is crucial to understand the specific guidelines that hospice organizations must follow when removing patients from their care in order to begin reducing the unnecessary discharge of patients. Some of these rules are fairly straightforward, such as the patient moving out of the hospice service area or transferring to a different hospice facility, but others, such as determining whether the patient is no longer terminally ill, or whether a patient's behavior is disruptive and impairs the delivery of care are a bit more subjective.[12] With these more fluid guidelines, the judgment falls on the individual nurse or center in deciding to discharge a patient, resulting in the untimely deaths of many individuals for the sake of profit. On a national level, these guidelines are adequate in their stringency, meaning that in order to prevent these premature discharges, individual hospices and communities must step in and adjust their regulations to benefit the needs of their elderly rather than for-profit motives. These changes might take the form of requiring a third party professional opinion in order to discharge a patient, or mandating a grace period before any individual is removed from hospice care.

Despite being well intentioned in their efforts, nonprofit hospices fall short in their outreach to low-income and minority communities, in part due to a lack of resources, and in part to a lack of diversity in their staffing.[13] Provided they receive funding from community or legislative efforts, or redistribute their resources to begin this necessary outreach, hospices could take steps to create outreach programs in settings where patients access care, such as hospitals, doctors offices, or even churches, pamphlets, posters, and testimonials from medical professionals and community leaders are compelling and effective methods in connecting with

[12] (n.d.). 42 CFR § 418.26 - Discharge from hospice care. Accessed April 1, 2023, from https://www.law.cornell.edu/cfr/text/42/418.26

[13] (2008). A review of barriers to utilization of the medicare hospice benefits in urban populations and strategies for enhanced access. Accessed April 1, 2023, from https://doi.org/10.1007/s11524-008-9258-y

target communities. Additionally, they could create partnerships with acute and long-term health organizations to improve their direct patient care and offer opportunities for education in their end-of-life care.[13] Along with these external suggestions, hospices should look inwards and ensure that the diversity of their internal teams reflects that of the communities they care for and serve.

Considering the amount of abuse that is swept under the rug at hospices and care centers for the elderly, providing better education and training regarding abuse to the health care providers that work at these facilities could provide a solution. A severe lack of training and knowledge regarding elder abuse amongst healthcare workers is one of the biggest causes of the continuation of the cycle of abuse. Better training could significantly decrease the amount of abuse that goes undercover, especially if it is well enforced. Mandated reporting should especially be emphasized, as it has the potential to help healthcare providers better recognize abuse when they witness it or become more comfortable in reporting it. Less than 2% of elder abuse cases were reported by physicians, attributed to lack of understanding of the guidelines.[14] The impact that mandated reporting has on preventing future abuse incidents is strong when its consequences are kept in mind. In a Stanford article regarding mandated reporting specifically surrounding elder abuse, they state the consequences: "If a mandated reporter fails to report, this is a misdemeanor punishable by up to 6 months in jail or $1,000 fine, or both."[15] Although these consequences are rigid, adding to their severity could enforce healthcare workers to be sterner in situations where mandated reporting presents itself as a necessity. Creating an environment in hospice centers where abuse is recognized and not tolerated, and where training is enforced, will bring about a culture where elder abuse is brought to light. Overall, this will create an improved outlook for the future of hospices and reinforce what they are known for: comfortable, end-of-life care for the elderly, surrounded by family and loved ones.

[14] (2006). Assessing barriers to the identification of elder abuse and neglect: a communitywide survey of primary care physicians. Accessed April 1, 2023, from https://pubmed.ncbi.nlm.nih.gov/16573305/
[15] (n.d.). Who is Required to Report? Stanford Medicine. Accessed April 1, 2023, from https://elderabuse.stanford.edu/reporting/who.html

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15. (n.d.). Who is Required to Report? Stanford Medicine. Accessed April 1, 2023, from https://elderabuse.stanford.edu/reporting/who.html