Neglect Assessment in Urban Emergency Departments and Confirmation by an Expert Clinical Team

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Background. Elder neglect accounts for over 70% of all adult protective services reports in the nation annually, and it has been estimated that there are over 70,000 new cases each year. The purpose of this study was to conduct elder neglect research in the emergency department (ED), using a dyadic vulnerability/risk-profiling framework for elder neglect.

Methods. Patients were recruited through four EDs in New York and Tampa from the beginning of February 2001 through the end of September 2003. Demographics, a Mini-Mental Status Examination score, and an initial elder assessment screen were collected. The diagnosis of neglect was then made by a Neglect Assessment Team (NAT) comprising a nurse, physician, and social worker, with extensive clinical experience in elder neglect.

Results. Of the 3664 ED screens of adults 70 years and older, 405 (11%) met the inclusion criteria and agreed to participate. Neglect was diagnosed by the NAT in 86 of the 405 cases reviewed. Demographic differences between neglect versus no neglect cases were examined using Fisher’s exact test, and differences emerged between the 2 groups.

Conclusion. This study documents the underreporting of cases of neglect as evidenced by differences in diagnoses by screeners versus experts. The research assistants screened positive for neglect in 5% (N = 22) of the 405 cases. The NAT made the diagnosis of neglect in 22% (86/389) of the cases. This markedly different rate of neglect may mean that ED screens are important but may underestimate the true number of cases. Conversely, an NAT may make the diagnosis of neglect in an older adult more often given a higher sensitivity and a more robust knowledge base of the problem.

The National Research Council (1) has defined elder mistreatment (EM) as “(a) intentional actions that cause harm or create a serious risk of harm (whether or not harm is intended) to a vulnerable elder by a caregiver or other person who stands in a trusting relationship to the elder or (b) failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm.” EM causes unnecessary pain and suffering among older adults, and uses enormous human resources in terms of social services and adult protective services (APS). EM, clinically, is generally agreed to be the outcome of the actions of abuse, neglect, exploitation, or abandonment. Neglect is a serious, potentially lethal problem accounting for over 60% of all EM reports made to APS annually, and likely accounts for the majority of EM among those cases not reported (2–4). Prevalence and incidence data on elder neglect are limited. Neglect was defined in one study (5) as the failure of a clearly designated caregiver to meet the needs of an older adult, and was operationalized by using the Older Americans Resources and Services (OARS) instrument subscale on activities of daily living. Operationally, 10 activities of daily living were identified, and neglect was established if 10 or more times in the preceding year someone did not help, and it was termed “somewhat or very serious” by the elder adult respondent. That study estimated neglect at a rate of 4/1000. This was a random sample survey in a community-based population, but no self-reported information was available on the caregiver.

In another study (6), an APS sample of reported cases of all mistreatment was used. Here, abuse and neglect were defined by virtue of report and corroboration to the state of Connecticut. The sample was obtained from a population-based study of 2812 community-dwelling men and women in New Haven, Connecticut who were over age 65 in 1992. An identification process was used so that those cohort members who were investigated by the Connecticut State Ombudsman on Aging in 1985 or 1986 were identified. Risk for report and investigation of EM included requiring assistance with feeding, being a minority older adult, being over the age of 75 at cohort inception, and having a poor social network as defined by a social network index. In a follow-up longitudinal study using that same cohort, this team reported on 184 individuals in the cohort seen by an ombudsman for any indication, and 47 cohort members were seen for corroboration of abuse or neglect for a sampling-adjusted 9-year prevalence of 1.6%. Of the 47 cases, 30 (64%) were neglect. Age, race, poverty, functional disability, and cognitive impairment were risk factors for reported EM; however, this study does not differentiate the independent risk factors for reporting neglect from those of other forms of EM, and does not identify risk factors specific for neglect in the sample. The researchers noted that, due to oversampling and the mechanisms for case finding within the social welfare system, race and poverty were likely to be overestimated due to reporting bias. In terms of the differences between abuse and neglect, in those
47 members, 9 (19%) were corroborated for abuse and 30 (64%) were corroborated for neglect by another party. (Eight were deemed as exploitation.) The National Elder Abuse Incidence Study (NEAIS) (7) reported that, of 70,942 incident cases of EM substantiated by APS, 34,525 (48.7%) were categorized as neglect (3,7). It should be noted, however, that the methodology used for the NEAIS (sentinel approach using random counties) has been criticized due to questions regarding generalizability.

Elder neglect has been hypothesized to be a function of the vulnerability of the older adult and the environmental risk posed by the caregiver (8,9) and the interaction of both within the elder–caregiver dyadic relationship (10). Ageism, the stereotypic prejudices that contribute to misdiagnosis, also contributes to underreporting of all forms of EM.

Although neglect is the largest category of reported EM, it is also the least understood. Child abuse theory posits that neglect is reflected in delays or deviations from normal growth and development (11,12). There are no norms or concomitant theories for normal development in older adults (13). Domestic violence theory does not apply because it assumes a deliberate violent relationship and not a caregiving relationship between the parties involved. To the best of our knowledge, there is no discussion in the domestic violence literature regarding failure to provide adequate care for someone in need of caregiving. Fulmer and Gurland (14,15) used a dyadic interview approach to understand the relative contributions of the older adult and caregiver, with regard to the outcome of unnecessary restriction. Given the study sampling procedure, there was not a sufficient number of neglect cases to study that particular problem. However, the caregivers of older adults in that study differed significantly in their profiles based on whether they were paid or unpaid caregivers. Effort must be made to study each type of EM very specifically, and under carefully defined circumstances.

Theories of causation for all types of EM include intrafamily violence, learned behavior (cycle of family violence), psychopathology of the abuser, dependency of the older adult, dependency of the caregiver, lack of social support, caregiver burden, and poor health of the older adult or caregiver. None have been specifically tested for neglect. Existing 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. In summary, neglect is a syndrome of grave consequence, and little is known about what causes or ultimately constitutes neglect. The purpose of this article is to report findings from neglect research conducted in the ED setting with an examination of congruence between ED screeners and an expert clinical team.

**METHODS**

Patients were recruited through four EDs in New York and Tampa from the beginning of February 2001 through the end of September 2003. Older persons were approached after their initial condition stabilized, and they were cleared by their health care team. Data were collected as part of the screening process for dyadic vulnerability/risk profiling for elder neglect, a National Institutes of Health-funded study designed to examine differences between neglect and non-neglect cases in terms of elder vulnerability and environmental risk posed by the caregiver (16). The goal was to identify a sample of neglect elderly persons and compare them with a group with no neglect. Inclusion criteria were as follows: being at least 70 years old, speaking English or Spanish, having a Mini-Mental Status Examination (MMSE) score ≥18, having a paid or unpaid caregiver at least 20 hours a week, and having a telephone in the home. Trained research assistants (RAs) provided written information about the study and obtained verbal consent prior to proceeding with eligibility criteria. After eligibility was determined, written consent was obtained. Demographics and results from an MMSE and an initial elder assessment screen, using the Elder Assessment Instrument (EAI), (17,18) were collected. The EAI is a 44-item Likert scale designed to identify possible markers of EM over several domains: general assessment, neglect assessment, usual lifestyle, social assessment, medical assessment, emotional and/or psychological neglect, and a summary assessment (18,19,20). Next, a sequential neglect screening and diagnosis protocol (20) was used with an expert neglect assessment team (NAT) that reviewed all completed assessment data. The NAT then made the diagnosis of neglect or no neglect after clarifying any questions with the RAs. The NAT consisted of a nurse, physician, and social worker, all of whom had extensive clinical experience with diagnosing and managing cases of elder abuse and neglect (21). The NAT diagnosis was then used for case designation and the outcome variable for these analyses.

**RESULTS**

Of the 3664 ED screens of adults 70 years or older, 405 (11%) met the inclusion criteria, and these adults agreed to participate. The remaining 89% failed to meet inclusion criteria. Only 686 lived at home with paid or unpaid caregivers for 20 hours per week or more; of those, 443 met the MMSE scoring criteria of greater than 18, and 405 agreed to participate. Thirty-eight (9% of those eligible) refused to participate. Our sample capture rate is consistent with previously reported rates of around 10% in complex clinical studies (22,23).

In 65 of the cases referred by the RAs, the diagnosis was changed by the NAT. This occurred after the NAT examined the records and, in most cases, called the RAs to obtain further clarification of the patient presentation and history. In all but one case, the change was made in the direction of the diagnosis of neglect. This might be explained in that an expert neglect team receiving screens and clinical information from other clinicians may be more informed on the nature of neglect and make the diagnosis more often. Previous work (20) supports this finding. Neglect was diagnosed by the NAT in 86 of the 405 cases reviewed. In 16 cases, the NAT did not assign a diagnosis because of an inability to agree or because they did not feel they had sufficient information. Therefore, analyses were run on 86 neglect cases and 303 no neglect cases.
In total, the older adults were predominantly female (63%), English speaking (78.8%), with a mean age of 81.5 years (±7.0). The most common reason cited for the ED visit was respiratory problems (28.1% of the sample). Approximately 27% of those screened cited cardiac problems as the reason for their ED visit; 14.8% cited falls. Caregivers had a mean age of 52.7 years (±19.7), were evenly split between the paid and non-paid categories. Paid nursing assistants accounted for 39.9% of all caregivers, followed by spouses (26.3%) and daughters (14.2%). Sons accounted for 8.9% of caregivers, a number higher than is reported in the literature (8.9% of caregivers, a number higher than is reported in the literature). Sons accounted for 8.9% of caregivers, a number higher than is reported in the literature.

Demographic differences between neglect (N = 86) versus no neglect (N = 303) cases were examined using Fisher’s exact test, and differences emerged between the two groups. Significant differences were found in all of the domains of the EAI including: general assessment (clothing, hygiene, nutrition, skin integrity), neglect assessment (bruising, contractures, decubitus, diarrhea, impaction, laceration, malnutrition, urine burns), usual lifestyle (ability to ambulate, continence, feeding, maintenance of hygiene, family support), social assessment (financial situation, interaction with family and caregivers, living arrangement, observed relationship with caregiver, participation in daily social activities, support systems, ability to express needs), medical assessment (greater than 15% dehydration, having bruises or trauma beyond what was compatible with history reported or having a failure to respond to disease conditions), emotional/psychological (being left alone for long periods, being ignored, receiving no news or companionship, having a subjective complaint of neglect). Finally, paid caregivers were significantly more likely to be neglectful (p < .05) than those who provided care without pay.

These data indicate that older adults who are assessed as more frail, dependent, and isolated and who show physical signs of neglect are more likely to screen positive and to then have the final diagnosis of neglect assigned by the NAT (Tables 1–3).

**DISCUSSION**

This study documents the underreporting of cases of neglect as evidenced by differences in diagnoses by screeners versus experts. The RAs screened positive for neglect in 60% (N = 2,056) of the 3,390 cases. The NAT made the diagnosis of neglect in 22% (86/389) of the cases. This markedly different rate of neglect may mean that ED screens are important but may underestimate the true number of cases. Conversely, a NAT may make the diagnosis of neglect in an older adult more often given a higher sensitivity and a more robust knowledge base of the problem.

Such expert teams may provide additional insight into cases or may simply be more sensitive in the diagnosis. The question remains as to how specificity can be validated. Accuracy in diagnosis might be examined by having
simultaneous screening and assessments by the RAs and the NAT. A limitation of this study lies in the fact that the NAT did not do an independent history, physical, and neglect assessment on the patients enrolled. This was not economically feasible, given the four ED locations, and the low rate of patient accrual. Future studies might compare synchronous screening and assessment data. Further, the EAI as a screen poses issues as there is no scoring algorithm, and any positive items must be interpreted within the context of other items on the instrument along with subjective comments. Efforts to refine the EAI are ongoing to address these issues.

In considering the results from this study, several issues should be noted. The first is possible selection bias, which may be working at several levels. Older adults who use ED services may be less likely to have a primary health care provider, and are accessing care through this setting. Further, this may be a proxy for income, which has been associated with referral to APS. Another potential area of selection bias relates to those older adults who met the eligibility criteria but were not approachable because they were too acutely ill to be seen by the research staff, were in a coma, or died before they could be interviewed. It is not possible to determine whether this group was at a different risk for neglect. Although these potential biases need to be kept in mind when interpreting the data, this dyadic sample is one of the largest available to date from which to understand this problem.

Finally, EDs are only one data point in the life of an older adult. Caregivers, paid or unpaid, may do their best to provide care to older adults but caregiving capacity may be exceeded as the older person becomes more frail, dependent, or ill. It is unacceptable to leave the “confirmation of cases” with APS workers alone. Further research should focus on the improvement of clinical accuracy in the diagnosis of neglect.

This article corroborates findings from an earlier pilot study that reported dependent and sicker older adults as more likely to be assigned the diagnosis of neglect. It goes further, by providing data that reflect the inconsistency of diagnoses between trained personnel (in this instance, health care student RAs) and experts.

Paid caregivers in this study were more likely to be neglectful, which is at variance from previous data that suggested unpaid caregivers were more neglectful (T. Fulmer, T. Kim, K. Montgomery, S. Fairchild, B. Gurland, unpublished data). Paid caregivers are far more likely to be hired when the caregiving demands of an older adult outstrip the caregiving capacity. However, these data suggest that even when a caregiver is employed to provide help in the home, there is still inadequate care. What is not known, to date, is whether that inadequate caregiving is due to intentional neglect, inability to meet caregiving needs when trying, or ignorance of what care is needed. This question needs resolution to be useful to health policy groups. We remain optimistic that screening and assessment of neglect can become a routine procedure in busy EDs, and older adults will benefit from the addition of expert clinical teams that can interpret confusing clinical presentations that may cloud the signs and symptoms of neglect. The APS network does an extraordinary job following up cases of “suspected” neglect, given the complexity of the work, low pay scales, and heavy caseloads. They cannot do it alone. With the inclusion of nurses, physicians, and social workers, representing over 2.5 million professionals in practice in this country, more can be done to detect neglect and better understand the more important goal: prevention. Future studies should propose ways to increase the sensitivity of
health care providers in accurate care settings to avoid underreporting of neglect. Rapid screening instruments need further work and refinement to assist clinicians in this important work.

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