Practice Concepts

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This article describes a 2-year collaborative project in Cleveland, OH, that improved the reporting and management of potential and suspected elder abuse situations involving persons with dementia. Educational curricula for cross-training, screening tools, and referral protocols were developed and tested for staff and volunteers in adult protective services and dementia care. A handbook for caregivers of persons with dementia was produced that enables caregivers to self-identify elder abuse risk and seek appropriate interventions to prevent abuse. Project organization, implementation, and evaluation are discussed along with strategies for replication in other communities.

Key Words: Curricula, Screening tools, Referral protocols

A Model Intervention for Elder Abuse and Dementia

Georgia J. Anetzberger, PhD,[1] Barbara R. Palmisano, MA,[2] Margaret Sanders, MA,[2] David Bass, PhD,[3] Carol Dayton, MSW,[4] Sharen Eckert, MS,[5] and Maria R. Schimer, MPH, JD[2]

Several recent studies suggest that persons with dementia are at increased risk of elder abuse. The research focusing on the caregivers of family members with dementia indicates more abuse in these families than in the general population (Wolf, 1998). Paveza and his associates (1992) used the severe violence subscale of the Conflict Tactic Scales (Straus, Gelles, & Steinmetz, 1980) to identify the frequency of violent behaviors between caregivers and care recipients in a 184-person sample taken from an Alzheimer's disease registry. In the year after diagnosis, 15.8% of care recipients were violent toward their caregivers, 4.4% of caregivers were violent toward their care recipients, and 3.8% were mutually violent. Coyne, Reichman, & Bergib (1993) surveyed callers to a dementia care hotline to explore the frequency of physical abuse that had occurred since they had become a caregiver. Among 342 respondent caregivers, 33% had been abused by the care recipient and 12% had abused the care recipient at least once. In 9% of the families there was mutual abuse between caregiver and care recipient. Pillemer and Suitor (1992) interviewed 236 family members providing care to persons who had received a diagnosis of dementia within the previous 6 months. They found that 20% of the caregivers feared they would become violent, 6% had been violent, and 25% indicated that the care recipient was violent. Other research also suggests a link between elder abuse and dementia in caregiving relationships (Anetzberger, 1987; Cooney & Mortimer, 1995; Lau & Kosberg, 1979; Steinmetz, 1988).

Studies on self-neglect show its association with dementia. In a national investigation of self-neglecting elders who had been reported to adult protective services, Duke (1991) found a high ratio of mental impairment. Among Vinton's (1992) sample of 227 competent but self-neglecting elders, 22% had Alzheimer's disease or related dementia. Dementia also was present in one third of the 1,500 cases of self-neglect studied by Longres (1994). Finally, in the recently released National Elder Abuse Incidence Study (National Center

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[1]Address correspondence to Georgia J. Anetzberger, PhD, Associate Director for Community Services, The Benjamin Rose Institute, 2373 Euclid Heights Blvd., Cleveland Heights, OH 44106. E-mail: georgia@benrose.org

[2]Office of Geriatric Medicine/Gerontology, Northeastern Ohio Universities College of Medicine, Rootstown.

[3]Margaret Blenkner Research Center, The Benjamin Rose Institute, Cleveland, Ohio.

[4]Adult Protective Services, Cuyahoga County Department of Senior and Adult Services, Cleveland, Ohio.

[5]Cleveland Area Chapter, Alzheimer's Association, Ohio.

on Elder Abuse, 1998), three quarters of substantiated self-neglecting elders had some degree of confusion.

Despite the recognized association between elder abuse and dementia, until now no intervention has been developed that addresses these interfacing problems. In this article we describe a multiagency, multifaceted project in greater Cleveland, OH, that improved the detection and management of elder abuse situations involving persons with dementia.

Barriers to Referral and Collaboration

Cross-referral and reporting between Adult Protective Services (APS) and the Alzheimer's Association were rare in greater Cleveland, as in other parts of the country. During the past decade there were less than a half-dozen reports of elder abuse by Alzheimer's Association staff and volunteers and a comparable few referrals for dementia care by APS at the Cuyahoga County Department of Senior and Adult Services. The scarcity of cross-referrals was even more striking given the large number of older persons in the county (i.e., more than 300,000 individuals aged 60 and older) and the high volume of referrals handled by each agency annually, about 2,300 and 1,800, respectively.

Barriers to cross-referral and service collaboration among agencies specializing in elder abuse and those specializing in dementia care have been recognized both locally (Balaswamy, 1992) and nationally (Flaherty & Raia, 1994; Haley & Coleton, 1992). Barriers include limited training about the other problem area and the interface between the two problems in home and community settings and failure of agencies to establish appropriate protocols for collaborative service delivery. Barriers also exist because of insufficient knowledge and trust regarding how other agencies contend with the sensitive issues of elder abuse and dementia. Finally, concern about differing agency philosophies along with fear of eroding client rapport and confidentiality further contribute to underreporting. In particular, professional codes of ethics that emphasize client confidentiality often inhibit even legally mandated reporters from contacting authorities about elder abuse experienced by their clients (Faulkner, 1982; Gilbert, 1986).

Project Purpose and Structure

The goals of A Model Intervention for Elder Abuse and Dementia were to increase case identification, improve care planning and intervention, and promote prevention of abuse in persons with dementia who are suspected of being or who are at risk of elder abuse. Supported for 2 years with funding from The Cleveland Foundation and in-kind agency contributions, the project involved five organizations. In addition to the Alzheimer's Association, Cleveland Area Chapter, and the Cuyahoga County Department of Senior and Adult Services, Adult Protective Services, project partners were The Benjamin Rose Institute, Northeastern Ohio Universities College of Medicine, and Western Reserve Consortium for the Prevention and Treatment of Elder Abuse. The major roles and responsibilities of each organization in the project are delineated in Table 1.

Project members developed several products to accomplish the project goals:

- An educational curriculum on issues of elder abuse, a parallel curriculum on dementia, and an integrative curriculum on effective intervention in situations of elder abuse and dementia.
- A cross-training program for Alzheimer's Association and APS staff and volunteers based on the educational curricula.
- A screening tool for use by Alzheimer's Association staff and volunteers to identify abusive and potentially abusive situations and tools useful in identifying cognitive impairment for APS staff.
- Protocols for referral and intervention among the three service-providing partners.
- A handbook for caregivers to self-assess risk of elder abuse and to identify community resources for assistance.

Table 1. Responsibilities of Partnering Organizations

Partner	Major Responsibilities
The Benjamin Rose Institute	Project administration and direction Evaluative research Services to potential elder abuse situations
Northeastern Ohio Universities College of Medicine	Project coordination Curricula development and implementation Caregiver handbook design
Alzheimer's Association, Cleveland Area Chapter	Advisory and Work Group participation Services to persons needing dementia care Recipient of cross-training
Cuyahoga County Department of Senior and Adult Services, Adult Protective Services	Advisory and Work Group participation Investigation of and services to reported elder abuse situations Recipient of cross-training
Western Reserve Consortium for the Prevention and Treatment of Elder Abuse	Caregiver abuse screening tool development Project dissemination among the Consortium's 100-plus individual and organization members

Three groups were formed to implement the project. The Advisory Group was led by the project's principal investigator (the first author of this article) and comprised executive staff from the partnering organizations. Meeting quarterly, the Advisory Group provided direction for project activities and reviewed and approved all products. The Work Group was led by the project's director (the second author of this article) and included key clinical staff from the service partners along with the evaluation assistant. Meeting on an average of bimonthly, it produced key elements of the educational curricula, referral and intervention protocols, and handbook for caregivers. Lastly, the Evaluation Group consisted of Benjamin Rose Institute research staff and students. It functioned to design and implement the project evaluation as well as to help develop and test the caregiver abuse screening tool in the handbook for caregivers.

Collaborative Process

Building relationships and trust among the partner agencies was an ongoing process that involved all levels of staff. Agency executives established core values for the project that assured a common purpose and reflected ethical values of service delivery. Staff and volunteers actively participated in the interactive sessions of the cross-training program and through representation in the Work Group.

The Work Group was an important component of the project. Membership of the group remained stable, and the group members established close working relationships and remarkable openness with each other. Meetings were conducted in a problem-solving forum, revolving around case discussions. The Work Group used the cases to explore ways to share resources, break down service barriers, and improve care management. Points of tension or "unsolvable" dilemmas emerged from these discussions. After the meetings, group members discussed the dilemmas with their administrators and colleagues.

The Advisory and Work Groups both faced challenges in resolving issues that emerged during the project. Initial meetings were spent dispelling misconceptions about partner agency roles and discussing agency responsibilities and limitations. Group members clarified legal, financial, and staffing constraints of their respective agencies. They examined issues of client confidentiality and violation of trust in terms of cooperative case management. Boundaries were set for disclosure of client information. The group members established clear lines of responsibility and authority to avoid confusion and duplication of effort when multiple agencies were involved in a case.

The challenges brought up during the case discussions led to the development of a new model for case referral: the Referral and Services Model for Prevention and Intervention of Abuse in Clients Affected by Dementia (Figure 1). The model, developed by the third author of this article, graphically demonstrates collaboration among the Alzheimer's Association, The Benjamin Rose Institute, and APS. The model is a fluid system with flexibility for the referral process to begin at any agency and proceed in a logical manner to the appropriate agency(ies). The client may enter the system at any point and go back and forth between agencies or receive concurrent services from more than one agency. A lead agency is established to direct and coordinate services.

Open communication among agency intake departments, case managers, and supervisors was developed so that staff have opportunities to seek counsel when making difficult decisions about clients. On an informal basis, staff are encouraged to use the expertise of the partner agencies through case consultation. Once a client is formally referred to another agency, the referring agency receives feedback on the status of the case. This feedback is important to assure the referring agency that the client is being served. The referring agency also is notified if the case is not accepted for service or upon discharge from services. This procedure helps to prevent clients from falling through service gaps.

Educational Curriculum and Cross Training Program

A 156-page Model Intervention curriculum was developed through literature review and synthesis as well as Advisory and Work Group contribution. It was pilot tested among volunteer staff from APS and the Alzheimer's Association. As a result of testing, we revised the curriculum for APS staff to recognize their knowledge regarding elder abuse and to empower them through demonstration of their ability to solve problems in difficult case situations.

The curriculum was organized into three modules:

- Module 1 emphasizes manifestations of various types of dementia, identification of early dementia symptoms, assessment of client capacity and competency, and referral and management of persons with dementia. The module is a full-day training program for staff from APS.
- Module 2 provides background information on elder abuse, theories of causation, ways to screen for possible abuse or neglect, elder abuse law and the APS system, and referral protocols. This module was designed as a full-day training program for Alzheimer's Association staff and volunteers.
- Module 3 is an integrative module that brings together staff and volunteers from the Alzheimer's Association and APS for a half-day training program. The module focuses on communication techniques, agency philosophies and roles, and legal and ethical dilemmas in cases of elder abuse and dementia.

The Model Intervention curriculum is available for use by other agencies. It includes faculty guides, workbooks for participants, and references. The faculty guide is complete with teaching instructions, optional interactive exercises, and case discussions. The content of the curriculum is tailored to specific agen-

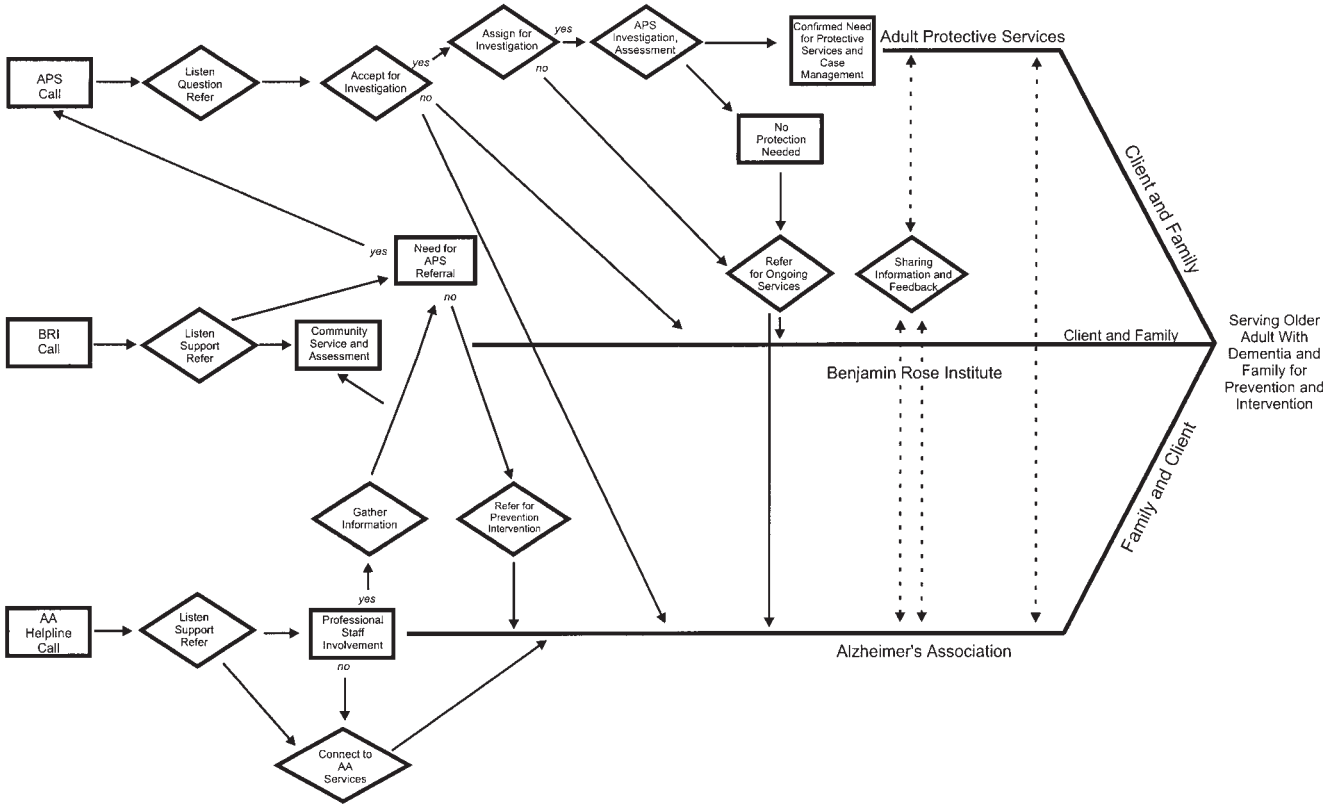

Figure 1. Referral and service model for prevention and intervention of abuse in clients affected by dementia. APS = Adult Protective Services; BRI = Benjamin Rose Institute; AA = Alzheimer's Association.

cies in Cuyahoga County, OH, and is based on Ohio law. However, it can be easily adapted to other communities, states, and service provider networks. Modifications of the curriculum have been used for training Area Agency on Aging staff along with police and other "first responders" who come in contact with older persons. The curriculum modules were developed to be given in a series but also may be presented as single training programs.

The training was mandatory for all staff at APS and all staff and volunteers at the Alzheimer's Association. The 2.5-day training program was repeated three times so that only one third of agency staff was involved at a given time. The sessions were team taught by various Advisory and Work Group members. All APS and Alzheimer's Association staff and volunteers attended the training.

Handbook for Caregivers

The Work Group developed a 10-page handbook as a resource to help caregivers experiencing strain to identify the risk of harm to themselves or to the persons for whom they are caring. The handbook includes three brief self-assessment instruments adapted for the project from research conducted at the Margaret Blenkner Research Center of The Benjamin Rose Institute, sometimes in collaboration with the Prevention/Education Committee of the Western Reserve Consortium for the Prevention and Treatment of Elder Abuse. The first instrument identifies disruptive behaviors of the care recipient that have been found to be highly stressful to the caregiver. The second instrument provides a list of physical and emotional indicators of strain to assist caregivers in identifying their reactions to stress. Finally, a list of caregiver behaviors that are indicative of elder abuse is included. The tone of the handbook is nonpunative, emphasizing that harm can occur without intent. Readers are made aware that they can prevent abuse by recognizing their sources of stress, identifying the effects of their response to stress, and seeking assistance. Community resources and educational references are provided throughout the text. The handbook was pilot tested among participants of Alzheimer's Association support groups before its broad dissemination by the project partners.

The handbook was originally written in English. However, because greater Cleveland has a large Hispanic population—mainly Puerto Rican—a Spanish version was produced by bilingual staff of The Benjamin Rose Institute using funds provided by the local Area Agency on Aging. The Spanish version was pilot tested across multiple Hispanic cultures and reading levels before distribution primarily through local Hispanic senior centers.

Evaluation

We evaluated several dimensions of the project to determine changes in knowledge, attitudes, and behaviors of partner agency staff and volunteers. The

evaluation involved assessment of the training program through participant completion of evaluation forms before training was initiated and after each session was completed. In addition, project evaluation included critical review of agency protocols and analysis of client outcomes. Finally, staff were asked for anecdotal reports regarding cross-referrals and consultations following the training.

Results of the educational training showed significant increases in understanding in 4 areas evaluated for APS workers (Table 2). After the training APS staff serving clients with dementia were more willing to collaborate with the Alzheimer's Association. Alzheimer's Association staff and volunteers had significant increases in perceived understanding in all 13 areas evaluated (Table 2). After the training, all Alzheimer's Association staff and volunteers showed a substantial willingness to collaborate with APS. Ratings for staff and volunteers of the Alzheimer's Association were significantly similar in magnitude and not significantly different.

A poignant example of the success of the project is the case of Mr. A and Mrs. A. Mr. A had been the primary caregiver for his wife for 10 years. Mrs. A had advanced Alzheimer's disease resulting in emotional instability, difficulty swallowing, and limited ability to communicate. Mr. A had been involved in the Alzheimer's Association family assistance program for at least a year; however, his participation was limited to monthly calls from the case manager. He was very resistant to accepting other services or another agency's assistance. An irate Mr. A contacted the Alzheimer's Association after he received a letter from APS, because a report had been made that his wife was being left alone and locked in a bedroom. The APS worker attempted to make a visit but was refused entry into the home. The case manager from the Alzheimer's Association called the APS social worker to discuss the situation. They agreed to make a joint visit to the home to minimize the trauma of the investigation. They diffused a tense situation by combining the trust established between Mr. A and the case manager and the interviewing skills of the APS social worker. The allegations of neglect were unsubstantiated. Mr. A was convinced to place his wife in a local day care program to increase her socialization and provide him with some respite.

Prior to the project, Alzheimer's Association and APS staff could not have effectively cooperated to address the situation of Mr. A and Mrs. A for two reasons: (a) the rapport and trust for communication did not exist and (b) there was insufficient understanding of the potential role each agency could assume in handling elder abuse situations known to both. Cross-training and referral protocol development established a climate of enhanced communication and collaboration between the Alzheimer's Association and APS to resolve difficult client situations like that of Mr. A and Mrs. A.

Table 2. Evaluation Results of Cross-Training

APS Results
Areas where perceived understanding significantly increased
• Prevalence of dementia and stages of Alzheimer's disease
• Services offered by the Alzheimer's Association
• Time at which to refer suspected dementia to the Alzheimer's Association
• Assessment of the decision-making ability of persons with dementia
Areas where likelihood of future interaction with Alzheimer's Association staff increased
• Referral of clients with dementia to the Alzheimer's Association
• Consultation on how to best assist clients with dementia
Alzheimer's Association Results
Areas where perceived understanding significantly increased
• Prevalence of elder abuse among families dealing with dementia
• Barriers to reporting elder abuse
• Types, causes, and risk factors of elder abuse
• Links to caregiving stress
• Guidelines for referring to APS and use of elder abuse laws
• Legal issues related to reporting elder abuse
• APS investigation methods for reported elder abuse and the service process that prevents elder abuse
• Confidentiality of reporting suspected elder abuse to APS
Areas where likelihood of future interaction with APS staff increased
• Referral of a family if there is suspected abuse
• Reports of cases of suspected abuse
• Suggestion that a family call APS about suspected abuse
• Consultation with someone from APS about a family

Note: APS = Adult Protective Services.

Outcomes and Discussion

A Model Intervention for Elder Abuse and Dementia represents the first initiative ever undertaken that addresses elder abuse and dementia as interfacing problems requiring referral and management by community agencies from diverse service systems and philosophies. The success of the project is evident in three ways. First, although the curriculum and handbook for caregivers were developed for greater Cleveland, their basic content is state-of-the-art, easily adaptable, and proven with other groups and in other communities. Second, project goals were achieved. Cross-training and collaboration on project Advisory and Work Groups improved communication and relations across partnering agencies. This improvement is illustrated in the pre- and posttraining test results, increased reports and referrals among service-providing partners, and greater consultation around difficult case situations. There had been less than a half-dozen referrals or reports between APS and the Alzheimer's Association in the 10-year period prior to project onset. Within 1 year following the cross-training, the Alzheimer's Association had made 27 elder abuse reports to APS, 17 of which were accepted for formal investigation, including 15 substantiated as abuse, neglect, or exploitation and in need of protective intervention. In addition, the intake supervisor at APS reported that staff at the Alzheimer's Association called her on several occasions to informally discuss other client situations. All situations identified as elder

abuse by Alzheimer's Association staff were either reported to APS or discussed with the APS intake supervisor. Although the Alzheimer's Association has not received formal referrals from APS, they have been called on as a collateral resource. The Benjamin Rose Institute has had 18 community service referrals of potential abusive situations from the Alzheimer's Association since the training. Seventeen of these were accepted for service. In all but one instance, intervention was effective in preventing elder abuse from occurring. Finally, the handbook for caregivers was so well received in the community that the initial supply of 1,500 copies was quickly depleted. Grants from the John P. Murphy Foundation and Wolfpert Fund were sought and obtained to print additional copies of the handbook.

A Model Intervention represents an effective approach for the prevention and treatment of elder abuse in situations involving persons with dementia. The approach also can be applied to other interfacing problems, such as elder abuse and domestic violence or mental retardation, which require intervention from diverse service systems. The lessons learned from A Model Intervention suggest four elements for effective collaboration under these circumstances. The individuals involved must demonstrate

- A belief in the value in interagency collaboration, manifested in the release of staff time and commitment of agency leadership.
- The capacity to build and sustain trust, evident in the ability to risk and to set aside past suspicions and misperceptions.
- The willingness to identify and solve problems, which requires honest and open communication.
- The ability to "let go" and change directions when initial efforts fail and alternative strategies need to be undertaken to achieve ultimate goals.

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