

Community Resources

In this module, learn about:

- Benefits and barriers of physicians linking patients and families to community services.
- Interactions with patients and families throughout the course of the disease.
- Strategies to effectively link patients and families with community

Most older adults receive their health care solely from their primary care physicians (Ganguli et al., 2004). When symptoms of dementia emerge, patients and their caregivers typically turn first to their primary care physician for answers to questions about memory loss and obtaining a diagnosis (Fortinsky, 2001). Therefore, primary care physicians are in a unique position to help patients and family caregivers improve their understanding of the dementia disease process, advise them on managing symptoms as they occur and refer them to appropriate community support services (Fortinsky, 2001).

In fact, family caregivers rely on physicians to provide information about management of dementia symptoms and availability of support services (American Medical Association, 1999). Often caregivers perceive a physician's referral as having greater legitimacy and are more likely to use services if referred by a physician than someone else (Maslow K, 1990).

BENEFITS OF COMMUNITY RESOURCE REFERRAL

The importance of these services cannot be overestimated. Numerous studies have shown significantly improved patient and caregiver outcomes when caregiver needs are assessed and education or counseling provided (Chow & MacLean, 2001). A study by Mittleman et al, (1996) showed that comprehensive support and counseling for spouse-caregivers delayed nursing home placement of patients with mild to moderate Alzheimer's disease. Another study showed that counseling by telephone assisted spouse caregivers in feeling more competent and knowledgeable about Alzheimer's disease and more independent in making caregiving decisions (Chiverton & Caine, 1989).

BARRIERS TO EFFECTIVE COMMUNITY REFERRAL OF PATIENTS AND FAMILIES

Physicians encounter and report challenges to providing up-to-date information and referral to services especially in rural areas where services might be scarce (Connell et al., 2004). In an earlier study by Fortinsky (1998), physician survey results indicated that unfamiliarity with community services was the most common barrier to ongoing management of patients with dementia. The shorter the amount of time that physicians were in practice, the more likely they were to report unfamiliarity with available community services for their patients with dementia. However, in this same study most physicians were interested in linking with community services and willing to share the ongoing management of patients with dementia and families with community services. Perhaps the most significant obstacle to referral for community support services is the lack of time available to physicians to learn about and remain apprised of specific available resources.

INTERACTIONS WITH PATIENTS AND FAMILIES THROUGHOUT THE COURSE OF THE DISEASE

Numerous studies have confirmed that the needs of patients and families change throughout the course of managing a dementing illness (Fortinsky, 2001). In early stages of dementia, the major focus of attention among physician, patient and caregiver is to establish the diagnosis and provide patient and caregiver education and support. As dementia symptoms become more persistent and numerous, the interactions focus on symptom management (with or without medication) and use of home and community-based services. In later stages of the disease, considering alternative living facilities and end-of-life care become the focus of family caregivers.

A paper by Boise & Connell (Aging and Geriatrics in press) found that patients and families want an accurate and clearly explained diagnosis and guidance from the physician in understanding the course of the illness over time. The article stated: "Specifically caregivers have noted they want physicians to listen to their concerns, devote more time to discussing the diagnosis and what it means, and include the patient even if he or she might not fully understand the implications of the diagnosis." Research has documented that these factors are strongly linked with caregiver satisfaction with the triadic relationship. Boise & Connell emphasize that the disclosure process should be tailored to the manner in which patients and families prefer to have information shared. They found, "For some, this means using a direct approach – having the physician come right out and tell them results of the clinical evaluation for dementia – while others prefer a softer approach. Many physicians and caregivers prefer to focus their discussion on

memory problems or safety concerns rather than on the term Alzheimer's disease. Most families eventually want specific information about the diagnosis and its prognosis".

Primary care physicians are encouraged to discuss advance directives as soon as possible after the diagnosis is disclosed, so patients can be involved to the greatest extent possible. Patients and families should also be urged to begin advance planning with regard to durable power of attorney and financial management (Cummings, 2002).

As the patient becomes more impaired, the physician depends on the family caregiver to ensure that the patient receives good medical care and follows the physician's instructions. In the AMA's 1999 guide, physicians are encouraged to assess the needs of family caregivers, ask how they are coping, provide information about what they can expect in the future, and provide resources that can reduce caregiver stress, anxiety, depression and sleep deprivation. In addition, Glasser and Miller (1998) recommend physicians build in brief periods of time to ask the caregiver how she/he is doing and coping. Also, if the caregiver is the physician's patient, the physician can assess their caregiver status as part of their regular exam. Physicians suggest in Connell's study (2004) that they should have increased time available to spend with patients and their caregivers. This supports a recommendation made earlier by the Council on Scientific Affairs of the American Medical Association (1993) to reimburse physicians for time spent educating and counseling caregivers.

A variety of issues may influence the timing and receptivity of family caregivers to physician recommendations about community services. Among these are (1) the degree of confidence, trust and credibility established in the triadic relationship; (2) the functional status of both the patient and caregiver; (3) cultural norms and factors related to a family's beliefs and attitudes about its responsibilities, decision-makers and involving outsiders; (4) awareness by the physician and family alike about the types and scope of available community resources, eligibility criteria, and enrollment procedures; (5) the physician's assessment of the family's readiness to consider alternative support strategies; and (6) perceptions about the responsiveness, quality and appropriateness of available services (Thakur & Perkel, 2002).

STRATEGIES AND SERVICE MODELS TO EFFECTIVELY LINK PATIENTS AND FAMILIES TO COMMUNITY SERVICES

To address the barriers physicians face in becoming familiar with and linking patients and families to local community resources, various strategies and services models have been developed. The AMA Guide for Primary Care

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Physicians on the Diagnosis, Management and Treatment of Dementia (1999) recommends that an office staff member be assigned to develop expertise on community resources and become the primary link between patients, families and the community resources they need. More recently, an intervention to restructure primary care practices to manage geriatric syndromes (Reuben et al , 2003) suggested that providing dementia-specific information designed to enhance patient and caregiver understanding of the condition and facilitate patients and families accessing community-based services (if easily available in the clinician's examination room) would reduce the physician's time in advising and counseling patients and families.

The final section describes three service models to support physicians in managing ongoing care of patients with dementia: 1) An Alzheimer's Service Coordination Program, 2) A Chronic Care Network for Alzheimer's Disease, and 3) Academic Detailing Community Resource Teams. The first model, based on the research finding that most physicians are willing to share the ongoing care of patients with dementia, was developed and piloted in Cleveland (1996-1998) to link primary care physicians with a community organization that specializes in dementia education and support. (in this case, a local Alzheimer's Association Chapter) (Fortinsky, 2002).

The Alzheimer's Service Coordination Program was designed to have physicians initiate the program by asking patients and families at the time of diagnosis if they were interested in referral to the local Alzheimer's chapter for educational and counseling services. If the patient and family sign a consent form, a referral is sent to the chapter listing the major concerns that the family expressed to the physician. This allows the Chapter to initiate contact with the family to address the concerns. After the six-month pilot project, 44 caregivers reported statistically significant increases in self-efficacy in managing dementia symptoms and using community resources. In addition, the 29 participating physicians and 62 participating caregivers reported satisfaction with the program (Fortinsky, 2002). Currently, adaptations of this program, called "positive referral service" are being initiated between physician offices and local Alzheimer's chapters throughout the country.

The second service model was called "Chronic Care Networks for Alzheimer's Disease" (CCN/AD), a joint project of the Alzheimer's Association and the National Chronic Care Consortium that was designed to achieve multiple goals in supporting family caregivers. The CCN/AD Initiative was a six-year demonstration project that implemented a model of dementia care that was designed to (a) improve the identification of possible dementia in health care settings; (b) adopt a practical model of dementia assessment; (c) improve coordination between medical care and supportive services through the development of partnerships between health care providers and Alzheimer's

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Association chapters and (d) introduce systems change that would guide the overall care of individuals, not just their dementia. The specific tool developed to improve coordination between medical care and supportive services was the Caregiver Support Grid (Table 3.)

It was designed to be used to identify the types of material and services caregivers may need at each phase and where there might be gaps in materials and services. Because the grid places an emphasis on the caregiver's tasks and challenges, it more likely that the information and programs provided to families will meet their needs (Maslow & Selstad, 2001). Similar to a referral method piloted through the Alzheimer's Service Coordination Program, the CCN/AD Initiative found it helpful for health care providers to use and fax referral consent forms to participating Alzheimer's Association offices. This allowed chapters to initiate contact with enrollees and their families and facilitate early linkage with information and non-medical support services (Maslow, 2003 unpublished).

A third strategy that will be piloted in summer 2005 to strengthen the link between physician offices and local community services is called "academic detailing community resource teams." In a program conducted by the Primary Care Dementia Leaders Network in Michigan, a team composed of a retired physician, a representative from the local Alzheimer's Chapter and the local Area Agency on Aging will schedule brief visits with interested physician practices in their area. Using a common marketing strategy found in health care, the visit is designed to introduce physicians and their staff to local community support services, describe how the services help patients with dementia and their families, and provide educational materials targeted to professionals, patients and families about support services. Results of the pilot phase of the project will be available in early 2006.

NATIONAL AND STATEWIDE RESOURCES FOR DEMENTIA INFORMATION AND COMMUNITY SUPPORT

The following tables are provided to assist the primary care physician and office staff:

Table 1 - Contains information about key resources nationally and in Michigan

Table 2 - Describes the broad array of services frequently used by patients and families.

Families can be encouraged to access printed and online resources about dementing illnesses and strategies that may help them cope with demands and role changes they will encounter in caring for someone with dementia. Such

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resources include newsletters, pamphlets, booklets, and fact sheets on the websites of the resources listed in **Table 1**. Specific books that physicians may wish to recommend to family caregivers include: “The 36-Hour Day” and “Alzheimer’s: The Answers You Need.” For patients in the early stages of AD, a book entitled: “Speaking Our Minds: Personal Reflections from Individuals with Alzheimer’s,” is very useful.

CONCLUSION

Familiarity with local community resources and development and implementation of a process that links people with dementia and their significant others with those local resources can go a long way in improving the care of patients with dementing illnesses and the quality of life for the patient, caregivers, and office staff members.

TABLE 1.

Alzheimer's Disease Information and Support Services

National Resources: Alzheimer's Association: Source of valuable information about all aspects of care for people with dementia and their families. More than 80 chapters nationwide provide care consultation, support groups, 24/7 support line services, education and safe return programs. For the nearest chapter contact:

(800) 337-3827: Website: www.alz.org

Area Agencies on Aging (AAA): Local AAAs offer information and assistance with locating a range of elder care services. These include: care management services, home-delivered and congregate meals, homemaker and personal care services, in-home respite, adult day and caregiver support services. Contact Eldercare Locator: (800) 677-1116.

Website: <http://www.aoa.dhhs.gov>

Alzheimer's Disease Education and Referral (ADEAR) Center: A service of the National Institute on Aging to compile, archive and disseminate information concerning Alzheimer's disease for health professionals, people with AD and their families, and the public. Specialists are available to answer specific questions about AD, send free publications, refer to local supportive services, offer Spanish language resources and clinical trials information: (800-438-4380: Website: <http://www.alzheimers.org>

Family Caregiver Alliance: A national organization dedicated to working with caregivers. They provide fact sheets, research updates and an e-mail-based support group. 415-434-3388: Website: <http://www.caregiver.org>

Michigan Resources: Michigan Chapters of the Alzheimer's Association

Greater Michigan Chapter, based in Southfield. www.alzgmc.org

Michigan Great Lakes Chapter, based in Ann Arbor.

www.alzmiggreatlakes.org

Area Agencies on Aging (AAA) – Comprehensive information for seniors living in Michigan. www.miseniors.net

Michigan Dementia Coalition – Web site includes excellent resources for Michigan caregivers of people with dementia.

<http://www.dementiacoalition.org/>

TABLE 2:

Frequently Used Home and Community-Based Support Services

In-Home Resources

Home health care: Provides medical assistance (skilled nursing, rehabilitation therapy, home health aides) to older persons in their homes. This is doctor-prescribed and the attending physician needs to be directly involved in order for this type of care to be covered under Medicare or private insurance.

Personal care services: Includes bathing and dressing and are not Medicare-reimbursed. They are available privately or through home health agencies.

Homemaking/chore services: Includes laundry, shopping, housecleaning and are not Medicare-reimbursed.

In-home respite care: Provided in the home by professional caregivers or trained volunteers; they can be employed privately or through an agency and either private, non-profit or government funded. Services may include: companionship, personal care, homemaking, or skilled care.

Community-Based Resources

Care management: provides help by a professional in coordinating services for persons with dementia and their families.

Support groups: help caregiver cope and gather information. Patients may participate in the early stages.

Adult day services: offer group respite care that is provided outside the home and designed to support the strengths, abilities and independence of each participant.

Residential/Overnight respite care: residential facilities may allow the person with dementia to stay overnight, for a few days, or a few weeks. Many hospitals and nursing home have specialized units for this purpose.

For more information about these services or help in locating them in your local community contact: your local Chapter of the Alzheimer's Association by calling: 800-337-3827 or your local AAA by calling: Eldercare Locator at: 800-677-1116.

TABLE 3.
Caregiver Support Grid

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Programs and Materials for People with Alzheimer's Disease and Related Disorders Diagnostic Phase



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	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Obtain an accurate diagnosis. Know how to get a second opinion if necessary.			
2.	Understand how the diagnosis was made.			
3.	Know how to approach the patient with news.			
4.**	Know what possible treatments exist.			
5.	Begin to accept the diagnosis and patient's limitations.			
6.**	Understand the need for proactive planning, including financial, legal, and care plans.			
7.	Seek out supportive services as needed (early-stage support groups, education sessions, etc.).			
<p>*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages. **These objectives were identified as most important by site-level project staff and were used for evaluation purposes (see page 32).</p>				

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