
PRO DEM: A Community-Based Approach to Care for Dementia

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Physicians in a region south of Bremen, Germany, created PRO DEM (for patients with dementia), a service coordinating medical care and social intervention for patients with dementia. The program now serves about 125 outpatients and their families, along with 360 patients in nursing homes. Two nurse consultants coordinate patient care. Treatment strategies are decided during a multidisciplinary case conference among physicians, nurses, and other professionals. Social intervention modules include various care groups for patients and respite services for caregivers. PRO DEM aims to provide fully coordinated care for a better quality of life for patients and caregivers, delaying nursing home admission as long as possible.

BACKGROUND

Early in 1998 a number of physicians in Stuhr and Weyhe (a region south of the City of Bremen with 80,000 inhabitants) decided to work more closely together. They negotiated an integrated contract of care with a statutory health insurance (VdAK). PRO DEM was one element of this contract. The planned cooperative network of physicians and statutory health insurance has not yet been put into practice. Sponsorship from the pharmaceutical industry, however, made it possible for a group of health care providers to launch PRO DEM. The sponsorship funds (nearly 250,000 U.S. dollars), were used during the

first 2 years to pay for (1) the hiring of nurse consultants and their salaries, (2) provider incentives, and (3) the scientific evaluation (Klingenberg et al., 2001).

Caring for the elderly, one of the main tasks of general practice, includes caring for people with dementia. At the beginning, however, it was uncertain about how to deal with this problem in the communities properly. In an attempt to cope with this challenge, PRO DEM was initiated. During several weekend training sessions with one of the neurologists, additional help was sought out throughout the region. At first, the project's main goal was to bring everyone who cared in any way for the elderly to a forum. The nurse consultants employed specifically for this project, were to assume tasks in the fields of consultation and coordination in addition to general practice and neurological care. The Institute for Applied Quality Enhancement and Research in the Health System (AQUA) was assigned to monitor and evaluate this project from its inception. The project has developed positively and is now continued as a registered association which collects membership fees, private and community sponsorship payments, and receives additional funds for social interventions from the Lower Saxony's regional government according to the *German Social Code Book No.XI § 45*.

Detection and Treatment Sequence

Either the physician who diagnosed the patient with dementia or the family caregivers approaches the PRO DEM Consulting

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Center and meets a nurse consultant. PRO DEM's two nurse consultants are highly trained experienced professionals. The family physician performs his examination of the patient (according to standard protocol) assisted by his nurse (who has received special training dealing with dementia patients) and one of the neurologists who has seen the patient by referral. The nurse consultant goes to the patient's home and conducts a comprehensive assessment of the patient's clinical status and needs. The nurse consultant prepares a written report for the family physician showing the findings.

Following this assessment the nurse consultant, in collaboration with the family caregivers, the patient, and the family physician, develop a temporary individualized care management plan which is later discussed and agreed on in the PRO DEM Multidisciplinary Case Conference (MCC). The MCC, the central decisionmaking institution within PRO DEM's case management process, consists of the neurologist, family physicians, speech therapists, ergotherapists, physiotherapists, and nurses.

Social Intervention

In addition to an evidence-based medical treatment, PRO DEM offers non-medical treatment called social intervention. This non-medical treatment is a distinctive feature of PRO DEM. It comprises a sequence of treatment and social response modules developed specifically for PRO DEM (German Society of Geronto-Psychiatry and Psychotherapy):

"The main precondition for the successful treatment of a patient suffering from dementia is a diagnosis made as early as possible as well as an overall therapy plan which, depending on how serious the illness is, comprises drug treatment, social

and psychotherapeutic measures as well as care by members of the patient's family. This plan should be agreed on by the patient, his family, the doctors as well as the therapists concerned, careers and social services, taking into account the extent of the patient's illness."

PRO DEM has established its own disease management program for this region, and their case conference can choose from the various modules of a sequence of social intervention treatments, such as the discussion group, group of people affected, day care, care group and day nursing. As the disease progresses, the treatment and the social intervention sequence are constantly reviewed and re-evaluated to fit the patient's needs.

SOCIAL INTERVENTION MODULES

Discussion Group

Dementia patients meet in the discussion group at an early stage. This group is guided therapeutically. Its aim is to find out, by talking about everyday life, how far the illness has progressed, identify personal deficits, and remaining resources of each participant. The group aims are (1) strengthening competence in maintaining one's own life-style, (2) promoting social contacts, (3) fighting against social withdrawal, and (4) recognizing and reducing stress.

During their discussion the participants talk about changes they are experiencing in their moods, becoming aware of their limitations, and the deterioration of their abilities. Also, fears of loss of autonomy, dependence on the goodwill of others, and the devastation of their plans in life are discussed. As well as their restrictions in social contacts and mobility.

Training Groups

The group of people diagnosed with dementia at an early stage is of utmost importance in cases where increases in failures leads to hurt feelings and depression. These patients react with social withdrawal. The group helps people to identify with the other members and is a place where they can count on support. This service is especially important if there are no relatives living nearby. The support group's aims are (1) strengthening competence in maintaining their own life-style; (2) positively influencing orientation disorders; (3) strengthening and furthering sense of perception; (4) reducing depression, irritability, and anxiety; and (5) fostering self-esteem and promoting mental well-being and stability.

TYPE OF CARE

Day Care

PRO DEM offers day care in a refurbished bakery, the oldest building in the village. In this setting, healthy elderly help the ailing elderly to cook and bake in a playful way. In the future however, we want to expand this care to bring in small children, youths and their mothers together with gerontopsychiatric patients.

Care Group and Day Nursing

The care group is similar to the training groups, but its members are at a much more advanced stage of the illness. Doing things independently is not a main priority in this group; however, the members do need more qualified staff support. These 3- to 4-hour sessions do not conflict with the day-to-day nursing, which is offered in nursing homes and means an 8-hour respite for the families. This group's aims

are (1) developing the abilities of working together, (2) strengthening self-esteem, (3) establishing the feeling of being secure, (4) combating impaired motor functions and reducing motor restlessness, and (5) using and encouraging aesthetic sense (flowers, herbs, music, dance, painting).

Volunteers

PRO DEM physicians have trained 20 volunteers in a course of 12 evening sessions. These workers visit families, keep patients company, go for walks with the patients, and assist with shopping. Taking patients out for a ride, reading to them, and baking have all proved to be very popular ways of simply spending time with dementia.

Thus, the PRO DEM program focuses on a single disease and offers a range of tools for managing that disease.

MANAGEMENT OF CHRONICALLY ILL PATIENTS

Destigmatization

Alzheimer's disease creates anxiety; because people know very little about it, and as a result they often attach a stigma to this illness. To foster early detection, more information needs to be provided about this illness to eradicate this stigma. This can be done only at the community level.

Deterioration of Condition

There is another important aspect to prevention: support for the patient/caregiver relationship. Like a mother and her newborn baby, a person with increasing dementia and the caregiver form a dyad: When the caregiver feels well, the patient benefits; when the patient is well cared for, the caregiver's health does not suffer.

Patient Participation

At its inception in 1999, PRO DEM was extremely physician oriented. A patient entered the PRO DEM project only at the physician's initiative—PRO DEM acted only on referral by one of the 32 primary care physicians in the communities. Today there are more and more direct contacts between families and the nurse consultants in the PRO DEM Consulting Center. But even now, physicians must be willing to work with the project.

Documentation and Reporting

One of the main goals of the project is to detect dementia as early as possible. If any suspicion arises, the general practitioner investigates, following a mandatory protocol. Examination results are reported in a separate document sent to the nurse consultants. The nurse consultants visit the patients at home and assess their personal needs. Their findings are noted on another document, which goes back to the family physician. The next step is the referral to the specialist, who decides whether the diagnosis is to be completed, for example, by special blood tests, spinal puncture, or magnetic resonance imaging.

These results are documented in a letter to the family physician, who presents all conclusions at the MCC which meets every 8 weeks. The periodic conference brings together 6 to 10 physicians and staff members from 9 nursing homes (1 with day nursing), 2 health and consulting centers, 5 private nursing services, and 3 ergotherapy practices, as well as, 4 speech therapists, and 15 physiotherapists. At the MCC, they all work together to develop a specific therapy plan that includes the appropriate medical treatment, as well as social intervention.

The MCC participants can choose from the sequence of care services previously described. The nurse consultant or ergotherapist who leads each of the support groups (there are currently eight) knows the patient's status, how members work together as a group, and what they are still able to do. Given that feedback, the MCC participants adjust the medical treatment and social intervention to fit the patient's situation. The family physician sees patients on a regular basis. The nurse consultants follow the patient's development in the groups, in day care, and reports their observations in a written document to the family physician every 6 months.

Support to Caregivers

PRO DEM addresses caregivers as well as patients. Physicians and the nurse consultants take the opportunity to talk to the caregivers about the caregivers' self-help group. This group meets two times a month, bringing together 12 to 15 caregivers and 1 nurse consultant or physician.

Proceedings within the group are standardized according to the concept of the therapeutic self-help group. The group consists of longstanding and new members. Time and again, it is observed how much the newcomers benefit from the experiences of the longstanding caregivers. They share information about dementia and its treatment, but even more importantly, the sense of relief and certainty that somehow life does go on (Moeller, 1981).

The progression of dementia continues—sometimes slowly, sometimes at a faster pace—and the PRO DEM alternatives from the care sequence will vary accordingly. The nurse consultants or the MCC participants determine the alternatives based on

what stage of dementia the patient has progressed to. The family physician is responsible for the continuous treatment of dementia and comorbidities. If complications arise and hospital admission is necessary, a letter describing dementia status and offering hospital visits from the nurse consultants should accompany the patient. This is the common procedure if there is advance notice, but more than one-half of the admissions follow an accident. Unfortunately, a great deal of ignorance is observed on the part of the hospitals concerning dementia. Patients often return home stressed and rarely, do they actually recover. So the family physician and the nurse consultant together—if time allows, in the MCC—must decide on what the next step of care should be: day nursing, sheltered accommodation, or admittance to a nursing home. If it is decided that patient is to be admitted into a nursing home, choosing the appropriate one and date of admittance are carefully considered.

Quality of Care, Health Outcomes, and Costs

As previously mentioned, PRO DEM was monitored during the first 2 years by the AQUA Institute (Klingenberg et al., 2001).

Evaluation Results

Two groups of patients were observed: those who participated to a great extent in the PRO DEM options with their family members, and another group of patients who were included in the evaluation, but received drug treatments only (no social intervention).

The comparison between participants and non-participants brought to light quite significant differences. Whereas, the PRO

DEM participants in the Mini Mental State Examination (MMSE) showed nearly constant results during the time checked, non-participants had deteriorated by 4 TFDD (test used to measure cerebral capacity) points per year. Due to the rather low numbers of participants, it should be noted that additional research is needed.

A particularly neglected field of research so far is the impact of dementia on the health status of the family and the caregivers, who according to our observations benefit a great deal from early diagnosis and a modular treatment sequence.

Providers' Participation and Payment

Of the 32 primary care practitioners, out of 20 primary care practices in the region, so far 16 have participated in the project at one time or another. This share may seem low, yet it is explained by the various patient populations in the different solo or group primary care practices. While the project was receiving financial support from the pharmaceutical industry, incentives paid to the physicians were quite attractive: A financial contribution was made for every patient involved, for each documentation completed, and for participation in quality circles. Today, without the payments from industry these financial incentives have stopped. Physicians are therefore expected to be supporting members of the association in order to benefit from the services of PRO DEM—up to now 9 out of the 20 practices cooperate intensively.

The number of patients treated within the project and their relatives per year has remained the same. Over the years PRO DEM is known to be a competent partner in the region. Patients pay little for the social intervention and they are reimbursed by payments from the long-term care

insurance (400 U.S. dollars per year as financial aid from the insurance for low-threshold options, as previously described).

This difficult overall situation could be improved if regional structural contracts were successfully negotiated with the statutory health insurances. But the statutory health insurances make the smallest financial contribution to the comprehensive treatment of dementia (3 percent, versus 30 percent from long-term insurances and 67 percent from families as a copayment). So they have only minimal interest in underwriting structural contracts as long as there are sectoral budgets and as long as the statutory health insurances and the long-term care insurances have separate calculations. Future trends forecast exponential cost increases for the treat-

ment of dementia patients in an aging population. Therefore, it would be advantageous to find comprehensive responses to this problem.

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