

Supporting Patients and Families Affected by Serious Mental Illness: The VA–National Alliance on Mental Illness Collaboration

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By joining forces with a private, not-for-profit organization, psychiatric staff from the Miami VA Healthcare System were able to reach out more effectively to patients' family members and the local community.

Mental health care providers are becoming increasingly aware of the importance of reaching out to their patients' family members and communities. Interpersonal relationships are the cornerstone of psychiatric care,¹ and patients with mental illness may experience reduced morbidity and mortality when their family members are involved in their care and decision making processes.² In addition, the family members themselves may experience better psychological and physical health as a result of collaborating with providers on their loved ones' care.²

Furthermore, family and community support is becoming more important as mental health care in the United States continues to shift away from extended care models and

toward increased outpatient management, which relies on effective follow-up care.³ A 2003 report by The President's New Freedom Initiative on Mental Illness stressed the importance of a mental health system that is driven by patients and their families.⁴ Similarly, Veltro and colleagues suggested in a 2007 research report that caregivers, along with patients and patient-caregiver organizations, "will play a meaningful role in all relevant aspects of the mental health service system."⁵

There are significant barriers, however, to collaborations between mental health care providers and patients' family members. Kass and colleagues noted that providers generally do not treat families of people with mental illness with the same respect as they treat families of people with physical illness. These authors asked mental health care providers who had just taken a course on provider–family member collaborations what they saw as the greatest barriers to such collaborations. The providers' responses included such factors as providers not having time to involve families, providers feeling conflicted about treating patients versus treating

families, providers believing that family involvement can harm patients, families losing hope or giving up, families' concerns about the stigma of mental illness, and families' feelings of guilt and shame.² Family members also may have difficulties related to the care and living situations of their relative that providers may feel helpless to change.⁶

In early 2002, psychiatric staff at the Miami VA Healthcare System (Miami VAHS) in Miami, FL began to discuss their own difficulties in meeting with patients' family members. Staff members speculated that these difficulties might result from such factors as a tendency for family members to leave care to the VA and not make an effort to participate, families' assumptions that getting involved would force them to take on more of the financial cost of their loved ones' care, language barriers, and a lack of family contact or support for some patients who have recently relocated.

In an effort to overcome some of these barriers, the staff decided to initiate a collaboration with the National Alliance on Mental Illness (NAMI), the nation's largest organization dedicated to improving quality of life for

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people with serious mental illness (SMI).⁷ Over the next few years, joint efforts of the Miami VAHS and NAMI led to several projects aimed at encouraging greater family member and community involvement in the treatment of people with SMI.

This article describes how the Miami VAHS initiated its collaboration with NAMI; the programs that resulted from this collaboration; the project group's efforts to maintain the programs; and the programs' effects on veterans, their families, and the community at large. First, however, we provide general descriptions of NAMI and the mental health program at the Miami VAHS.

NAMI

NAMI is a support, education, and advocacy organization that seeks to eradicate mental illness and improve the quality of life for people affected by such illness.⁷ Founded in 1979, the organization currently has over 220,000 members nationwide and a structure that includes a national office, state offices in all 50 states, and over 1,200 local affiliates.^{7,8} NAMI offers education and support programs for people with mental illness and their family members, and people with mental illness often are involved in developing and providing these programs.^{9,10} The organization also provides public information through its web site and telephone helpline, and it raises awareness of and fights the stigma associated with mental illness through such measures as an annual walkathon and commentary on misleading portrayals of mental illness in the media.¹¹ As a result of NAMI's advocacy efforts, the organization received the 2007 Lilly Reintegration Award for Advocacy.¹²

NAMI has worked with the VA in the past—especially through its Veterans Council, which promotes

mental health care improvements in the VA. The council includes members from each of the VA's 21 VISNs and serves as NAMI's liaison to the VISNs. NAMI has worked with the VA's Committee on Care of Severely and Chronically Mentally Ill Veterans, which is responsible for assessing the VA's ability to meet the needs of veterans with SMI.¹³ In addition, veteran patients who belong to the organization have provided testimony on the VA to congressional committees responsible for VA funding.¹⁴

Staff at the Miami VAHS were particularly interested in harnessing NAMI's expertise with regard to support and education for family members of people with SMI. NAMI support groups are held on a regular, ongoing basis—often monthly or every two weeks—and are conducted by facilitators whom the NAMI organization has trained to encourage full group

learn from one another, help one another navigate the mental health care system, and find friends who do not stigmatize them or their loved one for the illness.

In addition, NAMI offers a free, 12-week course called the Family-to-Family Education Program (FFEP), which is taught by and aimed at family members of people with mental illness. This course provides background information on specific mental illnesses, psychiatric medications, and SMI-related advocacy initiatives and discusses such topics as understanding the experience of mental illness, communicating more effectively, handling crises and relapses, coping with caregiver stress, and locating appropriate support and services in the community.¹⁶ Like the support group meetings, the FFEP is used as a platform for family members to share their own stories and receive individ-

NAMI support groups...are conducted by facilitators whom the NAMI organization has trained to encourage full group participation and provide a useful and helpful group experience.

participation and provide a useful and helpful group experience.¹⁵ During the meetings, posters detailing the principles of recovery for patients and families serve as reminders of how the meetings should be conducted. Family members share their experiences, challenges, frustrations, and triumphs. In so doing, they often find that they are not alone in their struggles and forge bonds with these others who are dealing with similar issues. Attendees may feel their burdens lighten as they

ual help and suggestions from other families who have "been there." Many family members have described the impact of this national program as life changing, and thousands have gained information, insight, understanding, and empowerment through it.

MENTAL HEALTH AT THE MIAMI VAHS

As the largest integrated health care system in the United States, the VA has a rich history of research pro-

grams—many of them targeted to the SMI population. It provides a wide range of services, programs, benefits, and treatments for veterans with SMI.⁶

The Miami VAHS serves veterans in three southern Florida counties (Miami-Dade, Broward, and Monroe). Facilities include a VA medical center (VAMC) and an attached nursing home located in Miami; an outpatient substance abuse clinic, also located in Miami; outpatient clinics in Broward County and Key West; and six community-based outpatient clinics in Coral Springs, Deerfield Beach, Hollywood, Pembroke Pines, Homestead, and Key Largo.

The Miami VAHS has an extensive mental and behavioral health service. At the system's VAMC, 32 inpatient beds and 58 psychiatric residential rehabilitation beds (including 24 for substance abuse, 18 for psychosocial and dual diagnoses, and 16 for post-traumatic stress disorder) are managed by this service. The Miami VAHS also provides outpatient services to several thousand patients with mental health, behavioral, and substance abuse disorders. In addition to the mental and behavioral health clinic located on-site at the VAMC, three off-site locations offer psychiatric services: the outpatient substance abuse center in Miami and the large outpatient clinics in Broward County and Key West.

INITIATING A PARTNERSHIP

In the early months of 2002, psychiatric staff from the Miami VAHS took their first steps toward a collaboration with NAMI. A psychiatric clinical specialist in ambulatory care at the Miami VAHS (M.J.G.), who had a record of entrepreneurial accomplishment within the VA, was chosen to serve as leader of the collaboration project. This leader contacted the state (NAMI Florida) and local (NAMI of

Miami) offices of NAMI to explain that Miami VAHS was looking for guidance in supporting thousands of VA patients with SMI and their family members. NAMI Florida's executive director referred Miami VAHS staff to contacts in the NAMI of Miami board of directors. These contacts led to the establishment of a VA-NAMI Project Group, which consisted of four members from the Miami VAHS and two from NAMI of Miami.

To build cohesion among this group, we decided to begin with a few lunch meetings. This approach allowed us to meet during a time that was outside of normal duties, thus making it easier for members to attend. The project leader provided lunch to the group to demonstrate a tangible commitment to the endeavor.

Over the course of the meetings, the group decided that its first project would be a support group for family members of Miami VAHS patients with SMI. The collaboration eventually led to two other projects at the Miami VAHS: an annual Open House conference on mental health and a Family-to-Family Education Program (FFEP).

MIAMI VA-NAMI PROGRAMS

Family support groups

The VA-NAMI Project Group decided that the best way to conduct support groups for family members of VA patients with SMI would be to hold group meetings for families, which would be facilitated by trained NAMI of Miami members on-site at the Miami VAMC on a twice monthly basis. Holding the meetings on VA property would benefit both the Miami VAHS and NAMI by providing a convenient location for VA patients and their families and allowing NAMI to expand its network without incurring additional expenses for space

rental. Since NAMI is an outside organization, however, it was necessary to obtain permission from the Miami VAHS director to hold these meetings on VA property.

At the group's request, the NAMI of Miami office wrote a letter to the Miami VAHS director, who subsequently granted written permission to the group and the NAMI volunteers to hold the meetings on VA property. This permission stipulated that any NAMI members who wanted to take part in the family support groups (as well as other VA-NAMI collaborative projects) would be required to become Miami VAHS volunteers.

As part of the volunteer process, NAMI members receive safety training, education, and tuberculosis testing. Once their training is complete, they are given access to rooms to conduct groups, work with VA staff on site, and provide services for families and patients. Until her retirement from the VA, the VA-NAMI program leader served as the staff supervisor for NAMI volunteers who provide services within the Miami VAHS. That duty has since passed to the psychiatric clinical nurse specialist at the VAMC's mental and behavioral health clinic.

The initial participants for the family support groups were recruited by the VA-NAMI Project Group, and the support groups began meeting in the fall of 2003 on the first and third Monday of each month at 2:00 PM at the VAMC. This twice monthly schedule continues to date. The meetings are open to family members of patients in the inpatient and outpatient mental and behavioral health programs.

Annual conference

The first annual Miami VAHS-NAMI Education Open House was held in 2003 and was highly successful. This

event is designed to provide education, promote a more caring and informed attitude toward SMI, and highlight the strengths of people with SMI by involving them in the conference. The Open House conferences generally last four to six hours and provide free lunch to attendees. NAMI has been an integral part of organizing and presenting the conferences, and NAMI members have been among the conference speakers.

Miami VAHS staff, Miami VAHS patients and their family members, NAMI of Miami members, and other community members are invited to the Open House conferences. Typically, about 45 to 75 people attend the conference. The patients with SMI participate actively in the programs as audience members and, occasionally, as speakers. The attending Miami VAHS staff members include not only psychiatric staff but also staff from other disciplines and departments. Continuing education credits are offered to staff who attend—which has added to the turnout and, eventually, to referrals.

The Miami VAHS Voluntary Service contributes lunch for the Open House conferences. The system's nursing, mental health, occupational therapy, social work, environmental, and other services also help to carry out the program. The Miami VAHS's associate chief of staff for psychiatry and mental health council have provided invaluable support for the program, especially with regard to contributing to good turnout.

The University of Miami's department of psychiatry eventually became involved in organizing and presenting the conferences, which further encouraged community members to attend. Starting with the university's involvement, the conferences have been held at various sites in Miami other than the VAMC. The Miami

Table. Principles for developing a collaborative project involving the VA and the National Alliance on Mental Illness (NAMI)

Initiation principles

- Commitment to the needs of family members struggling to help a loved one with a severe mental illness (SMI) (it is especially helpful to have leadership with first-hand experience with a family member with SMI or membership in NAMI)
- Understanding that a patient with SMI benefits greatly from family education and support
- Leadership with entrepreneurial spirit, skills, and experience

Collaboration principles

- Benefits and cost savings are inherent in collaboration
- The collaboration is mutually beneficial to the VA and NAMI
- Existing resources are utilized without overtaxing either system
- Collaboration and resources grow by adding other agencies and health care systems in the community to the ongoing projects

VAHS–NAMI Open House also inspired the VAHS's mental health and behavioral service to begin hosting its own annual conference.

FFEP

The first FFEP at the Miami VAHS began in the spring of 2004. No adaptations to the existing NAMI FFEP were needed to present it to the family members of veterans. In addition to family members of Miami VAHS patients, family members of nonveterans with SMI from the local community also attend the program, making the program a service to the community.

Before the first FFEP began, the author and publisher of the copyrighted NAMI Family Education Manual gave the VA–NAMI Project Group permission to photocopy the manual, and the medical media service at the Miami VAHS prepared these photocopied handouts for the program. Like NAMI's free access to VA facilities, the reproduction of the FFEP handouts by the Miami VAHS Medical Media Service were a cost

saving benefit to NAMI that helped foster its growing alliance with the Miami VAHS.

MAINTAINING THE PROGRAMS

The success of the VA–NAMI Project Group programs has required a great deal of work from many levels of management and multidisciplinary services at the VAHS and from NAMI volunteers (Table). While we have kept the core group (consisting of nurses, social workers, and occupational therapists) small to maximize its efficiency, we frequently bring in staff from other departments and disciplines on an as-needed basis. When eliciting the services of other clinical staff for a specific project, the group makes every effort to adjust the needs of the project to fit within the regular practice and procedures of the department from which it is requesting help. In this way, the group can be considered just another internal customer of the given service.

Miami VAHS police officers have been very cooperative and helpful in the process of granting non-VA em-

ployees access to the Miami VAHS for the programs. The VA-NAMI Project Group worked closely with the chief of police to pick a meeting room that was located securely for an outside group. The police helped with parking access and other security issues, and the group gave police a list of people expected to attend programs and classes.

The environmental services department at the Miami VAHS also was invaluable over the course of the project's growth. The department's staff set up the rooms for the programs, even when they were held in evenings or on Saturdays.

EFFECTS OF THE PROGRAMS

To date, observable outcomes from these joint ventures between the Miami VAHS and NAMI include attendance of family members and patients at educational programs, family member attendance at the FFEP, and family member attendance at NAMI support groups at the Miami VAHS. In addition, the Miami VAHS has been able to provide services to family members of people with SMI in the local community by open invitation. Through their involvement with NAMI, three patients recovering from SMI in the Miami VAHS were invited to serve on a community advisory board for one of the Florida Assertive Community Treatment Teams. These teams, run by the Florida Department of Children and Families, provide 24-hour services to people with mental illnesses.¹⁷ Advisory board appointments can help patients with SMI by improving their self-esteem and functioning in the community.

On a final note, the Miami VAHS-NAMI collaboration has led to a new initiative for veterans with SMI. The chief of the Miami VAHS psychology service is now working with NAMI's

national consumer education coordinator to bring training for veterans who will be hired as peer counselors at the Miami VAHS. The plan is to have this training financed through VA and community grants. ●

Author disclosures

The authors report no actual or potential conflicts of interest with regard to this article.

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