

VISN 5 MIRECC Research Abstract

Working with Families to Improve Quality of Care for Schizophrenia **Lisa Dixon, MD, MPH, PI & Shirley Glynn, PhD, Co-PI**

1. Objectives. We seek funding to promote the use of an evidence-based practice, family psychoeducation (FPE), in the care of veterans with schizophrenia and to involve families in advocating for the overall quality of care for patients with this devastating disorder. Schizophrenia afflicts 1% of the population, but causes disproportionately greater overall direct and indirect costs because individuals it afflicts are highly disabled, generally unable to work, and its onset occurs early in adult life. FPE is rarely offered in the VA, in spite of its established effectiveness for significantly reducing rates of relapse among schizophrenia patients. Our preliminary work suggests that the implementation of FPE faces considerable barriers in the VA related to patient, system and family level factors and that FPE may require modifications in the VA before a full-scale implementation succeeds in promoting the program and improving patient outcomes. Systematic research is thus necessary to understand the nature of these barriers and test strategies to enhance the likelihood of involvement of families in care.

It is notable that family psychoeducation is but one model in which the involvement of families has been found to be effective in the care of persons with schizophrenia. Other studies have demonstrated an association between family involvement with care and the likelihood that schizophrenia patients will receive follow up outpatient care after hospital discharge, the likelihood that patients will be adherent to medication, and the likelihood that patients will be employed. Family involvement in care also reduces family burden. Ground-breaking work (Dixon, PI) is now testing the hypothesis that involving family members in the care of persons with schizophrenia and addiction increases engagement of patients in dual diagnosis treatment; treatment dropout is the biggest treatment challenge for this daunting co-morbidity problem, and preliminary data are very promising. Additional work in which Dixon (PI) is collaborating is testing the possibility that teaching families about evidence-based quality of care standards in schizophrenia via a web-based portal will allow them to advocate for better care. Thus, the development of strategies to increase the linkage of families to the clinical care of persons with schizophrenia has the potential to promote the use of a specific evidence based practice, family psychoeducation, as well as possibly improving other patient-related outcomes in schizophrenia. **Unless we can develop methods to engage VA families, veterans with schizophrenia and the VA will be unable to access the powerful advantages of appropriately involving the families of persons with schizophrenia in patient care.**

2. Quality Improvement Program. We propose to adapt and test a brief three-session support and education program developed by Glynn (Co-PI) and Cohen (Co-Investigator) and others of VISN 22 as part of an on-going QUERI supported effort in VISN 22 (EQUIP, Young, PI) to improve outpatient care in schizophrenia through the use of systematic assessment, feedback to clinicians, and family engagement. The three-session family engagement intervention itself includes both patients and families and provides education about schizophrenia, support, assistance in accessing VA clinicians, and information about community resources. The EQUIP program is still ongoing and formal data analysis has not begun. Informal feedback from staff indicates that the materials have a great deal of content validity and the clinicians valued the training in the materials. However, further adaptation of the brief program is needed to improve engagement of families and to more explicitly address the obstacles to family work identified by many providers (e.g., hopelessness among family members, family lack of involvement, high levels of family disorganization). In addition to providing additional preliminary efficacy data on the EQUIP family intervention in a context not limited by the parameters of EQUIP, the proposed program will allow us to more specifically assess implementation obstacles and conduct a more formal assessment of clinicians' perception of the program. In addition, implementation at another site would allow us to evaluate the generalizability of this brief educational program, and make modifications to increase its potential use in a national system of care such as the VA.

We hypothesize that this program will result in greater likelihood of family participation in patient care defined by a meeting between clinician and family member, and be associated with improved short-term patient and family outcomes including increased patient and family satisfaction with services, increased likelihood of receiving outpatient care after hospital discharge, increased illness knowledge, and increased empowerment. The long-term outcomes demonstrated by FPE of decreased relapse, decreased symptoms and improved patient functioning will be tested in longer term studies if we find that this engagement intervention is successful.

The EQUIP family intervention focuses on motivating and providing hope to caregivers that are demoralized and "burned out" using motivational interviewing techniques. Home visits are possible and encouraged if necessary. Depending on patient and family needs, it can also be delivered over the phone. After the three support and educational sessions, ongoing consultation is available on a biweekly basis for up to three months. In order to ensure that peer- and family-linked perspectives maintain an influence on the service, an identified clinically experienced family member will be a member of the intervention supervisory team.

An additional part of this study that is a critical aspect of the quality improvement initiative is the opportunity to do an extensive assessment of family configurations, social support needs, and preferences regarding treatment of veterans who consent to have family contacted and those who do not. We will attempt to assess the needs and preferences of families who do not choose to participate in our program to determine what kinds of programs would better suit their needs. This kind of descriptive, detailed study will help us interpret the findings of our intervention study and move to the next phase of creating programs to engage and involve families and support systems of a larger group of veterans with schizophrenia.

3. Evaluation. This study will have two components and will be conducted on acute inpatient units of VISN 5 in the VA Maryland Health Care System (VAMHCS). Patients with schizophrenia, schizoaffective disorder, and schizophreniform disorder from the age of 18-70 will be eligible. The rationale for these sites is that families are most likely to be engaging in treatment during periods of crisis and patient need is greatest at this time. Recruitment will be otherwise inclusive and, in terms of demographics, should reflect the VA clinical facilities from which subjects will be recruited (i.e., approximately 65% African American, 95% male). All consecutively admitted patients will be assessed for eligibility. For phase one, eligible patients will be approached for consent to participate in the study and asked for permission to contact a family member with whom they have contact at least once a week. The family members of consenting patients will be contacted and attempts to engage them in care using our program will commence. Consent to participate in the research component of the project will be sought from family members. This phase of the study will not involve randomization; a randomized trial comparing this model to enhanced treatment as usual will be proposed for future funding through HSR&D after this preliminary phase. Patients and consenting family members will complete an interview at baseline and then in three months regarding symptoms, history, family and patient experience with treatment and needs, preferences and obstacles to inclusion of families in treatment. The patient will also be asked to identify a clinician whom he/she considers to be most involved in his/her care, and this individual will also be approached for an interview to identify perceived clinician barriers. We will attempt to recruit a total of 80 patients over the next four months. We expect that approximately 50 patients will consent to allow us to contact family members based on our previous work. We expect that approximately 25 families will agree to participate in the engagement intervention.

A second phase of the study will seek to interview patients who either do not have family contact at least once a week or who do not give permission to contact family in order to describe the nature of their current and past family relationships, support system, and preference regarding VA services. We will also seek consent to interview family members who do not agree to participate in the program to determine their views of their relationships with the ill family member and their perceptions and preferences regarding VA services. This aspect of the study will be critically important in understanding additional barriers that need to be overcome to involve important members of veterans' support systems in care. Patients and family members will be paid \$30 for each assessment to compensate for time and inconvenience.

This study will allow two general types of analyses. The first will describe the proportion of patients who provide consent to contact family and will summarize the relationships, extent of contact, and types of support provided to veterans by family members. We will also compare veterans who have involved family members to those who do not have involved family members on demographic and clinical variables with independent t-tests (continuous variables) and chi square analyses (categorical variables). We will use the same approach to compare families that consent to participate to those who do not on patient and family variables. In terms of the intervention, we will calculate the proportion of patients whose family members are successfully engaged in the three-session program, the proportion of family members who achieve contact with clinicians, the nature of the contact, and its perceived usefulness by family members and clinicians. We will use a chi square analysis to compare the rates of attendance at follow up care after hospital discharge to the rates of usual follow up care which we are tracking in Dr. Dixon's study of a Critical Time Intervention to improve follow up post hospitalization. Paired t-tests will be used to assess changes in knowledge, satisfaction, empowerment, and adherence for families and patients evaluated three months after the conclusion of the program. (MIRECC funds will be used to conduct the follow-up data collection.)

4. Staffing.

Key project personnel:

- Principal Investigator: Lisa Dixon, MD, MPH, Professor of Psychiatry and Associate Director for Research, VA Capitol Health Care Network MIRECC, Member, QUERI Executive Committee
- Co-PI Shirley Glynn, PhD, Clinical Research Psychologist, VA GLAHS at West Los Angeles, Affiliated Investigator, VISN 22 MIRECC, IIR 99270-1 (Glynn) 10/1/00 - 9/30/04 Online Family Education to Promote Treatment Compliance in Schizophrenia
- Co-Investigator: Amy Cohen, PhD - Health Services Researcher, VA Desert Pacific MIRECC
- Co-Investigator: Alan Bellack, PhD, ABPP, Professor of Psychiatry, Director, VA Capitol Health Care Network MIRECC
- Project Coordinator: Aaron Murray-Swank, PhD, Post doctoral Fellow, VA Capitol Health Care Network MIRECC