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Yale-Family Assessment of Needs for Services (FANS)

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As knowledge of mood disorders grows, it becomes apparent that families of those suffering are greatly affected by these illnesses. Books have been written about how a family can cope with and help a family member with a mood disorder (Golant, 1998; Miklowitz, 2002; Sheffield, 1998; Sheffield, 2003) and research has extended into examining those issues. Family-Focused Therapy incorporates the family and the patient in the therapy treatment (Miklowitz & Goldstein 1997). It is essential that researchers address families as well as patients because most people with a mood disorder must deal with how the family responds, positively or negatively.

Family Assessment of Needs for Services (FANS) was launched in the hopes of finding out what the needs of caregivers of people with bipolar disorder are. The prediction was; if those needs were met, the caregiver could more effectively help the person with the illness get and stay well. Also, FANS addressed the fact that caregivers who had been dealing with the illness longer, had more needs.

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It seemed that the more one knew about bipolar disorder and the healthcare system, the more needs they had, as if lack of knowledge in the early stages after a diagnosis caused caregivers to greatly underestimate the task of caregiving and the strains involved. After some time of caregiving, exhaustion from working outside and inside the home, dealing with hospitals and doctors, and chronic sadness about the illness, can dramatically change the relationship families have with the ill member. In addition, caregivers often neglect their own health, because they don't have time to take care of themselves. The FANS study hoped to identify exactly what the caregivers' needs were and how some of the strains could be reduced so family relationships work better.

Caregivers were recruited from two sites: the Mood Disorders Support Group of New York (MDSG-NY) and the Veterans Medical Center at Yale University Medical School. MDSG subjects were recruited from the Family and Friends Support Group. Veterans Medical Center subjects were families of the inpatients there. Caregivers were identified as primary or secondary based on the amount of contact with the patient and the amount of support they provided. Thus, a primary caregiver could be either a family member or a friend. Usually, only a caregiver was interviewed. However, in some cases, a patient version of the questionnaire was also administered.

The semi-structured questionnaire was conducted through an interview either in person or by phone. After demographic information, facts about the caregiver-patient relationship were obtained, including who was caring for the patient, spending the most time with the patient, supporting the patient financially, and who the patient relies on to help make decisions. The questionnaire queried what areas the caregivers needed help with including information about diagnosis, therapy options, psychotropic medications, finances and health insurance, communicating with the patient and dealing with noncompliance, and resources for the patient. Then data was collected on what needs the caregivers had for themselves including help to keep up with their own health issues, finances, household work, and if they needed time away from caregiving. Patients and caregivers were both asked to include information about what services they thought would be helpful for the caregivers.

Caregivers were 73.7% female (age = 52.2 +/- 12.8). 54.1% were married/cohabiting, 78.9% worked, 37.8% had an income below $60,000. 50.0% of caregivers were spouses and 34.2% were parents of the patient. The highest percent of unmet needs were information and stress management, specifically, 100% and 95% of subjects reported needing information about medication side effects and mood stabilizers, respectively, while 73.7% needed relief from caregiving strain, and 65.8% wanted stress reduction education. 40% of subjects wanted a more collaborative relationship with the patient's psychiatrist. Having siblings nearby was significantly correlated with fewer needs, while income and education were correlated with increased needs. 89.5% of caregivers felt they would benefit from services.

Preliminary findings show that caregivers have substantial unmet needs and are interested in supportive interventions. Also preliminary, but overwhelmingly, caregivers perceive the healthcare system as a confusing maze of limited resources that are discovered either serendipitously, or after exhaustive efforts.

Future studies may explore the best way to unravel "the system." This refers to access to healthcare in a hospital or clinic, caseworkers, day treatment, health insurance and disability, career training and counseling, therapy and support groups. FANS' attempt to assess the supportive needs of caregivers is unique enough to have lead to cooperation with the System Treatment Enhancement Program for Bipolar Disorder (STEP-BD). STEP-BD, lead by Gary Sachs, PhD, has become the largest project for bipolar disorder to date, treating people with bipolar disorder across numerous cities. In addition, Deborah Perlick and Li Lippman will explore treatment for caregivers based on the FANS study. The treatment will provide 2-15 sessions for primary caregivers addressing lifestyle management, cognitive and behavioral techniques, and health issues. The growing number of resources for family members and friends of those with mood disorders is an indicator that programs are needed for caregivers. Pinpointing caregivers' specific needs and then delivering solutions is essential and should be explored further.

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