

From Anguish to Advocacy: Responding to My Daughter's Schizoaffective Disorder

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Shared-Care Conference

June 16, 2012

Typical Problems of Parents Learning Their Son/Daughter has a Psychotic Disorder

- Lack of accurate background knowledge
 - era of nurture not nature
 - media representations of parents as abusive
 - lack of basic information in public discourse so don't recognize early signs of psychosis

Typical Problems, cont.

- Contact with mental health professionals not trained in science based approaches to mental illnesses leads to:
 - delayed referrals for medical help/early psychosis intervention
 - parent blaming leading to alienation of vulnerable patient

Typical Problems, cont.

➤ Competing paradigms

- what some social scientists say...

Professor Neree St-Amand, a sociologist in the University of Ottawa's School of Social Work, with a focus on "empowerment" and alternative therapies, has a view of mental illness that is common in his academic field, but at odds with the mainstream.

He thinks psychiatrists aim to control people, who then become fat and suicidal, with no libido, hating themselves. He thinks untreated schizophrenia can be a gift, and that in other cultures, hearing voices is revered as a bridge to the spirit world. He thinks psychiatrists mislead the mentally ill about the risks and benefits of drugs, discouraging them against other options, such as spirituality, nutrition and yoga. He is blunt about the dilemma facing their families.

"If people cared for their people, then it changes a lot of the problems," he said in an interview. "It changes the perspective on the problems, and you don't necessarily want to give them a diagnosis and treatment, you want to love them and care for them."

More unusually for an academic social theorist, Mr. St-Amand sits on an advisory committee of the Mental Health Commission of Canada, representing family caregivers of mentally ill people, and devising policy to support them.

Ongoing Problems for Parents

- Difficulty in accessing accurate and ample information
- Involvement is undermined:
 - told not to limit independence
 - made to feel their involvement is hurtful
 - confidentiality limits their knowledge
 - confidentiality limits their input, needed for best medication and psr choices

Families are Impacted

➤ Emotionally

- families feel loss, grief, fear, exhaustion
- psychotic people can be abusive
- siblings impacted

➤ Socially

- lack of accurate public knowledge leads to isolation

➤ Financially

- expenses of the illness
- lost income

Information Families Need from Mental Health System

- awareness that Canadian Psychiatric Association calls schizophrenia a treatable brain disorder that is not caused by poor parenting
- science based info about the illnesses

www.nimh.nih.gov

www.bcass.org

Info Needed, cont.

- lack of insight: 40-50% of people experiencing psychosis don't understand that they are ill so often don't consent to treatment

www.treatmentadvocacycenter.org

- parents need to know it doesn't violate human rights to get person out of psychosis
- need to know why people stop taking medications

Info Needed, cont.

- how to navigate the mental health system
- organizations that offer science based family education
ex. BCSS/SSC Strengthening Families Together,
Ontario Family to Family (www.nami.org)
- support groups
- legal options, BC Representation Agreements (like Power of Attorney) – help with education/finances/healthcare

Info Needed, cont.

- appropriate psr programs for son/daughter
 - where won't hear that medications are useless and oppressive
- predictable cognitive losses and educational options, need for cognitive remediation

Families Need Family Physicians and Psychiatrists to Be Allies in Advocating for:

- science based education about psychotic disorders in all programs training mental health professionals (e.g. counselling psychology, social work)
- professional development for colleagues who haven't had this kind of education
- collaboration with family caregivers

Families Need Allies in Advocating for, cont.

- involvement of genuine family caregivers in planning and evaluating mental health programs
- opposing healthcare funds for groups against anti-psychotic medication
- recognition of need for involuntary treatment: families don't want ill family members left to deteriorate in untreated psychosis

My Story

From Anguish to Advocacy

- initial ignorance and resulting problems
- daughter with worst prognosis now stable
- writing the family caregivers' perspective
- *After Her Brain Broke, Helping My Daughter Recover Her Sanity*