Survey of Families of People with Severe Mental Illnesses and Their Relationship with the Health System

By the Family Alliance on Severe Mental Illnesses (FASMI)

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Executive Summary

The Family Alliance on Severe Mental Illness (FASMI) surveyed family caregivers across Canada to assess the strength of communication and collaboration between families and clinicians treating severe mental illness. Over 80% of Canadian family caregivers reported that clinicians or hospitals had failed to provide needed information, and they said that this failure had often placed their loved one at risk. Almost half of Canadian family caregivers said that they had offered clinicians clinically relevant information that was either refused or ignored. Notably, more than half the respondents said that clinicians rarely or never communicate with them.

These findings are consistent with findings from other countries and should be considered in the light of international research that has consistently shown that family involvement reduces relapse, improves medication adherence, decreases hospital readmissions, and supports continuity of care in the community.

There is clearly an urgent need to improve communication training for mental health professionals. Appropriate family involvement in treatment planning will only happen when hospitals and clinician organizations update their policies governing caregiver participation in clinical care and discharge planning.

Introduction

Nothing is more devastating to a parent than watching a sick child and being shunned by the professional carers. Sadly, that is the situation that many families of those with severe mental illness find themselves in and it has long been a contentious point between parents, doctors and other mental health professionals. The mentally ill child is, in these circumstances, over 18 and considered adults even when they may not have competence due to their illness.

But one reason for this split may go back to the discredited theory that schizophrenia is caused by "schizophrenogenic mothers". Another is the privacy law to be discussed below.

Schizophrenogenic mothers is a widely discredited 1950s-1970s theory blaming cold, unemotional parenting for causing autism and childhood schizophrenia. Coined by Frieda Fromm-Reichmann it falsely suggested maternal rejection caused children to withdraw, causing immense guilt and stigma. However, today, modern science identifies autism and schizophrenia as neurobiological disorders, not caused by "bad parenting".

But, despite being discredited, the view still seems to linger and cutting out parents is rationalized by many using protection of privacy legislation that prevents doctors from disclosing confidential patient medical information even to family when the patient lives with that family and is supported emotionally and financially by their family. Put simply, many of those treating and their agencies argue that they cannot speak to family if their patient is over 18 and they make no effort to seek permission to do so from their patient. If a doctor violates that in Ontario, he or she can be fined up to $200,000 and jailed.

We can certainly understand their reticence but there are solutions. The patient can be asked for permission (often they are not) or the doctor can suggest they not disclose certain facts defined by the patient but rather provide other information that might not be as contentious.

Respecting privacy is important but numerous reports and studies including the Canadian Mental Health Commission argue for the value of working with families. The effort should be made.

When caregivers are involved according to the Commission:

"they save the Canadian economy an estimated $25 billion annually. The unpaid care and support family caregivers provide represents a major contribution to our health and social service systems, and replacing that care and support with formal services would be very costly. If, instead, we enhanced family caregiver engagement, we would improve the health of clients and their families."

Numerous papers point out that *"family involvement has a positive impact on patients and their families. For the patients, it leads to less chance of relapse, better medication, fewer hospitalizations, and less strain on the healthcare system. The families can provide better care and support for the patients."*

And the reason put forth for the reluctance to involve families from the paper cited above were *"lack of competence and experience with family involvement among the staff in the treatment units, lack of awareness of measures that can be made to involve families, negative attitudes towards family involvement, limited access to training and guidance, lack of priorities, routines and practices of family involvement, lack of managerial support and lack of resources in the units."*

Fortunately, in the past few years there has been an improvement in involving parents thanks to reports from groups like the mental health commission mentioned above and a survey done by The European

Federation of Families of People with Mental Illness EUFAMI) They are a non-profit organization that advocates on behalf of family carers. They conducted an international survey on the impact of serious mental illness on families in 2015.

The results are not pretty!

The survey of over 1000 people was conducted in 22 countries including Canada.

Four in ten respondents were dissatisfied with the support they received from doctors and one in three were dissatisfied with support from nurses. Only three in 10 were happy with the help they received from their social workers. Two thirds of people complained that they were not considered in important decisions being made for their family member and more than 60 per cent did not feel that the system professionals took them seriously.

EUFAMI points out that the shift away from hospital-based care makes the role of the caregiver essential in the support of their family members and yet they are often left out and ignored. Those who replied to the survey had been involved for over 15 years and were typically females aged 60. Three quarters of them are caring for a child and many feel depressed, lack proper sleep have feelings of anxiety and an inability to cope.

The FASMI Survey:

The Family Alliance on Severe Mental Illnesses (FASMI) still hears comments from family members about the problems on communicating with doctors so we decided to conduct our own small survey to determine the extent of the problem.

Using Survey Monkey, we created 17 questions to explore this and gather basic demographic information. After a pretest, invitations to fill out the survey were advertised to our members via email, in our regular news letter, and by similar advocacy groups like the BC Schizophrenia Society, Pathways, Nova Scotia Moms, Home on the Hill Supportive Housing and Mothers for Mental Health Reform and others.

We ended up with 151 returns from every province in Canada except for New Brunswick and Newfoundland and Labrador. What amazed us is that the responses were overwhelming in their consistency that health care providers were still ignoring the value of family in the care of their ill relatives. We do, however, have one caveat. Mental illness treatment should be and often is a long term process. People have numerous providers ranging from bad to excellent so when people report bad experiences, it means that there are times when they had to deal with uncaring and insensitive staff at some point in their travels through mental health care. This fact is reflected in our results as you will see. In fact, in a star rating system where we asked Rate your overall satisfaction with the clinicians' responsiveness to your concerns, people gave them 2.8 out of 5.

In addition to about 83% of respondents reporting that at some point, hospitals and/or clinicians failed to give them needed information and that close to 85% felt that caused danger to their loved ones, we gathered quite a bit of consistent data.

Almost 50% of people tried to give those treating their relatives with information they felt could help the professionals but it was refused. Forty-nine percent reported that information given to health care staff in confidence was passed on to the patients. Most people with schizophrenia either live with family or are in close connection to family and the family observes behaviours not seen by health staff. Their observations can be very relevant but it is often ignored.

Families reported that about 60% of them rarely or never interact with the clinicians. Only 12% do so either daily or in weekly sessions. In addition, one-third of respondents reported that the communication skills of the treating staff were poor or very poor. 30% said it was good or excellent.

Over one-third (36%) felt the mental health staff had poor communication skills. Other views of those skills were:

Excellent	8.8 %
Good	21.6 %
Average	35.8 %

Health care supports given to family (multiple responses accepted) were:

In terms of knowledge that staff have about their patients, families said:

very much	23.7%
somewhat	31.8%
neutral	19.6%
somewhat unknowledgeable	18.2%
Not at all	6.8%

Getting an appointment with a family member's treatment team is also difficult. Only 25% said it was very easy or easy. Most (54%) said it was either difficult or very difficult. When asked how much empathy the staff had towards their patients, 26% of family said very high or high while almost 35% said it was low or very low. In terms of involving family in decision making, 49.0% said poorly or very poorly while only 24% very well or well

In terms of demographics, almost 90% of respondents were females and 86% were over 55. 62% of their children were over the age of 35 and 29% were 25-34.

Comments from Respondents

Almost every person who filled out the survey made a comment on the open ended question expressing their wishes and/or concerns. They were very consistent and these were the ones that stood out:

increased caregiver involvement

I would like to be treated as a valued member of the care team.

In Saskatchewan person with serious mental illness have to volunteer for treatment. Family information that meets the requirement for committal requirements of the Mental Health Act is ignored.

Structured plan and conditions that are in effect

Treat this like an illness and provide deserving care and compassion. We were so in the dark and had to maneuver the maze for years to understand the illness and everyone's rights.

would like the clinician to treat my daughter's condition the same as any medical condition. I should be included in her circle of care & not be excluded because she is delusional and unaware that I'm helping her. Why should someone so diagnosed with a condition that makes her unaware of their condition have the right to make decisions.

My son's capacity for decision making is limited due to severe bipolar disorder and anosognosia, he does not believe he is ill, yet he continues to be able to make decisions about treatment which puts him in grave danger. Laws must change to protect some of our most vulnerable people

Collaborative discharge plans.

Tailoring care to address anosognosia. IE not just accepting my loved one's answer of "no"every time help is offered. Understanding that he will not say yes since he's "not sick".

that they would listen more carefully to the information we give them regarding our loved one and take that into consideration better when providing treatment for our loved one

Listen to my concerns

Listen to our concerns and document our information

Discussion:

Serious mental illness frequently impairs insight and reliability. Family members provide longitudinal and contextual knowledge unavailable in clinical encounters. It is the family who are in contact with their il relative who see them on a regular basis and are in a position to report what may be hidden from the physician. Many years of research has demonstrated that family involvement results in relapse reductions of approximately 20–50% in schizophrenia populations.

In addition, it significantly reduced rehospitalization rates over extended follow-up; improved medication adherence and continuity of care and led to earlier detection of relapse and reduced crisis admissions System-level benefits include reduced length of stay and improved outpatient engagement These findings are reflected in national and international policy, including the Mental Health Commission of Canada and the UK National Institute for Health and Care Excellence, both of which recommend routine family involvement. System-level benefits include reduced length of stay and improved outpatient engagement

Many advanced countries do recommend that families be involved with the care of their ill relatives. The Australian state of Victoria in its mental health act stipulates that he psychiatrist must have regard to the views and preferences of the patient and the views of the patient's carer, if any. Provisions define carers broadly and require that they be involved in treatment planning and discharge processes. The Act repeatedly emphasizes that decision-makers must "have regard to" carer perspectives, elevating family input to a legally relevant consideration.

The Mental Health Act, New Zealand, 1992 adopts a consultation-based model grounded in whānau (family) involvement.

Key provisions include:

"The clinician shall consult with the patient's family or whānau, where practicable."

and

"Every patient shall be encouraged to maintain connections with family, whānau, and support persons."

In addition, New Zealand legislation and practice guidelines require that family members be notified of key events and included in care discussions unless impracticable.

he Mental Health Act for England and Wales, 1983 creates a formal legal role for the "nearest relative."

Key elements include:

- requirement that an Approved Mental Health Professional consult the nearest relative prior to admission (s.11);
- power of the nearest relative to apply for discharge (s.23);
- participation rights in tribunal proceedings.

The statutory scheme effectively recognizes that family members have independent legal standing within the mental health process, rather than merely advisory roles.

In a guide to the best practice in mental health care in Scotland is the Triangle of Care.There are six key elements that must be adhered to. These are:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols re: confidentiality and sharing information, are in place.
4. Defined post(s) responsible for carers are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available. In addition to the above, there also needs to be regular assessing and auditing to ensure the six key standards of carer engagement exist and remain in place.

Conclusion/Recommendations

The evidence, comparative law, and clinical realities converge on a single conclusion: **family involvement must move from discretionary practice to statutory requirement. All mental health practitioners should be required to involve family in the care of their ill relatives. Failure to do so without good reason should be considered professional misconduct.**

We realize that for many, this would require a totally new mindset and skills but FASMI is willing to work with the relevant organizations and medical schools to help make this a reality.