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Family involvement means information sharing

A SPECIAL ISSUE ON THE SHARING OF INFORMATION WITH FAMILIES

A lot of lip service is given to family involvement, sometimes tacked on in policy documents and clinical guidelines with bureaucratic rigour. In a recent early psychosis intervention document here in B.C., for example, the words “family” and “families” appear 168 times.

Such references are understandable because, clinically, family involvement produces better outcomes.

Without the sharing of clinical information with families, however, pledges of commitment to family involvement ring hollow.

Vancouver Coastal Health and many other service providers in B.C. turn a blind eye to this disconnect...and the failure that goes with it.

No difficulty presents itself when the patient grants permission for the information sharing. The clinical failure or hypocrisy arises when patients, because of their psychotic delusions and paranoia, or lack of understanding of their illness, object, and the psychiatrist or other service provider unthinkingly goes along.

It's exactly when someone is so acutely ill, however, that sharing information with close family members, and getting their feedback, is crucial – crucial to producing optimal outcomes and crucial to preventing tragedy.

As regular readers of the NSSS Advocacy Bulletin know, the law in B.C. specifically allows for sharing in these circumstances. It's a myth that confidentiality provisions in the law prevent it, quite the contrary.

Section 33.1(1)(m)(i) of the Freedom of Information and Protection of Privacy Act (FIPPA) points out that information can be shared, even without permission of the patient, where “compelling circumstances exist that affect anyone's health or safety.”

Serious mental illness, with its devastation, trauma, chronicity and difficulties, very much qualifies. It's not just a momentary, superficial ailment that can be looked after in a few days with a cut-and-dried procedure.

Given the high suicide rate of the mentally ill, not to mention the dramatically high rate of suicide attempts, serious mental illness also presents a continuing risk to safety, especially in its acute phase.

The Ministry of Health Fact Sheet on FIPPA makes this clear, pointing out that “public bodies may release necessary personal information to third parties without the consent of the client where disclosure is required for continuity of care.” The need for continuity of care is inherent in “compelling circumstance.”

Families can, and usually do, play a crucial role in continuity of care, hence should have all the information that matters. Most of the examples in the ministry fact sheet have to do with cases of mental illness.

Keeping families out of loop serves only to hurt patients

The refusal to share information with family members not only hurts the patient and is clinically wrong-headed, it also, ironically, contributes to stigmatizing the patient.

Family members know their loved one is mentally ill – in an acute phase, that they're “crazy.” They are probably responsible for getting the person into hospital in the first place. They've seen all of the disordered behaviour.

Revelations that might hurt the patient in society's eyes, then, are already known to the family.

Sharing clinical observations with them and getting their feedback consequently doesn't add to any stigma or any loss of privacy that counts. The opposite is the case. It normalizes the madness as a biological illness of the brain where information and observations can be exchanged matter of factly without artificial concern, just as they would be in other medical fields.

The information sharing removes the black mystery surrounding psychosis and builds respect in so doing.

FIPPA has a provision as well to cover instances where talking to families may agitate the patient, especially where family members are part of a patient's paranoid delusional system.

Section 31.1(1)(m)(ii) of the Act states that telling the patient about disclosure isn't necessary where it “could harm someone's health or safety.”

The excuse that talking to family members where consent isn't available would destroy the psychiatrist's or case worker's relationship with the patient doesn't stand up.

In summary, if family involvement as an integral part of the treatment team is to properly work, then families need to be in the loop in the same common-sense way that psychiatrists, psychiatric nurses, social workers, and case workers are in the loop.

The law, moreover, taking into account the special circumstances of serious mental illness, provides for such sharing to take place, even without the patient's consent. The Ministry of Health fact sheet on FIPPA, which is also included in the Guide to the Mental Health Act, provides further guidance.

The “system” ignores law and clinical best practices; weakens family involvement

Some psychiatrists and other service providers both understand the law and use their common sense, and share information with family members as a matter of course, even without the patient's permission. They may not even ask for it.

Some mental health teams, notably acute care at St. Paul's hospital, understanding the nature of psychosis, will also talk to families regardless and fill them in.

For the most part, though, they appear to be exceptions. Here are a few contrary examples.

- The director of Mental Health and Addiction Services on the North Shore, in a formal letter to NSSS, stated categorically that information cannot be shared without permission. Neither she, nor the senior manager who drafted the letter for her, seemed to be aware of what the law actually says.

- A senior Vancouver psychiatrist indignantly maintained that such sharing cannot be done and that it also would be totally unethical. He was wrong on both counts.

- He argued that 99 out of 100 psychiatrists in Vancouver would agree with him. If that's the case, they would all be wrong, too, not to mention clinically ignorant. It turned out the psychiatrist had never heard of FIPPA.

- The director of risk management at Vancouver Coastal blithely and with authority explained to a grieving relative that such sharing of information wasn't allowed.

- Many acute care social workers will encourage patients, when they're being discharged, to give consent to sharing information with their family members, explaining its value. If, however, the consent isn't forthcoming, they may discharge them, sometimes directly to family care, without telling the family anything regarding the illness, the patient's medication or dosage, signs of relapse to look out for, or even what the diagnosis is.

- Psychiatrists and case workers regularly plead confidentiality and will sometimes even insist they need written consent from the patient, whatever the clinical circumstances, the degree of psychosis, and the extent of the family member's involvement.

- References are frequently made to "policy," as in, "I'd like to share the information with you, but our policy doesn't allow it." Vancouver Coastal's privacy policy, however, does in fact allow it, with its wording properly mirroring the wording in FIPPA.

Then there are the individual cases, leading to tragedy.

In the Marek Kwapiszewski case, both the patient's general practitioner and Vancouver Community Mental Health refused to share relevant information with his sister, who was very concerned. This hindered her efforts to get him involuntarily admitted to hospital. The system didn't respond, and he committed suicide.

For more details on the Kwapiszewski case, please go to the Media Centre page at the NSSS website.

In the heart-breaking Ross Allan case in the Fraser Valley, also ending in suicide, the denial of information to the parents was shameful. For the coroner's verdict in that case, go to www.pssg.gov.bc.ca/coroners and enter "Ross Allan" in the Search box.

For some earlier cases, including the 2004 death of Stephanie James that highlighted Vancouver Coastal's ignorance and incompetence on the issue, see the Information Sharing page on the NSSS website and click on "Case histories."

Harm to patients and often tragedy that comes from not sharing information has been endemic.

Mental health managers just don't seem to get it

Ignorance of the law, ignorance of privacy policy, lack of professionalism, absence of common sense, and entrenched myth – all contribute to the syndrome.

Maybe most responsible, though, is a bureaucratic culture that can't quite grasp clinical reality or where managers don't have the courage to follow through although they may understand.

Take, for example, Vancouver Community Mental Health Services' guidelines on family involvement, Policy 333 in their "Clinical Policies and Procedures Manual."

The manual does have a policy statement on information sharing: "Clients have a right to privacy while keeping in balance the value of family involvement and continuity of care."

The statement, alas, is useless as a guideline because nowhere in the document does it say, simply, that clinical information may generally be shared with family members, in cases of serious mental illness, even without the consent of the patient, which is the issue. Nor does it give any practical hints as to how best to manage this.

In the reference list of legislation and documents in the policy statement, the Ministry of Health's fact sheet on FIPPA – the key document on the issue – is omitted.

The nicely worded policy sentence is backwards to begin with. The leading right of mentally ill patients isn't privacy but the right to receive the best possible

treatment and have the best possible outcome, for which sharing of clinical information with involved family members is in most cases essential.

Or, in the words of the privacy commissioners of B.C. and Ontario in 2008, "Life trumps privacy, and our laws reflect that reality."

Moreover, as we have noted, privacy concerns that might apply, say, when a teenage girl has gonorrhoea and doesn't want her parents to know, don't apply in cases of serious mental illness. The family members already know of the illness, in vivid detail.

With Policy 333 drafted in such a way as to avoid clearly addressing the issue, it's no wonder service providers keep getting it wrong.

In a statement to NSSS September 20, 2010, arising out of the Kwapiszewski case, Vancouver Coastal finally conceded, after a great deal of explanation and patience by NSSS, that the relevant clauses in FIPPA and the Ministry of Health fact sheet do apply.

The statement goes on to say that they "appreciate that VCH and NSSS might disagree when a threshold is reached about determination of 'compelling reasons.'"

The suggestion is that in only the most exceptional of situations, and after the most intricate considerations of pros and cons by the clinician, will the policy of sharing without consent apply.

Should psychiatrists, then, not share information with nurses and nurses with case workers, and vice-versa, except in extraordinary situations?

And if family members are to be integral members of the treatment team, shouldn't sharing with them occur in the same way?

As our headline says, "Family involvement means information sharing." Vancouver Coastal, in not understanding this, doesn't understand family involvement and its importance either, notwithstanding all the references to it in various VCH documents.

They still have a lot of learning to do.

We welcome your comments on anything you read in the *Advocacy Bulletin*. Call us at 604-926-0856, mail us a note at the Family Support Centre, or send us an email at advocacy@northshoreschizophrenia.org.