Family members and
mental health practitioners:
Disagreements & understanding
the perspective of the other.

Simon Davis, Ph.D.
simon.davis@vch.ca

Vancouver Coastal Health
Promoting wellness. Ensuring care.

UBC

Family involvement

From the Mental Health Commission:

- "It is important to begin with the assumption that families can play a potentially positive role in recovery and well-being."
- "The role of families in promoting well-being and providing care [should be] recognized, and their needs supported."

Source: *Toward Recovery & Well-Being: A Framework for a Mental Health Strategy for Canada.* MHCC (2000).

Practitioner perspectives:

- "Is family involvement in medical treatment decisions a common experience for most adults? I don't think so. In the interest of wellness and a return to a normal pattern of living, I respect and value a client's autonomy in all aspects of their lives. Therefore, I am very judicious when I involve families. Bottom-line: is family involvement in my clients' best interest? This is a very strong value I have held 18 years of working."
- "Where possible, family involvement is desirable. But, sometimes family involvement may be part of the problem."

Source: 2010 VCMHS staff survey re. family involvement.

A mother's perspective:

- "Over the years I have seen too many ill people die with their rights on. And too many professionals who have shirked their professional duty with phrases like, ***'I had to respect my client's rights" or "I didn't want to jeopardize the therapeutic relationship with my client.'*** Being a professional means taking responsibility for sometimes having to make judgment calls that may not be easy. Professionals who cannot or will not make a decision because they are unsure of themselves or fearful can cause great harm. ***Hiding behind "individual rights" to avoid doing one's job properly and making a decision on behalf of a very ill client is cowardly - and not exactly unheard of in the mental health system.*** Patients know this. And so do their families." (VCMHS focus group, Feb. 2009).

Sources of tension

1) Family-blaming.

2) Information-sharing.

3) Duty-of-care vs. recovery.

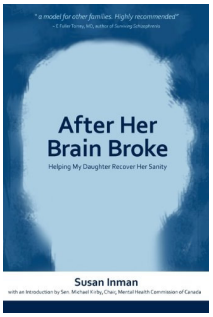
1) Family-blaming

- Freudian theory.
- The "schizophrenogenic" mother.
- "Refrigerator mother" (Bettelheim re. autism).
- The "double-bind hypothesis", mid-1950s, Bateson et al. Idea that contradictions in the interaction between family members predisposes them to schizophrenia.

  - " a scientifically respectable theory" (Goldenberg & Goldenberg, ***1980***) and one that is "practically useful" (Koopmans, ***1997***)

Continued….

- **Expressed emotion**: "Family members high in expressed emotion cause relapse in psychological disorders such as schizophrenia, alcoholism, children with learning disabilities, and bipolar disorder……
- The relative becomes so overbearing that the patient can no longer live with this kind of stress from pity, and falls back into their illness as a way to cope" (McDonagh 2005).



2) Information-sharing vs. confidentiality

Why protect confidentiality? To do otherwise:

- May be unlawful (although legal guidelines in this area are not clear cut).
- Could violate agency policy.
- Could violate ethical codes.
- May be seen by the client as a betrayal of trust and thus damage the therapeutic relationship.
- In effect, treats an adult client like a child.

Withholding information from family is usually more an ethical problem than a legal one.

Code of ethics example:

- "Be considerate of the patient's family …. and cooperate with them in the patient's interest….However, ethical psychiatrists will recognize that *relatives' needs come second to the obligation to maintain confidentiality with the patient."* (Canadian Medical Association Code of Ethics, annotated for Psychiatrists, 1996)

Case example….

- A 25 year old man with schizophrenia, living on his own in Vancouver, is spending most of his money on alcohol. The team is concerned. His parents live in Toronto and send him money. One staff suggests calling the parents and warning them about this. Another staff states this is an unsupportable breach of confidentiality, since the client won't give his consent. Is safety (or continuity of care) significant enough here to support the "breach?"

The importance of trust

Source: Gumpp, R. (2009) **Hope and Fear: Consumers, Psychiatric Medications and the Therapeutic Relationship**

"Trust is huge. Trusting someone makes you far more likely to listen to their suggestions and try their ideas."

- Trust takes time to develop.
- Trust is necessary when treatment seems like trial and error.

Legislation

Information-sharing is governed by the *Freedom of Information and Protection of Privacy Act* (FOIPPA), which permits sharing with a third party in three situations:

- A) If the client consents.
- B) "If the purpose for the release is consistent with the purpose for which it has been collected." (What does *that* mean?)
- C) Where "compelling circumstances exist that affect anyone's health or safety."

A) Client consent

- Forms exist, or can be made, to specify with whom, and what type of, information can be shared. Sometimes this can be in the form of a crisis or "WRAP" plan.
- More work needs to be done to support the utilization of these tools, at an early point in the activation. A suggested guideline is to place the onus for initiating the consent process *on the practitioner*, not the consumer or family member (Bogart & Solomon, 1999).
- Consider information-sharing as taking place along a continuum, rather than as a static decision at one point in time which is binding (Glyn et al, 2006).

Continued…..

- Conceivably, an issue such as information-sharing could be addressed as part of a representation agreement, the purpose of which is:

  "to allow adults to arrange in advance how, when and by whom, decisions about their health care, personal care or financial affairs or about other matters will be made if they become incapable of making decisions independently" (B.C. *Representation Agreement Act*, s. 2(a)).

B) "Consistent purpose" and continuity of care

- Information can be released without specific consent, if the purpose for the release is consistent with the purpose for which it has been collected (e.g. health care). This is routinely done with mental health clinics/GPs/hospitals under "continuity of care."
- The release must be in the client's best interests.

An example:

(source: *Guide to the Mental Health Act*, 2005)

- An adult with schizophrenia is being discharged from a psychiatric unit. Although she does not have a close relationship with her family, they do take an active role in ensuring her day-to-day needs for food and shelter are met, and they also monitor her health status. The client is suspicious and distrustful of her family members, and asks her clinician not to share any information about her with them.

Continued…..

- In deciding whether or not to disclose the client's personal information to the family, the health care provider should consider whether the family's "need to know" outweighs the client's wishes. If the provider believes it is in the best interests of the client to disclose personal information to the family so they can provide care to the client, the health care provider may do so [section 33.2(a)]. The provider should exercise caution to ensure only necessary information is released.

In sum:

- Can the parents (or other third party) be considered care-providers?
- Is the release in the client's best interests?
- Is the release on a limited, need-to-know basis?

c) Safety

Persons with a serious mental illness are at higher risk for:

- Suicide
- Financial and sexual exploitation
- Self-neglect
- Higher rates of various illnesses (e.g. cardiovascular, diabetes, pulmonary disease), resulting in higher mortality rates.

There are legal/ethical obligations under *duty of care* and *duty to warn*, either of which may result in breaching confidentiality.

Guidelines?

- "Compelling circumstances" (FOIPPA).
- Agency policy: "Within the parameters of 'best clinical judgment' concerns for the safety of others will take precedence over client confidentiality" (VCMHS).
- The Supreme Court of Canada in *Smith v. Jones* (1999) provided very narrow criteria to justify a "duty to warn" breach.
- Privacy commissioners: In B.C. and Ontario: serious safety concerns "trump privacy."
- Mental health act definitions of "harm" – in BC "protection" can include "social, family, vocational or financial harm" (beyond simply physical danger) as per *McCorkell* (1993).

Confidentiality, revisited:

- Practitioners need to address information-sharing and limits to confidentiality early in the treatment process. Transparency is the goal.
- Definitions of "safety" and "continuity of care" are neither clear nor well understood by practitioners.
- Breaching confidentiality requires a very careful cost-benefit analysis, which differs from case to case. Often, positive treatment outcomes are contingent on a trusting therapeutic relationship, which a confidentiality breach can undermine.

3) Duty-of-care vs. recovery.

- What is "duty of care?"

  "A requirement that a person act toward others and the public with *watchfulness, attention, caution and prudence* that a reasonable person in the circumstances would. If a person's actions do not meet this standard of care, then the acts are considered negligent."

  (the freedictionary.com)

Continued…….

- What is "recovery?"
- A model that differs from the "medical model," which uses symptom remission as its standard. In this new model recovery is possible despite the persistence of illness.
- The importance of self-determination.
- There are many pathways to recovery: "Professionals do not hold the key to recovery, consumers do" (Anthony, 1993).

Recovery and risk

- "Professionals must embrace the concept of the ***dignity of risk***, and the right to failure if they are to be supportive of us" (Deegan,1996).
- "Providers should…encourage independent thinking…support consumers' freedom to make their own mistakes…support risk-taking as leading to growth…avoid controlling behaviors…foster a sense of hope…shift from a stance of demoralizing pessimism to rational optimism" (Coursey et al, 2000 – *an article on desired competencies for working in mental health*).

One consumer's perspective:

"Authoritarian families curtail growth with coercive interventions…accentuating the non-negotiable authority of the medical profession….perhaps the hardest, arguably the most important part of parenting is to trust the child enough to let go. Even children with disabilities deserve to be let go." (Caras, 1998, pp. 763-764)

Natural consequences?

- Should adult mental health clients be subject to the "natural consequences" of their actions?
- In *parenting* discussions this approach is not supported, because these consequences may be too severe, or too inconsistent to reinforce desired behavior.
- But what about *adults* with a psychiatric disability?

Families, risk and recovery

- "There's a constant feeling of vigilance, especially when the illness is more active. A feeling that if you let your guard down when they are ill, they will commit suicide" (VCMHS Focus group, Feb. 2009).
- Family members may be nervous about a model that talks about risk-taking and "alternatives" to psychiatric care.
- "Family involvement becomes difficult for case managers when the client's and family's recovery pathways do not match."
  (Source: VCMHS staff survey re. family involvement.)

An actual letter from a family member.

"On behalf of our family, I would like to make the following recommendations to his care givers and doctors:

- That he be immediately moved into an adequate care facility or hospital if necessary;
- That he immediately be enrolled in a drug detox program;
- Mandatory drug testing upon completion of the program;
- AA meetings for the duration of his life;
- That he be supervised/required to take his daily medication;
- That his nutritional needs are met through supervision;
- That he get assistance with his personal hygiene."

Recovery as anti-psychiatry and anti-family?

- "If people cared for their [family members], then it changes a lot of the problems….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" (quoted in Brean, 2010). (Controversy over Professor Neree St-Amand sitting on the Family Advisory Committee of the Mental Health Commission of Canada.)

So, what to do? Considerations:

- Safety must be addressed by practitioners. Safety is enhanced by services that are *proactive* and have an *outreach* orientation/capacity.
- Family collateral is vital to supporting crisis interventions.
- Many tools exist to support safety, such as crisis plans, WRAP, "Managing Risk in Community Integration" (Temple University). Note however that risk management is *shared*.

Continued….

- "Safety first" is a principle of most treatment models, e.g.:
  1) Safety
  2) Containment
  3) Control and regulation
  4) Exploration and change
  5) Integration and synthesis

  (phases of change in treatment per. John Livesley)

Recovery models also address safety in early stages, e.g. Ragins' model:

- Stage 1: At high risk (Focus: safety, crisis management)
- Stage 2: Unengaged and not coping (Focus: relationship building , reduce symptom distress, identifying needs with client)
- Stage 3: Engaged but not coping well
- Stage 4: Coping, Recovering & Rehabilitating
- Stage 5: Recovery, Reconnection Self Responsibility
- Stage 6: Advanced Recovery

"Rescuing": the limitations of hospitalization

- Certification can be traumatic for the client, and may alienate them from the treatment team.
- Given the above, and given that admissions are often very brief, certification is not an easy decision.

Alternatives (also in short supply):

- ❑ Intermediate facilities
- ❑ Home-based crisis management
- ❑ Tertiary care

But…..

- Practitioners have a responsibility to go beyond crisis management, to identify client interests, and facilitate involvement in other existential domains.
- "Recovery" as a term and concept may not work for all clients or family members, and cannot be used simplistically.
- A possible guiding concept, when balancing safety and self-determination, is ***dignity***.

Simon.davis@vch.ca