

Sharing Information with Families that Carry the Burden of Care for Relatives with Severe Mental Illness

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ABSTRACT

Most individuals suffering from severe and persistent mental illness, who are unable to live independently, are cared for by their families. These families provide both support and clinical services for their ill relatives. Families complain that the clinicians involved in their relatives' care frequently fail to provide information needed for the family to safely and effectively fulfill their responsibilities. Clinicians usually respond that their ability to divulge information is constrained by privacy legislation. This is true, but we suggest that clinicians have a duty to their patients' relatives, and that clinicians regularly fail to take available practical and legal steps to ensure that families receive the information that they need.

Key Words: Privacy, health information, families, clinical information.

The Problem

Many people with severe mental illness lack the skills to live independently. As a result some become homeless (Goering, Veldhuizen, Watson, Adair, Kopp, Latimer, Nelson, MacNaughton, Streiner, & Aubry, 2014). For others, the choice is generally to live in a group home or with their family. Due to the limited availability of suitable supportive housing (Goering et al., 2014) and lack of long-term hospital beds, most live with

family (Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003; Sinha, 2012).

Relatives who care for individuals with severe mental illness take on both therapeutic and supportive functions. The caregiving role for these relatives is both arduous and stressful (Flyckt, Löthman, Jörgensen, Rylander, & Koernig, 2013; Jungbauer & Angermeyer, 2002). They often worry that their relative will default on treatment and constantly monitor for signs of impending relapse.

Many families live in fear of being assaulted by ill relatives. People suffering from severe mental illness have a modestly increased risk of perpetrating violence compared with the general public (Brennan, Mednick, & Hodgins, 2000). Most of this increase stems from individuals with untreated psychotic illnesses. While popular media focuses on violent acts perpetrated by mentally ill individuals on strangers, these incidents are rare (Nielsen, Bourget, Laajasalo, Liem, Labelle, Häkkänen-Nyholm, Koenraadt, & Large, 2011) and relatives are much more likely to be the victims of violence than are the public at large (Nordstrom & Kullgren, 2003; Solomon, Cavanaugh, & Gelles, 2005; Steadman, Mulvey, Monahan, Robbins, Appelbaum, Grisso, Roth, & Silver, 1998).

In view of the shortage of beds in psychiatric units and the scarcity of long-term supported housing, one might expect the mental health system to make every effort to support family caregivers. This is especially so because research shows that involving family can improve the outcome of treatment for people with severe mental illness (Glick, Stekoll, & Hays, 2011; Hartmann, Bänzner, Wild, Eisler, & Herzog, 2010; Martire, Lustig, Schulz, Miller, & Helgeson, 2004). It is therefore surprising to hear families complain that clinicians do not provide basic information about their

relative's illness (Flyckt, et al., 2013; Dixon, Lyles, Scott, Lehman, Postrado, Goldman, & McGlynn, 1999; Repper, Grant, Nolan, & Enderby, 2008; Solomon & Marcenko, 1992) let alone offer the complex training and support necessary so that families can safely and effectively care for a relative with a serious mental illness (Hervey & Ramsay, 2004; Rapaport, Bellringer, Pinfold, & Huxley, 2006). Clinicians usually respond to such criticism by noting that they have a legal and ethical duty to maintain confidential the information they have obtained in their interactions with patients (Gray, Robinson, Seddon, & Roberts, 2008).

However, legal and ethical duties to maintain confidentiality must be balanced against the duty to ensure the safety and well-being of patients and their families. Furthermore, clinicians should endeavour to promote the best interests of their patients even in situations that do not involve a risk of physical harm to self or others.

Below we describe a fictional case that highlights the difficulties obtaining information that are frequently encountered by families providing care to an ill relative.

Clinical Scenario

Brian is a 22-year old man who lives with his parents. He was diagnosed with schizophrenia at age 18 while in his last year of high school. In the year prior to the diagnosis, Brian progressively withdrew from his friends. He then started to hear voices and concluded that the voices were coming from members of a motorcycle gang that was planning to harm him. Brian was treated with antipsychotic medication as an outpatient and the auditory hallucinations and delusions dissipated.

After six months, Brian stopped taking medication and again became floridly psychotic, exhibiting paranoid delusions and auditory hallucinations. Brian was arrested when he tried to stop traffic at a busy city intersection. The police took Brian to the emergency room of the local hospital for an assessment, and he was admitted to the hospital's psychiatric ward. In hospital, Brian was treated with antipsychotic medication and his hallucinations and delusions again resolved.

Brian did not return to school after his hospitalization, and he showed little motivation to find employment. Brian's parents prepared his meals, did his laundry, and purchased his clothing and personal items using money from Brian's small disability pension. Brian did not believe that he had a mental illness and reluctantly attended bi-monthly appointments with a psychiatrist. His parents drove Brian to these appointments and to the pharmacy to pick up his antipsychotic medication. Brian often neglected to take his medication and his parents noted that he would become suspicious and irritable with his younger siblings when not taking medication. When this happened, Brian's parents would insist on observing Brian ingest his medication each evening until this irritability diminished.

Six months after discharge from hospital, Brian's parents called the police when he threatened them with a kitchen knife. The police again brought Brian to the emergency room, and he was admitted to the psychiatric unit for a second time.

Shortly after his admission, Brian's parents called his psychiatrist to request a meeting, but their phone call was not returned. They then asked nursing staff on the psychiatric ward for the information about Brian's symptoms and medication. The nurses told Brian's parents that they could not talk to them because of "confidentiality issues". After 10 days in hospital, a social worker from the hospital called Brian's parents to inform them that Brian was being discharged back to the parental home.

Analysis of the Family's Role

In this scenario, Brian's parents provide for his basic needs including shelter and nutrition. They assist with activities of daily living that Brian neglects. Most importantly, Brian's parents perform many clinical tasks: monitoring his mental state, transporting Brian to his clinical appointments, ensuring he obtains his medication, and when necessary supervising adherence to medication. Because Brian threatened his parents prior to his last admission, his parents likely continuously assess the risk that he might assault them or someone else.

Had Brian been provided with case management following his last discharge, the case management service would have insisted on access to information about Brian's mental illness and treatment. At minimum, the service would want to know the nature of Brian's illness, past symptoms, early signs of relapse, information related to the risk of self-harm or harm to others, current treatment including name and dosages of medications, actual or potential side effects of those medications, past adherence with treatment, and whether substance abuse has played a role in triggering symptoms. As Brian's parents are providing the same clinical functions as a case management service, surely they also need this information so that they can ensure the best care for Brian?

Brian would typically have clinical appointments scheduled every few weeks or months. The duration of these appointments represents a small fraction of Brian's waking life, and they occur in an artificial clinical setting. In contrast, Brian's parents interact with him for many hours each day in his normal surroundings. While Brian's parents lack clinical training, their continuous observation of Brian in the home provides a more comprehensive assessment than the limited observation in the clinic. Furthermore, as Brian does not appreciate that he is ill, his parents are usually able to provide a more accurate description of his symptoms and behaviour. Therefore, even after discharge, it is important that Brian's psychiatrist and other clinicians continue to gather information from his parents.

Readers may wonder how often clinicians fail to provide clinical information to caregivers such as Brian's parents. One of us (ROR) has worked in hospitals and community clinics for over 30 years and has repeatedly encountered variations of this clinical scenario. Another (JG) has been the president of a national organization for people with schizophrenia and their families, and has noted that the failure of clinicians to communicate is a perennial complaint of family caregivers. A review of the literature confirms that failure of clinicians to meet with or to provide information to relatives is a major and chronic complaint of families (Repper et al., 2008; Eassom, Giacco, Dirik, & Priebe, 2014; Marshall & Solomon, 2000; Petrila & Sadoff, 1992; Ryan, Callaghan, & Large, 2014).

Why do Clinicians Not Talk to Relatives?

There are complex reasons why clinicians, working in the mental health field, do not communicate with families. Most “Western” countries place a high value on individualism. In contrast, other countries have a culture of collectivism that stresses the importance of family bonds. In Western society, there is an expectation, based on *parens patriae* duty, that the state is responsible to care for individuals who cannot care for themselves. Whereas, in most Latin American and Asian countries, the expectation is that such individuals will be cared for by their family. These different expectations shape policy and legislation that determine what clinical information will be shared and with whom.

Every Canadian province has legislation governing the sharing of health information and these laws can facilitate or discourage family involvement in the care of individuals with mental illness. For example, the British Columbia Mental Health Act requires that hospitals inform a person’s nearest relative when that person is involuntarily admitted or discharged from a psychiatric unit (British Columbia *Mental Health Act*, 1996). In sharp contrast, informing family members about a person’s admission or discharge from a psychiatric unit without the person’s consent is considered a breach of confidentiality in several other Canadian provinces. Ontario’s *Personal Health Information Protection Act* (PHIPA) states that such a breach could result in a fine of \$50,000. Incomplete understanding of the law is an additional barrier to the appropriate sharing of information. When legislation is complex or ambiguous, clinicians are apt to make idiosyncratic interpretations, often influenced by their personal values and beliefs.

Another reason why some clinicians are reluctant to share information with families is the lingering belief that families are a cause of the patient’s illness. While more outlandish theories such as that of the “schizophrenogenic mother” (Fromm-Reichmann, 1948) or R.D. Laing’s theory that schizophrenia is an understandable reaction to intolerable family dynamics (Laing & Esterson, 1964) have been thoroughly discredited, family blaming persists in theories that propose that schizophrenia is caused by child abuse (Reid, 2005).

Although family-based therapies are helpful for many mental disorders, most clinicians are trained in, and therefore practice, individually-based psychotherapies. Individual-based therapies do not emphasize the importance of family; therefore, clinicians may not even consider the possibility of asking patients for permission to contact their family. Even when contact with family is essential, as in Brian’s case, clinicians seldom attempt to encourage the patient to change his mind if he initially refuses.

Finally, there are important logistic barriers to involving families in the care of their hospitalized relatives. Lengths of stay in psychiatric units have become progressively shorter and clinicians progressively busier trying to manage the volume of patients passing through these wards (Lee, 2011). The rapid turnover limits the opportunities to meet with families. Such meetings usually must be arranged in advance, often at inconvenient times. Arranging clinical meetings with families is more difficult and less efficient than spending time on a ward and seeing several individual

patients. Many jurisdictions using a model of remuneration based on a fee-for-service do not pay for the time a physician spends talking to a person by phone, even though phone calls are probably the most efficient way a physician can contact family members. Furthermore, in some jurisdictions fees are higher for time spent directly interacting with the patient compared to time spent meeting with others, such as family members. Practical barriers are compounded when hospital managers do not provide the necessary flexibility to accommodate family involvement (Eassom et al., 2014).

Proposed Solutions

When a patient consents, there is no barrier to giving a family member the information needed to provide their relative with good care. When a patient refuses to allow clinicians to provide information to families, it creates an ethical tension between the need to share information and the patient’s right to refuse access to their personal health and social information. In most cases, clinicians appropriately respect a person’s right to confidentiality. However, in other situations, such as Brian’s, we suggest that the essential clinical roles undertaken by his parents and the risks of harm require information to be shared. Many cases are not as clear cut and in this paper we will not attempt to determine where the line is; rather, we outline a series of sequential steps necessary to ensure that Brian’s family will receive that information.

a) Encouraging the Patient to Provide Consent

First, clinicians must actually ask Brian for permission to talk with his family. Remarkably, several studies show that clinicians often fail to take this first step (Marshall & Solomon, 2000; Kaas, Lee, & Peitzman, 2003; Marshall & Solomon, 2003; Slade, Pinfold, Rapaport, Bellringer, Banerjee, Kuipers, & Huxley, 2007). If Brian refuses, his clinicians should explore the reasons for his refusal. Many patients do not understand why their clinicians wish to talk with their family and readily agree to family involvement when these reasons are explained. Some patients may have specific information that they do not want disclosed, such as details of sexual behaviour. Most of these patients agree to family involvement when reassured that these details will not be shared. In some cases, clinicians might suggest meeting family in the patient’s presence; this often allays a patient’s fears. These steps are similar to an approach recommended in the United Kingdom (Slade et al., 2007) and to recommendations made by the Mental Health Commission of Canada (MacCourt & Family Caregivers Advisory Committee, Mental Health Commission of Canada, 2013).

The stepwise approach outlined above is more likely to be followed by clinicians who have been trained in a professional program that has involved patients and families in course design and provided students first-hand exposure to the perspectives of patients and families as part of their training.

b) When Consent Is Not Forthcoming

Families can be given general information about mental illness and suitable support organizations even if the patient refuses consent for personal information to be shared.

Brian's parents may have important information to give to his clinicians; for example, they may have information about emerging psychotic symptoms or side effects. In all Canadian provinces, a clinician is allowed to *indirectly* gather information necessary for the provision of health care when such information is not likely to be fully or accurately provided by the patient. If Brian's clinicians suspect that his story is inaccurate or incomplete, they can receive information from his parents without divulging information about Brian's condition.

Legislation defines when health information can be shared without consent. Therefore, it may be possible to craft legislation that better meets the needs of caregiving relatives. A comparative analysis of the legislation in different Canadian provinces is beyond the scope of this paper, but it is informative to examine some aspects of legislation in British Columbia and Ontario. As noted, the British Columbia *Mental Health Act* requires information to be provided to the nearest relative or appointed representative of an involuntary patient upon admission and discharge. Thus, the onus is on the hospital staff to obtain consent from the patient *not to* contact his or her family. British Columbia also permits disclosure, without consent, of information to relatives if that information is necessary to provide for "continuity of care" (British Columbia Guide to the Mental Health Act, 2005). Ontario lacks these "family friendly" provisions. However, if a patient is deemed to be incapable of releasing personal health information in Ontario (Ontario Personal Health Information Protection Act, 2004), a substitute decision maker is authorized to make a decision on the person's behalf. The substitute decision maker may be someone nominated by the patient, but in most cases it is the family member who is requesting the information. In our experience, this provision is rarely used.

Many families play a less comprehensive role than Brian's parents in the care of ill relatives. For example, a person with severe mental illness may live on his or her own, but have family who maintain regular contact and who are the first to detect deterioration, side effects, or evidence that treatment plans are not being followed. Chan and O'Brien (2011) suggested that a family role in the provision of services should be officially recognized through legislation that authorizes families to receive information from clinicians. While most families are tireless advocates seeking appropriate care and treatment for their ill relatives, other families are not so altruistic. (Acierno, Hernandez, Amstadter, Resnick, Steve, Muzzy, & Kilpatrick, 2010; Laumann, Leitsch, & Waite, 2008). In our view, enacting legislation that gives families the same status as clinicians tips the balance too far and appears to require that clinicians release information even in situations when it would be inappropriate.

Clinicians need guidance and some leeway to decide when and what information can be released without a patient's consent. One model is the British Columbia Freedom of Information and Protection of Privacy Act, which states, "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" (British Columbia Guide to the Mental Health Act, 2005, p. 121).

Conclusions

Many families undertake the burden of caring for relatives with severe mental illness. Caregiving tasks are multifaceted and include important clinical functions. Clinicians frequently fail to provide families with the information necessary to perform these tasks. A lack of appreciation by clinicians of the roles played by family caregivers, theoretical perspectives that encourage the exclusion of families, restrictive privacy laws, and misunderstanding of the law are the main reasons for the failure to communicate with families. Professional training programs should place greater emphasis on cooperation with family caregivers and clinical services should develop protocols to ensure the involvement of family when appropriate. In some jurisdictions, legislation may need to be amended to permit this family involvement.

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