Final Words on Family Work

Issues of Confidentiality and Privacy

An issue that is significant to both families and mental health professionals is patient confidentiality—the moral and legal obligation of the clinician to keep personal details about the patient private. The difficulty arises when those who are caring for a severely ill patient are told by the clinician that s/he cannot discuss the patient. In most cases the carers are not looking for personal details of the clinical relationship but only for information that will help them to carry out their responsibilities as caregivers. This is not privileged information unless the patient has specifically asked the clinician not to talk to his/her parents about anything, a circumstance that is very rare in the families who bring their relative to treatment. The issues that family are interested in are usually related to taking the medications and advice about their caring role. Here is an example of the experience of one family.

> After an especially troubled time, our son, who had schizophrenia, was committed to a state hospital. Time passed and he showed improvement, but remained angry at his mother and me and would not give the hospital authorities permission to talk with us. They wanted to let him go home on a pass, but needed to review procedures with us. A very experienced psychiatrists said he would handle the matter. He invited us to the site of the hospital and had us wait in his office. Then he brought in our son and explained to him that it was necessary that we understand the use of medications-- when to take, how many, and so forth, and he wanted to explain this to us. Would that be okay? Our son agreed. This went on with the doctor carefully explaining to our son each thing he was going to tell us and getting his agreement. There was no problem, and this gentle and sensitive procedure was a kind of turning point in our son's rehabilitation.

Something that families do not always realise is that they are at liberty to inform the clinician of symptoms or behaviours observed by the patient that could help him/her with the treatment regimen, whether or not the clinician is willing to give them any information. It is important that services providing family work have a clear understanding of what is and what is not possible in order to avoid a situation where the rules interfere with optimum treatment.

Several family organizations have drawn up a Bill of Rights for families in order to lobby for better understanding of their position as carers. Rethink published a Briefing Paper on the issue of sharing mental health information with carers (Rethink, 2006).The paper identifies eighteen key points which indicate the complexity of the issue. We reproduce four of these points.

- Carers play an important role in many service users' lives. Their knowledge and expertise represent an enormous resource for statutory and voluntary mental health

services. These are reasons why it is so important to include them through sharing information.

- Providing carers with information to support them in their role can improve outcomes for both service users and carers.

- Carers fear being denied access to important information to help them in their role. They are also concerned that their own confidences may be broken.

- It is not helpful to involve carers uncritically. Involvement must be based on a clear understanding of the context of care, the long-term relationship between service user and carer, the service user's wishes, and the needs of the carer.

Families often feel that claiming that the information is confidential is an excuse some staff members give in order not to deal with them. One of the principles of good practice cited in the Briefing paper is the following:

> It is important to train staff to work with carers, and to provide policies and guidance, including supervision, to help them to decide appropriate levels of information sharing. Service users may also need support to understand the needs of carers in terms of information sharing; carers may need help in accepting less information than they might like, in order to respect the service user's wishes.

It is interesting to note that this issue does not come up in Asian countries where cultural and societal norms dictate a duty to society and to family as well as a responsibility to look after one's first degree relatives. In some countries this can be attributed to the lack of a welfare state as well as huge populations served by few health professionals.

In some other societies, however, a general assumption has arisen that the individual is independent of his community and his family. If this results in a loosening of family ties it may also end up with the alienation of the most vulnerable as is seen in the vast homeless populations of the so called western world. Nevertheless, it is clear that we are all interdependent and that society cannot function without the offering and giving of love, support and care when needed. Arguing independence above all things flies in the face of familial ties, familial love and familial duty. One father puts it this way:

> "We respect our son and admire the stoic way he has coped with his disability over 20 years. We have loved him unreservedly throughout that time. He has taught us a lot about life, about compassion and about what the old maxim says: There but for the grace of God go I. Through him the family has recognized its own strength. With the psychosis under control, he too has realized to a great extent the value of this strength. He recently said; "I don't know what I would have done without you. I'd certainly be dead by now."

A good reason to make every effort to involve family that are close to the person, particularly those on whom he depends – it could be his parents or a sibling—is that serious mental illnesses "impair the individual's ability to make social contacts" (Leff & Warner, 2006), and often impair his/her thinking processes. Without the help of their caring relatives a large number of people who are unwell fail to express their needs or fail to follow up on treatment recommendations.

Denial of Family Involvement

Related to this issue is the person's denial that he has any family member that could be involved. While the treating team must adhere to their patient's wishes it may be relevant to raise a few reasons why the patient gives these responses.

As stated in chapter 1 when mental illness strikes the family is perplexed and often does not know what to do. Without knowledge and understanding of the situation, the person's actions and words or his inaction and strange behaviour create unbearable tensions in the family that often lead to family break up. Despite this, when the person is properly engaged by the treatment team and an interest taken in his life outside medication and symptoms, a change often occurs which sees the person beginning again to interact with his relatives. Here is an example, one of many, from a local family organization support program.

> Our branch of the family association had from quite early on interacted positively with any consumers who approached us or who we met in the course of our work. Because there were a number of needy individuals we began a program to help consumers in need. We provided them with clothing, furnishings, advice on personal issues, for example debt acquired while in college, in fact anything that they wanted to speak about. In order that they would come in to see us regularly we provided them with a small stipend. Gordon was one of our members. He came to us when he lost his housing. He had no family or financial support. We enabled him to get a disability pension, found him an apartment and directed him to a psychiatrist. For over a year he would come in and talk to us. We used to ask regularly about his family. He maintained that there was none. Then suddenly one day a young man showed up in our office. He was Gordon's brother and just behind him was Gordon himself. This is Jim, he told us. They were going out for a drive, Jim said and he wanted to drop in and meet the people who Gordon talked about.

We have no idea what events occurred to reunite Gordon and Jim. Perhaps Jim and Gordon had never been estranged. The point here is that when you engage with a patient or client in broader than medication or symptom terms, you create an opportunity for greater trust. By never accepting at face value that there is no family you open the gate to an introduction to family (if they do exist) when circumstances are right.

This is an opportune time to mention that involving family is not necessarily involvement of the parents of a person—sometimes a sibling has a closer relationship and should be invited to attend with the client. The client might not automatically think of her sibling as someone she should involve.

Recovery and Family Interventions

Family interventions were around a long time before it became fashionable to talk about recovery. However, to a great extent that is what they have always been about – a better prognosis for the person with illness. Therefore, when we implement family interventions we can happily embrace the concept of recovery as described by Mueser & Gingerich, as a process rather than an event, and thus avoid the pessimism that surrounded treatment in earlier times.

Recovery viewed in this way does not mean that the person arrives at a point when all symptoms are absent; it means that the person can live with a decent quality of life while coping with symptoms.

The "sea change" described briefly in the opening chapter can assist us in our implementation efforts. Better research tools, improved treatments, a growing mental health lobby of families, and a number of consumers insistent that recovery is possible have raised the bar for the mental health field. While we may recognize that recovery for the most seriously impaired patients may be a journey for a lifetime, for others the optimism expressed by consumers who have written books, articles, created websites, run weblogs, and spoken in public, will create optimism and give all the stakeholders the encouragement they need to pursue a recovery orientation.

The following factors have been found to relate to medical recovery (p. 34, Mueser & Gingerich, 2006, based on Liberman, Kopelowicz, Ventura, & Gutkind, 2003):

- **Positive family relationships**: Low stress and high support facilitated recovery.

- **Access to care**: Recovery was associated with better access to continuous care, including medication, psychotherapy, social skills training, family psychoeducation, vocational rehabilitation, and self-help groups.

- **Little or no substance abuse**: Recovery is associated with little or no current or recent use of alcohol or drugs.

- **Duration of untreated psychosis**: People who recovered had received more rapid treatment for their psychosis after it developed.

- **Initial response to medication:** Recovered people received more benefit from their first trial on antipsychotic medications.

- **Adherence to treatment**: People who took medication and adhered to treatment recommendations were more likely to recover.

- **Supportive therapy**: Recovery was related to having positive and supportive relationships with psychiatrists, psychologists, social workers, or other mental health professionals.

- **Cognitive abilities**: People who recovered had good cognitive functioning, such as attention, concentration, memory, and ability to solve problems.

- **Social skills**: Recovered people had better interpersonal skills.

- **Premorbid functioning**: People who recovered functioned better before they developed schizophrenia in areas such as social relationships, educational level, and work.

Family is a factor in recovery and family interventions such as family psychoeducation can play a role in that recovery (see Chapter 2):

- A meta-analysis of 25 studies showed that family psychoeducation reduced relapse by 20% compared with treatment as usual.

- Criticism and hostility without expressed warmth – in both families and mental health professionals - have been associated with higher relapse rates in patients and

are reduced by these interventions, thus clearing the environment of a major obstacle to recovery.

- The problem-solving perspective in psychoeducation supports the skill-building, positive focus of recovery.

In many recovery stories, former patients often thank parents for continuing support. This support is undoubtedly strengthened by participation in family interventions. With education and guidance, families are better prepared to "foster in (their) relative a vision of recovery imbued with hope, personal responsibility, and a sense of purpose." (p.32)

As family interventions play a role in recovery, recovery can also play a role in family interventions. Families confronted with serious mental illness often feel hopeless about their relatives condition and about their own situation. Providing hope for recovery for families is important for their own self-care and to give them strength in their caregiving role. Indeed, family interventions intrinsically espouse recovery; family work assumes that the situation can be improved, that relapse can be reduced, and that family can take an active role in supporting this.

Both recovery and family interventions are directly linked and the exponential benefit of combining both of these perspectives will improve the lives of both families and consumers.

Conclusion

In this book we have tried to give information and advice on the nature of family work, or family interventions. We have explained the overall concept and identified and described the models. We have raised and refuted the challenges and given practical information on beginning and sustaining this work. The response of families who have had the opportunity to work with professionals to better the situation of their relatives has been noted, along with the personal experience of one carer, among the many, who decided to get involved in services for families.

The importance of training professionals to do this work has been emphasized and examples have been cited by professionals working in well run, comprehensive services. The example of policy making in the field of caregiving in the United Kingdom will give future policy makers in other countries the confidence to approach this subject as it relates to mental illness care. The experience of one family based NGO in campaigning and lobbying for services gives an outline of the activities that must be undertaken, not only by NGOs but by mental health professionals and professional bodies to influence government and society. We have given examples of services that have been successfully operating for a number of years, both in developed and low-income countries-the latter, doing the best they can do when psychiatrists are few, and other mental health professionals practically non-existent. Finally, in this last chapter, we have dealt in a little more detail with the issues that are constantly raised: stigma, denial of illness, confidentiality and recovery.

The aim of the book was to clarify the topic and to encourage more people to undertake this work that is rewarding, both from the perspective of personal and career satisfaction and from the perspective of obtaining a better outcome for patients and families. We hope that we have succeeded.

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