CONSUMERS, CARERS, CLINICIANS IN COLLABORATION

WHAT DOES THIS MEAN?

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Summary

The puzzling nature of major mental illnesses creates conflict among the 'key players.' This causes family carers, consumers (patients) and clinicians to work in different directions. In order to achieve better results for people with schizophrenia, this paper suggests a three stage model of treatment and care that utilises the 'experiential knowledge' of the consumers and carers with the professional knowledge of clinicians in a process of collaboration. This process gradually changes the power dimension from the clinician to the consumer and carer, so that the latter are more able to take control of their situation as self-esteem and confidence are restored. This further enables family carers and consumers to take on active roles as advocates and advisors in many areas of mental health policy and reform.

Underlying these techniques is the basic understanding that carers, consumers and clinicians are equal partners. Doctors must change their negative attitudes, join with family carers and consumers in an equal partnership, and support consumers/carers to develop their own strengths and resources .

Some family carers and consumers are then able to become valuable assets in many aspects of treatment and care.

Key words: consumers (patients), family carers, clinicians, collaboration, care.

Of all the medical conditions suffered by human beings, it is probably the case that major mental illnesses have the greatest potential to create conflict amongst those 'key players' who become involved, namely, the consumers, their family carers and the clinicians.

The primary cause for this has been, and still is, the often puzzling nature of mental illness itself. Many of the symptoms create situations which turn people against each other. For example, paranoid ideation is frequently directed at family members. Consumers blame their families for many of their problems. Families feel ignored by the clinicians' lack of attention to their needs as carers, and insignificant because of the doctors' unwillingness to communicate with them. Doctors are often placed in unrealistic positions by families and consumers who expect them to have all the answers, and to provide a complete cure – an uncomfortable situation for doctors who are aware that major mental illnesses are not necessarily able to be cured, and that treatments may not always bring about the desired results. Frequently, the end result of these conflicts means that professionals, family carers and consumers are isolated from each other, striving to achieve resolution of problems but often working in different directions.

Attitudes of mental health professionals

In the last two decades, in western countries that have undergone a process of transferring the treatment of the mentally ill from psychiatric institutions to community-based mental health facilities, family carer and consumer surveys have reported dissatisfaction with the therapeutic relationship between mental health clinicians and family carers and consumers. For example, two surveys from the Asian region have reported problems with this relationship. Phillips,1999, found that 'mental health professionals tend to share community beliefs about the dangerousness and unpredictability of the mentally ill, about the burden the mentally ill place on society, about the advisability of avoiding social contacts with the mentally ill, and about the need to impose restrictions on the social activities of the mentally ill..... If they convey these attitudes to their patients (which is likely) they could easily magnify the damaged self-esteem of their patients and, thus, decrease patients' and family members' willingness to seek care and to comply with treatment..

We must change clinicians' attitudes about the mentally ill, improve their understanding of the negative effects stigma and discrimination have on their patients, and provide them with interventions that they can use to help patients and family members 'positively reframe' the illness. Interventions that decrease patients' and family members' loss of self-esteem and that provide hope despite the altered social status of the patient, need to become an integral component of the comprehensive treatment and rehabilitation of all schizophrenic patients.'

Kim1999, states that 'Among mental health professionals, attitudes towards the mentally ill, especially schizophrenic, can be characterized by a tendency to focus on highly functioning patients, a tendency to have unrealistic expectations for the rehabilitation of this section of the population. There is little success or satisfaction associated with the treatment of these people because of the high refractory rates and negative prognosis and therefore a lack of personal fulfillment in one's work. It is the current consensus among Korean health care professionals that this section of the population is not worth the effort. People with these diseases demonstrate behaviour which makes engagement with them difficult. There has been a general upgrading in both education and autonomy among mental health professionals. This has enabled them to move away from what has been a medically dominated field and to seek opportunities with other more diverse populations.'

These negative attitudes of healthcare professionals towards people with schizophrenia and their families increases their already existing low self-esteem and loss of confidence. Healthcare professionals are therefore working against more positive outcomes for these consumers/patients.

How is it possible then, to work in collaboration, to work together in a more equal partnership, in order to produce better outcomes for our consumers and their family carers, and to give better work satisfaction to professionals?

A collaborative model of care, which involves a process of education and training for the 'key players' in the management of mental illness can be developed. This model emphasises the need for clinicians, carers and consumers to develop greater respect for each other, thus enabling a more fruitful outcome for all concerned. This model is divided into three stages.

Stage 1. Initial Contacts - Engagement

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In the beginning of mental illness, families are bewildered and confused, anxious and frightened, particularly if their relative displays a total lack of insight and cannot be reasoned with. Consumers are equally terrified by their experiences. There is often denial.

Clinicians need to be in control of the situation in these early stages, hence the diagram places the clinician at the top of the triangle.

It is often in these very early stages though, that clinicians do not empathise enough with the distress of their patient and his/her family. There can be many reasons for this, but one of the major ones relates to their professional training which tends to emphasise the need for 'objectivity', which often causes clinicians to behave in a cold, formal and uninvolved manner.

In these early stages then, it is vital that clinicians openly express greater compassion and understanding of the fears of their patients and their families, combined with a much more positive attitude of hope than they have shown in the past. It is also important for clinicians to tell families that they have not caused this illness, as well as to say that they need the families to help them in the treatment and care of the patient. This process is called 'engagement', or 'joining with' the carers and consumers. (McFarlane, in Lefley and Wasow Eds.1994)

What is it that families and consumers can explore with the clinician in the engagement and joining process in Stage 1?

- Exploration of precipitants. What stress has the consumer experienced? People with schizophrenia are sensitive to environmental pressures.

- Review of prodromal symptoms/signs. These can be very specific for each individual.

  These first two points are aimed at learning how to prevent relapse.

- Discussion of the emotional and behavioural reactions of the family and consumer to illness
- Coping strategies. How are they coping?
- Social supports. It may be too early, but clinicians should refer family members to family support organisations, and consumers to peer support groups. This should be seen by clinicians as a vital part of help for families and consumers; often it is only when family members join family organisations that their emotional distress, sense of isolation and powerlessness disappears, leaving them with greater energy for positive coping.
- Mourning. What are their experiences of grief and loss? How are they managing this?

  The next four points are designed to help families develop the best social and emotional environment in which the person with schizophrenia will be able to function most effectively.

- Preparation for this education and training program. In the early stages, families and consumers cannot absorb much information. It is therefore important to recognise that education and training is a process that needs to continue for as long as it is needed.

When the doctor involves the family carers in an education and training program, the family feels reassured because they are made aware of the fact that this will be a partnership; they need not fear that they will be abandoned, and will have to cope by themselves.

Meeting these needs through initial positive contacts with families enhances their ongoing relationship with mental health service providers, and prevents the occurrence of experiences with professional workers that leave family carers feeling frustrated, angry, depressed and powerless.

Stage 2. Rehabilitation

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This stage is characterised by an awareness that the illness is a long-term one; that the mentally ill person is not going to make a complete recovery, or to become the person with the capabilities that he/she once had. It is often a time of sadness and depression for the families, as well as the consumers. It is also a time when professionals are often not as available as much as is required, nor are there enough services to provide for the rehabilitation needs of consumers.

It is a time when the negative symptoms of schizophrenia become the primary focus. In the past, and still far too often, the negative symptoms are the ones of least concern to clinicians, mainly because, since the discovery of antipsychotic medications, their training emphasizes more the control of positive symptoms; they are not trained in techniques for the improvement of negative symptoms.

It is a time too, when family carers, consumers and professionals tend to have different priorities for what is considered important. Shepherd et al, 1995, carried out a study which revealed a general consensus on the important elements of 'packages of care', but some differences in the priorities as seen by each group. 'Users (consumers) gave more emphasis to practical help (housing, finance, occupation), whereas the professionals emphasized treatment and symptom monitoring. Families felt that everything was important.'

Given these different emphases, it is therefore vitally important that the partnership between the clinicians, the families and the consumers does not disappear. This is the time when it is too easy for the three groups to be working in different directions.

The diagrammatic depiction of this stage, shows family carers, consumers and clinicians interacting along a straight line. This is to represent the fact that the contributions of each group to treatment and care, are all of equal importance.

'Experiential' knowledge

By this stage, clinicians need to recognise that family carers and consumers

have accumulated a great deal of experience in learning how to live with mental illness on a day-to-day basis. It is often only through a trial and error process, that families and consumers learn the best way of coping with the symptoms and their behavioural consequences. When a consumer is unable to develop insight into his or her condition, families are in the best position to know whether or not the medication is useful; they understand the person's illness better than anyone because they are in closer and more regular contact.

Families have many strengths and resources. These include the development of an optimal emotional and social atmosphere, the provision of information on a very wide range of issues, protection of their mentally ill relative from adverse community responses, personal connections - particularly if they belong to self-help support groups - which they can use in the person's rehabilitation. There is a need to work out a plan of action that shares the responsibility of treatment and care with clinicians.

As well as relying on medication, consumers can learn a variety of psychological and social techniques for managing the effects of their symptoms. It is important that they feel free to reveal the nature of many symptoms and problems. Consumers report that they do not feel free to discuss shameful matters with their clinicians, and that these problems prevent them from making as good a recovery as is possible. They need to be able to share all of this information about their symptoms with their clinicians, without fear of being punished or made to feel ashamed.

Problem-solving and Empowerment

The role of the clinician in this stage of rehabilitation, as well as continuing to monitor symptoms, is to act as a facilitator for the resolution of problems that arise, and to help in the determination and implementation of goals that families and consumers wish to achieve.

Structured problem-solving techniques are well documented in the literature (Andrews et al, 1995). They are 'structured', because the lives of people with mental illnes and their family carers can often become chaotic, particularly if people are working with different goals in mind. There is a need to look at problem resolution in a formal and structured way. Problem-solving involves definition of the exact problem, lisiting possible solutions to the problem, evaluation of the suggestions, choosing the most practical solution, careful planning of how to implement the solution, and later, a review of progress with the plan.

When family carers and consumers learn these techniques, they become empowered to take control over their own lives; this improves their self-esteem and confidence; it helps them to realise that the illness is manageable; it helps them to realise that they do not have to be passive victims of this illness. When this stage is successfully completed, then families and consumers are able to move into stage three of this model.

Stage 3. Family and Consumer Empowerment

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For many family carers and consumers, stage three becomes possible with an acceptance of their situation, and a belief that they are able to manage their circumstances in as effective a way as possible. The diagram depicts this by placing family carers and consumers in an equal partnership, with clinicians in less of a position of control but available when and as needed.

As well as continuing to use Stages 1 and 2, this acceptance can lead to family carers and consumers becoming active as advocates and advisors in a variety of different mental health areas.

Family carers and consumers can become:

- Educators and trainers of mental health professionals.

The 'experiential' knowledge that family carers and consumers accumulate as they learn to live with mental illness, is an essential part of mental health training. Without this, professionals tend to see only the symptoms and the need for medication; they see an illness, and not a person. Mental health service consumers wish to be accepted as human beings, not just as symptoms of a particular mental disorder.

It is only when professionals learn from and accept the individuality of each patient, that they will be able to provide an idividualised treatment plan that the consumers and families are able to implement.

- Advisors in policy development for mental health services

Family and consumer perspectives must inform mental health policies through family and consumer advisory groups alerting governments to mental health issues

- Developers of pilot rehabilitation projects

Because governments have not provided community-based services, non-government family support organisations are among those groups who have developed many pilot rehabilitaiton programs.

- Advocates for community acceptance of mental illness

Stigma and discrimination associated with mental illness can be overcome when family and consumer groups themselves take on the role of community education and awareness. This means that they themselves are no longer ashamed of their illness, and are prepared to talk openly about their condition. This is a hard task, and is not achievable unless family and consumers have successfully gone through stages 1 and 2 as described, and can continue to rely on support from the shared partnership with professionals.

- Educators and trainers of other families and consumers.

In many countries throughout the world, family education programs and consumer peer support programs are being developed by carer organisations where family members educate, train, and support each other (Alexander,1991. Burland, 1998). Trained family members have the advantage of personal experience in caregiving, and are particularly appropriate for helping each other come to terms with the distressing emotional feelings that accompany the development of mental illness in a relative. These programs are cost-effective in that families support other families without payment. Consumer groups also support each other - a process that is particularly beneficial for overcoming isolation and stigma.

Summary and Conclusions

The paper recommends a three stage progression of treatment and care for people with schizophrenia - stages of treatment and care that are not mutually exclusive, nor do they imply that there is a steady and uncomplicated progression from one stage to the next. The model is

designed to help keep in mind the overall goal of helping families and consumers learn the most effective methods of managing mental illness; methods which enable them to move from feeling passive and powerless to feeling they can be active and powerful in achieving positive outcomes.

In order to make this model effective, the greatest changes have to happen in the attitudes of clinicians, who will then need to be educated and trained in a different way of working with families and consumers; this important change must commence at the very first contact with families and consumers.

This way of working with families and consumers demands an equal partnership based on mutual respect for each other's expertise. In the beginning of the development of mental illness, unless there is the development of equal partnerships with families and consumers, this model will not work and opportunities for better outcomes could be lost.

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Note: Margaret Leggatt was president of WFSAD from 1996 – 2000. She is the founder of SANE Australia, a national mental illness charity and the Victoria Schizophrenia Fellowship, Australia. Margaret was instrumental in developing the WFSAD program "Families as Partners in Care.