

# Who Cares for the Caregivers? Families and Schizophrenia in Hong Kong

The March 2008 issue of the Journal focuses on family experiences. Two authors have generously contributed their first person accounts of their intimate knowledge of schizophrenia, one who has lived with the illness since she was 17 and the other whose brother has been ill for many years.<sup>1,2</sup> Reading them will give us, as psychiatric professionals, a rather different understanding of their lives than we get in our usual interviews with patients and families. In particular, as the family member's story unfolds, it becomes very apparent how easy it is for us, when the patient attends appointments regularly and is medication compliant, to remain unaware of how much the family are having to tolerate: a 'don't ask, don't tell' unwritten rule that allows both professionals and families to maintain the fiction that all is well.

We have also benefited in this issue from an original paper on the validation of a scale in Chinese that measures the levels and kinds of caregivers' involvement with patients with schizophrenia.<sup>3</sup> This scale, which is relatively quick to administer, will provide an invaluable tool for both clinicians and researchers and should significantly enhance our knowledge of carers' responses to looking after someone with schizophrenia.

As a number of papers in this volume of the Journal are about caregiving, the editor invited me to write an editorial that would provide some background to caregiving as it relates to schizophrenia. To do this I have drawn on published local and international research as well as clinical experience. The vast majority of people with schizophrenia over the world live with family members. If they did not, the formal rehabilitation services would be completely overwhelmed. Indeed, these family members are the major caring resource for people with a serious mental illness. Their importance as caregivers has increased and their contribution has become even more vital since the advent of community care and the deinstitutionalisation movement that began in the 1960s. In the Chinese context family care may be even more important than it is in some other countries. Looking after someone with schizophrenia in the family is a daunting task, often performed by elderly parents with love and devotion over many years. Some carers find satisfaction in looking after their loved ones despite the challenges, but many feel weighed down by the responsibility and unsupported by both family members and health and social services. Because of the importance of the extended family to Chinese people it seems reasonable to assume that family care would be shared amongst many, but this appears not to be the case, either in Hong Kong or China.<sup>4-7</sup> Instead carers, usually a parent and often the mother, describe trying very hard to keep the illness a secret from even close family members (e.g. siblings, aunts, uncles

– even a spouse). Even when family members are aware of the situation, few seem to offer much support or assistance. This is a measure of the level of stigmatisation associated with schizophrenia that directly affects both patients and their families.

As is the case in many international studies, Hong Kong carers report being more distressed by the negative symptoms than the positive ones and find the patients' sleep disturbance, lack of employment and reluctance to attend clinics or take medication the most difficult behaviours to handle.<sup>8-10</sup> Carers report extensive impacts on their lives; financial, restricted social activities, effects on their own health and well-being and ability to work, family conflicts, not being able to take good care of other family members and disturbance in domestic routines.<sup>8,10,11</sup> Mothers tended to feel more psychological burden than fathers, probably because they carry the major caregiving responsibility, and male patients were thought to impose more of a burden than female patients.<sup>8</sup> All of this raises the question; as psychiatric professionals, what can we do to help?

## What do Patients Need?

An article reporting on the outcome of an international study of optimal treatment approaches for schizophrenia clearly states that everyone with schizophrenia should be provided with a) the optimal dose of anti-psychotics, b) strategies to educate themselves and their caregivers to cope more efficiently with environmental stresses, c) assertive home-based management to help prevent and resolve major social needs and crises, including episodes of symptoms.<sup>12</sup> Sadly, the article then goes on to comment that 'despite strong scientific support for the routine implementation of these... strategies, few services provide more than the pharmacotherapy component, and even this is seldom applied in the manner associated with the best results in the clinical trials'.<sup>12</sup> It should be noted that two of these evidence based approaches involve family members — emphasising the importance of the patient as part of an interactive and holistic family system from which effective care cannot be divorced.

## What do People Who Care for Family Members with Schizophrenia Need?

### *Information and Education*

In an on-going project with the theme of recovery and remission in schizophrenia, a senior and very experienced Community Psychiatric Nurse held a focus group with family carers to explore their ideas about what recovery meant. When I asked her how the focus group had gone her

immediate response was that she had been very surprised at how few of the group members could name the illness that their relative suffered from. They coped on a daily basis with its effects and had devised a management system through trial and error but they knew little about the disorder. This lack of formal knowledge has been reported before in Hong Kong.<sup>8,13</sup> Carers may be told the diagnosis and given some information about the illness during the first episode but that is a time when they are likely to feel too distressed to absorb the information. Some doctors may feel that carers are not sufficiently educated to understand facts about symptoms, prognosis and course or that they would find such information too distressing as the outlook may be pessimistic.

Looked at another way it cannot be denied that families do most of the caring work. No one can do a job effectively without being properly equipped and that includes having as full an understanding as possible of both the illness and the available services. For example, it is not uncommon for family members to misconstrue the lack of volition so common in people with schizophrenia as the character trait of laziness. This misunderstanding often leads to negative and critical family interaction, factors demonstrated to be associated with relapse. Ideally, efforts at education should be targeted at the whole family, rather than just the main carer (usually the mother). Without having the necessary support and authority to do so the carer is put in the position of, for instance, having to convince other family members that the patient is genuinely ill rather than having a flawed character. How should such material be presented? Good sense suggests that a variety of methods should be used over a period of time. Written material presented in an attractive, user-friendly fashion is necessary but so are more interactive ways. These could involve small groups of relatives and professional staff.

### ***Family Approaches***

Education is a valuable component of a treatment and rehabilitation programme. It is likely to improve engagement and adherence to treatment but it is not sufficient in itself to have a major effect on the reduction of illness episodes or to promote clinical and social recovery.<sup>14</sup> A review article written by the then Chair Professor of Psychiatry at the University of Auckland, Ian Falloon, identifies a number of elements in family approaches that have statistically robust effects in improving outcomes for patients.<sup>15</sup> The first, carer-based stress management, derived from cognitive behavioural therapy, seeks to enhance the problem solving efficiency of both patients and carers to promote actively the achievement of life goals. The second educates caregivers in stress reduction strategies to increase acceptance of behaviour associated with both positive and negative symptoms. Falloon finishes his article with the following statement:

‘There is sufficient scientific evidence to conclude that strategies that enhance the caregiving capacity of family members and other people involved in the day to day care for people with mental disorders have a clinically significant impact on the course of major mental disorders...

and the evidence is strongest for schizophrenia and bipolar disorders. The best results appear to be associated with comprehensive methods that integrate carers into the therapeutic team through education and training in stress management strategies, with continued professional supervision and support over a period of at least 2 years’.<sup>15</sup>

### ***Carers as a Resource***

Professionals need to be honest about their limitations. How much do we really know about how to handle the daily difficulties that arise when living with someone with schizophrenia? Probably not very much. Providing answers may be akin to groping in the dark. This leads to disappointment on the part of the relatives who expect us to have solutions. Much more effort needs to be used to identify those families who show resilience and positive adaptation and learn from them what works and what does not. Self-help groups for relatives of people with a mental illness were pioneered in Hong Kong by the psychiatric unit at a regional general hospital. The success of these kinds of groups and organisations in Hong Kong demonstrates that Chinese people can feel comfortable discussing personal troubles with strangers when those strangers share the same stigmatising condition. Support groups also offer people who are so often on the receiving end of help the opportunity to be helpers, an ego-strengthening activity. Experience shared and advice given is on an equal footing and is based in reality.

### ***Accessible Services***

Whatever improvements could be made in psychiatric services in Hong Kong the community is inestimably fortunate to have comprehensive psychiatric services that are provided free or at low cost by the government. Thus all those who require medication have access to it and can be monitored regularly. There are other non-monetary costs to this system; there is little or no continuity of care because of the rotation system among junior doctors in public clinics; patients are usually not treated by experienced practitioners; and contact is normally less than 5 minutes per appointment. There is no choice of doctor and the new generation of atypical anti-psychotics is available to only a few because of the government’s reluctance to pay for them; and it is costly in time because of the queues. Those who can afford it may seek treatment from a private psychiatrist but may not then have access to the services of a multi-disciplinary team. But what is not always present either in the public or private sectors is recognition that the family is an integral part of the patient’s life, that respecting and supporting the main carer’s work is vital. Indeed, we need to acknowledge that they are our partners in care.

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