

# The impact of mental illness on family members

**BACKGROUND** Mental illness is a common problem managed in general practice. It is often not appreciated that the effects of mental illness extend beyond the patient to the family. The effect of a serious mental illness on the health of family members has been studied, but not in relation to the types of mental illnesses seen in general practice.

**OBJECTIVE** The author uses the literature to examine his experiences of factors which affect families who contain a mentally ill member. In doing so he examines issues relating to the care of such families. Some means by which assistance may be given to families will be outlined in a paper to be published in this journal later this year.

**DISCUSSION** Family members experience a number of stresses. The common stresses seen in general practice include the perceived sensitivity of a mentally ill patient, the perceived problems with medication, a fear of suicide and a restriction of personal time. Limited evidence suggests that the stresses have a negative effect on the health of family members.

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General practitioners frequently manage patients with mental illness, but the author's experience would suggest that because of the pressures of practice, GPs have little time to recognise and respond to the impact of the illness on family members. It has been known since the mid 1960s that the health of family members living with a person who has a serious and persistent mental illness is negatively affected,<sup>1</sup> but whether this applies to the broad spectrum of disease in general practice has not been documented. This paper sets out to explore the issue of mental illness as seen in general practice and the effect it has on family members. In a future paper the author will explore approaches to this problem for GPs.

Key issues which seem to affect family members when one of them has a mental illness are:

- the patient with mental illness is perceived as overly sensitive to the stresses of living
- the perceived negative effects of medication
- a fear of patient suicide, and
- a restriction of personal time.

## The family impact

The following case examples exemplify these concerns.

### Michelle and Tony

Michelle has a major depressive disorder that responds well to counselling and the prescription of a selective serotonin reup-

take inhibitor (SSRI) antidepressant. One of the issues discussed in counselling is a history of sexual abuse as a child. Michelle has longstanding low libido that is unaffected by the SSRI and is, perhaps, attributable to the abuse.

Tony is aware of the abuse, and admits his feelings about Michelle fluctuate. Tony perceives Michelle as being 'fragile' and needing his protection, and suppresses his own feelings and desires. Sometimes, Tony personalises Michelle's low libido as meaning that she does not love him. He then feels rejected and sulks.

### Peter and his parents

Peter is a 22 year old living with his parents. At age 20 he suffered a first and only episode of schizophrenia after

**Table 1. Burden of mental illness on family members**

- Restriction of leisure time
- Interference with employment
- Interference with a personal social life
- Fear of physical violence by the patient
- Fear of suicide or self harm by the patient
- Concern that the carer may develop a mental illness
- Concern that the relationship with the patient may be affected by the mental illness.

returning from a trip to Bali. Since that time he has been well. He stopped his medication 18 months ago and returned to his university studies at that time. He has a part time job in a local supermarket.

Peter's mother resigned her job to look after him when he developed schizophrenia. She perceives Peter as sensitive and needing protection. She is concerned about the high risk of suicide in people with schizophrenia and has reduced her commitments in order to look after Peter.

His father regards Peter as weak. When Peter was ill his father expressed the opinion that Peter would be better 'if he would just pull himself together.' He was unhappy when Peter was taking medication ('it's addictive and messes with your brain'). His advice to Peter was to leave home and learn to care for himself. ('It will toughen you up and make a man of you.')

Peter's father feels uncertain about Peter's future because of his demonstrated 'weakness.' Peter's mother continues to protect him because of his 'weakness.'

### Dolly and George

Dolly is 76 years old and 12 months ago developed an agitated depression. She refuses referral to a psychiatrist. She has not been able to tolerate any SSRI antidepressants, but was started on high doses

(200 mg) of dothiepin six months ago. Despite additional minor and major tranquillisers, she continues to be agitated.

George, her husband, who is 80, tries to keep her calm by not saying anything that will upset her. He retires to a nearby park if things get too difficult. He hides her medication so that she cannot take an overdose. He has lost most of his friends and his children refuse to visit or have them at their houses.

### Andrew and his parents

Andrew, who is 20, is a quiet, reserved person. Six months ago his girlfriend of 12 months 'broke off' their relationship. Since then he spends most of his day on his bed. He is sleeping poorly and lacks energy. He has depression, but his parents advise him not to take 'drugs.'

His parents are concerned about his behaviour, and do not understand him. They spend most of their time 'walking on eggshells' to avoid upsetting him. They do not like the idea of medication, as it treats the symptoms without treating the cause. They have not been out together for fear that he will suicide while left alone. Their friends are slowly giving up on them.

### Discussion

These cases are only too common in general practice.

Two recent studies bring together the results of research with the severely mentally ill. Ostman et al<sup>2</sup> described the development of an instrument to measure burden on family members. The instrument was validated with 74 relatives of inpatients of a psychiatric unit. The authors provided a list of 15 burdens but indicate the first seven are the most significant for relatives (*Table 1*).

Stern et al<sup>3</sup> used a qualitative process to analyse the narratives of family members caring for a relative with a long term serious mental illness. The main themes from this study applicable to patients seen in general practice can be summarised as follows:

- a patient with a serious mental illness is believed to be a sensitive person
- the worst fear is that the patient will commit suicide
- the difficulty coping with behaviour that is not understood (how to combine acceptance with setting limits)
- the difficulty distinguishing 'illness' from 'personality' and 'circumstances'
- the unpredictability limits future planning
- the fear that the illness will become a lifelong condition (if the patient is young)
- concerns over medication, and
- stigmatisation.

These studies reveal the stresses caused by caring for a patient with a serious mental illness and the author's experience would indicate they apply in some form to families in general practice.

### Carer beliefs — myth or reality?

#### Sensitivity

That mentally ill patients are sensitive people is a very common belief among their relatives. It is often perceived as a 'cause' of the mental illness and is seen in each of the cases presented. In Peter's case his parents respond to this belief in different ways. Peter's mother became protective, while his father wanted to toughen him up so that he will get better.

In Michelle's case Tony responds as if she is sensitive (fragile), but even when he personalises her behaviour he responds by withdrawing rather than getting angry with his fragile partner.

#### Medication

Concern about medication is also common. Both Jorm et al in Australia<sup>4,5</sup> and Angermeyer et al in Germany<sup>6,7</sup> have examined public opinion of psychopharmacotherapy. The results in both countries confirm that the public takes a negative view of drug treatment of mental illness. Concerns include a fear of adverse effects (including dependency), a belief that their action is limited to modification of symp-

toms without affecting the underlying disease, and drugs are ineffective with only a transient effect at most. Andrew's parents show these feelings. George, who supports the use of medication, is concerned about the risk of suicide.

### Fear of suicide

Fear of suicide is a common concern, even when the risks are extremely low. It may reflect a concern that the family member would feel guilty if 'they allowed it to happen' while caring for the patient. Sometimes this fear is misplaced, as with Peter's mother, but in other circumstances is quite realistic.

### Reduced personal time

Restriction of personal time can take the form of reduction in leisure time and/or restriction of social interaction. In all the cases, except for perhaps Peter's father, there is a reduction in free time for family members. This is particularly seen in Andrew's parents and George where so much time is spent caring and worrying that no personal free time is left.

### An impact on family life

Very few studies of the effect of psychiatric illness on family members have been carried out in general practice. In 1993 Leach et al<sup>8</sup> reported on the consultation rates for children of 174 families.

Analyses of the data showed that the factors most significantly associated with a child's consultation frequency were the psychological state of the mother, the mother's own consultation frequency and (inversely) the number of children in the family.

In 1998 Sobieraj et al<sup>9</sup> reported on a study of the consequences of depression to the health of the family. The study examined the burden of illness in families where a member suffered from depression and was compared to matched control families. The authors calculated three scores of burden: the family mean; the family mean with all patients with depression excluded; and the family mean with the index patient

excluded. In all cases the score for the families with a depressed member was statistically greater than the control families.

Studies of the effects of serious mental illness on family members have been more frequent. The effects of a seriously mentally ill individual on family members is perhaps best summarised by Gallagher et al<sup>1</sup> when they state:

When other predictors of health are controlled, sharing a household with a mentally ill person is associated with poorer self reported physical health, increased risk of reporting some activity limitation, and increased service utilisation — both greater risk of hospitalisation, or visiting a physician, and a greater number of days hospitalised and number of physician visits among those utilising these services.

A number of explanations have been proposed for the effect of a mentally ill individual on the family. MacGregor<sup>10</sup> and Solomon and Draine<sup>11</sup> have written about grief as a possible mechanism. The most popular explanation, however is that the effects are due to the stress caused by living with a person who is mentally ill.

While not directly studying the effects of mental illness, Parkerson et al in 1989<sup>12</sup> and 1995<sup>13</sup> examined the effects of perceived family stress. The first study showed that a family member who perceives stresses from other family members had more symptoms, poorer emotional function and decreased physical function. The second study revealed that '... baseline, patients with high self reported family stress ... had lower quality of life, functional health, and social support scores and higher dysfunctional health and social stress scores than other patients.'

Whatever is the cause, the negative effects of mental illness are substantial and extend beyond the individual to the family. By taking on the broad role of a family practitioner, Australian GPs can assist the patient, and have the opportunity to help other family members to have a less stressful and perhaps a more rewarding and healthier life style.

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