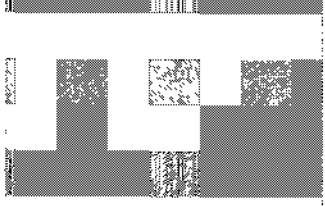

Chapter 1

THE PROBLEMS OF PEOPLE WITH PSYCHOSIS

1.1 WHAT CHARACTERISES PEOPLE WITH PSYCHOSIS?

The problems of people with psychosis are characteristically complex and heterogeneous. As well as problems directly associated with psychotic symptoms, most people with psychosis will also have problems associated with emotional disturbance and social disability. We will attempt here to provide an orientation to the way in which an individual 'person with psychosis' may present in the clinic. This is a difficult task as individuals typically have multiple problems which combine in different ways, and one case can differ markedly from another. To illustrate the range and variation in presenting problems that may be encountered, we will describe three cases.

Case 1: Erica

Erica was a 40-year-old woman living in a supported hostel. She was unable to work and only occasionally attended a social day centre. She had received a diagnosis of schizophrenia, and had a 17-year history which was characterised by severe symptomatic disturbance and difficulties in living independently in the community. On initial assessment, Erica's most obvious problems appeared to be associated with auditory hallucinations and paranoia. Erica reported that she frequently heard distressing voices that made highly critical remarks about her; these voices sometimes engaged in discussion with her, or commented on her actions. Erica heard voices most days. Sometimes these were just fleeting experiences, but often the voices would be continuous and very demanding of her attention. Erica also reported that she was distressed because people were staring at her, and talking about her critically when she left the hostel. She said that she felt that people were setting things up and were against her, and that she firmly believed that the police were watching her every move. Whenever Erica heard police sirens, or saw police cars or anyone in uniform, she believed these to be events associated with the police being after her. Erica's mood fluctuated.

She was most often moderately depressed, sometimes very severely so. Erica said that she felt completely worthless, and castigated herself for being unable to live independently or hold down a job. She frequently described herself as suicidal, and reported experiencing impulses to throw herself under cars. Erica would agree that she had schizophrenia and would take her neuroleptic medication regularly; however, she also reported that she strongly believed that her voices and beliefs about the police were real and not an aspect of mental illness.

Case 2: Lawrence

Lawrence was a 34-year-old history graduate who lived with a supportive partner. He had received a diagnosis of schizo-affective disorder. Since his first admission 11 years previously, he had been admitted to hospital on nine occasions. Despite continuing problems and a poor absence record, he held a full-time job as a clerical officer. At first assessment Lawrence reported that he was being personally threatened by evil forces. He said that he felt that poison was being put into his food, that people at work were staring at him, and gathering together to talk about him. These persecutory experiences tended to occur episodically, but when they occurred Lawrence would be very preoccupied for around three to four days. When preoccupied, Lawrence would sometimes act on his beliefs, occasionally becoming aggressive and confrontational with work colleagues. Even when less tormented by his persecutory ideas, he would still describe beliefs that there was an ongoing battle between good and evil in the world, and that he was a vessel for the flow of evil and good. Lawrence also described times when he thought he had special powers, including the ability to influence events and to use telepathic contact to communicate with others, and times when his actions were being controlled by others. Unfortunately, episodes of this type often had very serious consequences and had led to compulsory hospitalisations. When preoccupied with feelings of special powers, Lawrence would write letters to political and religious leaders. More seriously, he would also persistently pester people whom he thought to be good, sometimes even complete strangers. After these episodes Lawrence would be ambivalent about the validity of his experiences. In general he would agree that they were a set-back and disruptive to his life; however, he described himself as unable to stop believing that the telepathic contact and his mission were real. He firmly disagreed that he had a mental illness, and he would often stop taking his medication.

Case 3: Derek

Derek was a 28-year-old man who lived at home with his parents. He had a diagnosis of schizophrenia, and had had four admissions over the past seven

years. He attended a sheltered workshop and was described as a steady worker. He was also described as having difficulties getting on with others, and a bit of a loner. Derek reported a variety of problems relating to paranoid beliefs and experiences of thought disorder. He believed that there was a general conspiracy going on involving both Health Service employees and the police, and that he was about to be 'fitted up' for a series of murders and sexual crimes. He said that when he went out to pubs people stared and laughed at him, and that people could read his mind and knew about his sexual feelings and inadequacies. He reported that, when watching television or listening to the radio, he would feel that news stories related to him. Derek reported that he had complete contempt for himself as a person. He was also very frustrated about the fact that he had never had any close relationship with a woman. He described a conflict in which he felt that he should leave home, but also that he was terrified of living alone. He described himself as trapped and was often very severely depressed. Occasionally Derek would report that he wished that he could be caught and sent to prison, as 'at least that way it would all be over'. Like Erica, Derek would agree that he had schizophrenia and would take medication reasonably reliably; however, he strongly believed that his experiences and beliefs were real and not an aspect of mental illness.

All of these people report distressing and disabling problems associated with psychotic symptoms, despite taking neuroleptic medication. The psychotic symptoms themselves are probably the most immediately striking features, but emotional disturbance, and problems associated with risk of relapse and social disability are also prominent problems. In an attempt to address what are often complex and multidimensional problems, the therapy described in this book focuses on a number of different goals. Psychotic symptoms such as hallucinations and delusions provide important targets for therapy, but other goals may include fostering feelings of control, and promoting hope for the future and self-esteem. Other aims may include working collaboratively with the person to decrease the likelihood of further relapses and hospitalisations, and to prevent and manage social disability. In the following pages we will provide more detailed information about the problems of people with psychosis that constitute targets for cognitive behaviour therapy.

1.2 DRUG-RESISTANT PSYCHOTIC SYMPTOMATOLOGY

Problems associated with chronic and drug-resistant psychotic symptomatology appear to be quite common. Lieberman, Mayerhoff and Loebel (1991) report that around 14% of patients in their first episode of schizophrenia did not respond adequately to antipsychotic drugs, and of those

who had experienced many previous episodes at least 25% failed to respond. Many people with psychosis (like the cases we have described above) receive some benefit from neuroleptic drugs, but still experience distressing and disabling positive psychotic symptomatology despite taking medication. The following studies provide further indications of the prevalence of these problems. Harrow, Carone and Westermeyer (1985), reporting data from a follow-up study of 34 people with delusions, suggested that up to 55–60% still had delusional beliefs one year later. Johnstone et al (1991), in a follow-up study of over 500 people who had received a diagnosis of schizophrenia, reported that over 30% had moderate to severe levels of hallucinations, and around 50% described moderate to severe delusions. Curson et al (1985), in a follow-up study of 40 patients seven years after their first admission to hospital with a schizophrenic syndrome, found that around 23% still reported positive symptoms. Other surveys reveal that much higher proportions of people with psychotic disorder continue to report anomalous schizotypal experiences and overvalued ideas (Huber, Gross and Schuttler, 1975). A conservative estimate of prevalence is that somewhere between a quarter and a half of people who at some time have received a diagnosis of schizophrenia may still have problems with continuing psychotic experiences and beliefs despite the prescription of neuroleptic medication.

The extent to which more reliable medication management may reduce the prevalence of problems is difficult to determine. Certainly in some cases, like Lawrence, taking medication more reliably and consistently may help. However, medication is unlikely ever to provide a complete solution. Numerous controlled trials clearly indicate that neuroleptic medication can often provide dramatic and clinically significant relief from the experience of acute episodes of positive psychotic symptoms, and that neuroleptic medication can reduce the rate of relapse (see Remington and Adams (1994) for a recent review). However, if one examines the data from trials of neuroleptic medication closely, it is clear that the effect is most often a highly significant moderation, rather than the abolition, of positive psychotic symptoms for most patients. Even the successful use of new pharmacological agents for treatment-resistant psychosis does not always eradicate psychotic experiences; instead the effect appears to be a moderation of what has previously been continuing acute psychosis (Meltzer, 1992). (The case of Erica is a good example of someone who had shown quite a dramatic improvement on taking clozapine; this had led to her discharge from hospital, but she still experienced problems associated with psychotic experiences and beliefs which were highly distressing and disruptive to her life.) The effects of neuroleptic medication on psychotic symptoms (in particular acute psychosis) are then indisputably highly beneficial, but rarely provide a cure.

The diversity of problems associated with psychosis is often striking and can be bewildering when first encountered. What was described in the cases above appears to be typical, and has been revealed in a number of careful descriptive studies. Psychotic symptoms rarely occur alone; much more often they occur in combination. Individuals may report psychosis as an altered experience of the world in a number of different sensory modalities (Hamilton, 1984). Auditory hallucinations vary considerably in their content, and in other dimensions such as loudness, clarity, tone of voice and the extent to which they are perceived as distressing or disabling by the individuals who experience them (Slade, 1972; Junginger and Frame, 1985; Hustig and Hafner, 1990; Chadwick and Birchwood, 1994). People who experience chronic hallucinations often report that their 'voices' vary considerably in their content: how long they last, how often they occur, and how threatening they are perceived to be (eg Fowler and Morley, 1989; Chadwick and Birchwood, 1994). Cognitive behavioural analyses often reveal a variety of different antecedents to psychotic experiences, such as hallucinations, experiences of thought disorder and perceptual disturbances. Some individuals may report hallucinations and other psychotic experiences only in certain situations, or at certain times of day, or under certain stresses. Others may report psychotic experiences which appear to have no clear precipitant (Fowler and Morley, 1989; Tarrier, 1987; 1992).

Delusional beliefs also appear to be complex and multidimensional phenomena. Traditional psychiatric approaches to the classification of delusions focus on the remarkable differences between individuals in the content of delusional beliefs (eg between paranoid, grandiose, depressive and explanatory beliefs). However, as was seen in the case of Lawrence, it is common for paranoid, grandiose and explanatory beliefs to co-occur in an individual. Furthermore, close observational studies of delusional beliefs suggest that these beliefs may vary independently across a number of dimensions (Garety, 1985). The extent to which someone believes in their delusion (conviction), how often they think about the belief (preoccupation) and the degree to which they are distressed by their beliefs may vary independently of one another in the longitudinal course (Brett-Jones, Garety and Hemsley, 1987). Over time the presentation of symptoms in an individual case can vary dramatically. Repeated assessments from longitudinal studies have revealed that quite different patterns of symptoms may be reported at different times in any individual case (Brockington and Meltzer, 1982). Only careful and individualised assessment can capture the variability in an individual's experience of psychotic symptoms such as delusions and hallucinations. A number of different processes may contribute to this variability (see Chapters 5, 6 and 7).

It is increasingly recognised that a range of cognitive behavioural strategies may offer a very useful adjunct to medication in helping patients to manage their experiences. A number of studies dating from the early 1960s reported the successful use of a variety of different types of cognitive and behavioural strategies in the management of psychotic symptoms such as delusions, hallucinations and the subjective experience of thought disorder. (Reviews of this literature, which consists of a series of reports of modifying a psychotic symptom in a single case, have been provided by Gwynne Jones, 1979; Hemsley, 1986; Slade and Bentall, 1988; Shepherd, 1988; and Tarrier, 1992.) More recently, case series and controlled trials have provided firmer support for the use of such strategies (Fowler and Morley, 1989; Chadwick and Lowe, 1990; Lowe and Chadwick, 1990; Tarrier et al, 1993). Within our approach a wide range of potential cognitive behavioural strategies for psychotic symptoms is available to the therapist. These involve both pragmatic behavioural strategies (eg training people to distract themselves from voices) and also attempts to relabel, redescribe or otherwise alter beliefs about the nature of the experiences of psychosis. An important characteristic of our therapeutic approach is that we aim to take full account of what appear to be remarkable individual differences in the experience of psychotic symptoms. The particular strategies used are then carefully selected according to a detailed assessment and cognitive behavioural formulation of the symptoms presented in each case.

1.3 EMOTIONAL DISTURBANCE

It is increasingly recognised that symptoms of emotional disturbance are highly important aspects of the subjective experience of psychotic disorder. People with psychosis often report that feelings of severe anxiety, despair, loneliness, unworthiness and rejection are of equal, if not greater, importance to the symptoms which define psychosis itself (MacCarthy, Benson and Brewin, 1986).

Surveys reveal that severe symptoms of depression and anxiety are very common amongst people with chronic psychotic disorder. Such symptoms may precede, occur concurrently with or follow acute episodes; or occur independently between episodes (Barnes et al, 1989). Estimates of the prevalence of severe depressive syndromes at the time of acute relapse range between 20% and 50% (Siris, 1991). Period prevalence of depressive episodes is also high. Up to 65% of patients who have been diagnosed as schizophrenic may experience a depressive episode over a one- to three-year period (Johnson, 1981). Panic and anxiety symptoms occur in around 60% of people with chronic psychotic disorder (Siris, 1991; Moorey and Soni, 1994). Several studies have shown that symptoms of emotional

disturbance may be predictive of risk of relapse (Goldberg et al, 1977; Johnson, 1988) and of risk of suicide (Drake and Cotton, 1986; Caldwell and Gottesman, 1990). Rates of attempted suicide and suicide are disturbingly high amongst people with psychotic disorder. Of those diagnosed with schizophrenia up to 30% may attempt to kill themselves (Johnson, 1981) and around 10–13% succeed (Caldwell and Gottesman, 1990). The case of Erica is typical of a person with psychosis who presents a continuing risk of suicide.

Many recent cognitive formulations of the problems of people with psychosis suggest that emotional disturbance is a central aspect of psychotic disorder. We review these formulations in detail in Chapter 7. Depression in people with psychosis is associated with feelings of helplessness, distress and despair and can often be understood as deriving from a comprehensible reaction to the adverse experiences of psychotic disorder and its associated life predicament (Estroff, 1989; Appello et al, 1993; Birchwood et al, 1993). In addition, apparently meaningful and emotionally salient themes occur in much of the content of psychotic symptoms, such as delusions and hallucinations (Bannister, 1983; Romme and Escher, 1989; Chadwick and Birchwood, 1994). It is likely that affective as well as biological processes may be involved in the formation and maintenance of psychotic symptoms such as auditory hallucinations, and paranoid and grandiose delusions (Neale, 1988; Bentall, 1993).

Collectively, these new cognitive–emotional formulations of the problems of people with psychosis, imply the need for a new approach to cognitive behaviour therapy for these people in which the understanding and treatment of emotional disturbance are at centre stage. Addressing emotional disturbance amongst people with psychosis is an important aspect of the therapeutic approach described in this book. Often the use of strategies to manage emotional disturbance is closely integrated with the use of strategies to manage psychotic symptoms. Cognitive behavioural therapy makes extensive use of adaptations of many of the existing cognitive therapy strategies for managing emotional disorder, which are already of known efficacy in the management of emotional disturbance in other psychiatric disorders (see Hawton et al, 1989; Williams, 1992). We have found adaptations of cognitive behaviour therapy strategies developed for the management of depression in chronic physical illness and some of the strategies used in schema-focused cognitive therapy for personality disorders (eg Young, 1990) to be particularly useful.

1.4 COGNITIVE BEHAVIOUR THERAPY AND THE MANAGEMENT OF RISK OF RELAPSE AND SOCIAL DISABILITY

Cognitive behaviour therapy for psychosis offers a change in emphasis from the more didactic and behaviourally oriented therapies which have been traditionally associated with psychiatric rehabilitation. Within cognitive behavioural therapy the person's subjective experiences, both of psychosis and of emotional disturbance, are given prominence. However, while we believe that this change in emphasis is necessary and important, we also believe that the traditional emphasis of rehabilitative interventions on the management of social disability and the prevention of relapse should not be neglected. Indeed, we will argue that a cognitive behavioural perspective offers a new approach to addressing these problems.

1.4.1 Risk of Relapse

A central problem for people with psychosis who live in the community is risk of relapse and rehospitalisation. Risk of relapse is particularly high amongst those who have continuing psychotic symptomatology and reported emotional distress (Goldberg et al, 1977). Many carefully conducted studies have indicated that risk of acute relapse is considerably increased in the context of social adversities such as difficulties in interpersonal relationships with close relatives or others, and is associated with the presence of disruptive life events (see Kuipers and Bebbington, 1990). Taking long-term neuroleptic medication reduces the risk. Around half as many patients are likely to relapse over a two-year period if they do take medication than if they do not (Leff and Wing, 1971; Hogarty et al, 1974; Crow et al, 1986). However, even amongst those successfully maintained on neuroleptic medication around 25% may still relapse over a two-year period, and between 40% and 60% may relapse over a five-year period (Remington and Adams, 1994).

Although medication is clearly a protective factor, taking high doses of neuroleptic medication is not without a cost, and the adverse effects can include highly distressing and sometimes permanently disabling side-effects (see Hindmarch (1994) for a recent review). For many people with psychosis, weighing up the benefits of taking medication against the costs of side-effects is an important issue. For a variety of reasons somewhere between 20% and 65% of out-patients may discontinue its use (Curry, 1985).

Although some people with psychosis may deny any problems associated with risk of relapse, for many, fear and anxiety about the return of severe psychotic symptoms are a central concern. Fear of relapse is one of the most commonly reported subjective complaints of people with psychosis, and it appears that such worries become most prominent when patients experience minor 'warning signs' of relapse (Hirsch and Jolley, 1989). From the patient's perspective such fears are understandable. For many patients the experience of acute psychosis is highly aversive and may be described retrospectively as having a terrifying and nightmarish quality (Laing, 1960; Arieti, 1974b; Wing, 1975). McGorry et al (1994) have described the incidence of the symptoms of post traumatic stress disorder (PTSD) after the first psychotic episode. Such symptoms may include flashbacks of psychotic images, or memories of the trauma associated with compulsory hospitalisation. Very severe PTSD symptoms are relatively uncommon (prevalence of around 5%) but moderate PTSD symptoms are common (prevalence of between 30% and 40%) and may persist for long periods after the acute episode has passed.

Aversive experience at times of psychotic relapse is not universal. Some people with psychosis (such as Lawrence described above) can experience pleasant feelings and even euphoria associated with psychotic experiences. However, the wider experience of periods of relapse also frequently includes additional aversive factors. These include hospital admission, the deprivation of liberty, problems in close relationships, and other severe disruptions to everyday life. These all constitute severe threats to an individual's sense of personal identity. Problems associated with risk of relapse, and the associated problem of fear of relapse, constitute highly important targets for cognitive behaviour therapy.

1.4.2 Social Disability

Of equal importance are problems associated with social disability. Behavioural disturbances and social disabilities are common problems amongst people with chronic psychotic disorder. Surveys suggest that up to 60% of patients with schizophrenic syndromes, as well as substantial minorities of people with other chronic psychotic syndromes, may show signs of moderate to severe social disability (eg Johnstone et al, 1991). These problems can include an inability to function at work, in relationships and in carrying out normal activities of daily living. The extent to which problems associated with psychotic disorder interfere with the capacity to work and to take a part in day-to-day life varies considerably both across individuals, and within individuals over time (Strauss, Carpenter and Bartko, 1974). Some

patients, like Lawrence, manage to struggle back to normality and to maintain some fulfilment from work and relationships despite continuing problems. However, others, like Erica and Derek, may report a range of difficulties in carrying out day-to-day activities, and may not be able to maintain valued social roles.

The reasons for the presence of severe social disability appear to be complex, and cannot be explained solely by the presence of psychotic experiences. Wing (1983) notes that the presence of social disability is likely to depend on at least four separate factors. These include: the presence of chronic impairments (eg cognitive–neuropsychological deficits); acute psychosis; adverse social circumstances; and attitudes to self and to recovery. This multifactorial approach to understanding usefully implies that there may be different reasons for social disability in different cases, and reflects what is often the complex nature of the social problems of different individuals. For example, with Erica it appeared that basic problems of concentration and attention (cognitive deficits) as well as problems associated with acute symptomatology (paranoia about other people) interfered with her ability to work and take on major life roles. However, in the case of Derek it appeared that, although symptomatic, it was not his psychotic symptoms which were interfering with his abilities to function at work. Instead it appeared that problems associated with lack of confidence, combined with poor abilities to form relationships with other people, were the critical factors. Such differences in the nature of the problems contributing to social disabilities imply the need for a range of different approaches to the management of social disability. Successful interventions to manage social disability probably need to be carefully tailored to the nature of the problems presented.

1.5 DIFFERENCES BETWEEN COGNITIVE BEHAVIOUR THERAPY AND EXISTING PSYCHOLOGICAL APPROACHES TO THE MANAGEMENT OF SOCIAL DISABILITY AND RISK OF RELAPSE

Considerable progress has already been made in identifying strategies which may help to prevent or manage symptomatic relapses when they occur, and to reduce the risk of social disability (see Wing, 1975; Birchwood and Tarrier, 1992). The strategies recommended in contemporary supportive and psychoeducational therapies include: providing information about the nature of psychotic disorder and the effects of neuroleptic medication; close self-monitoring of symptoms and warning signs; and the provision of advice about changing lifestyle patterns, including the use of strategic

social withdrawal, and adopting stable but active daily routines. Much of this advice is sensible and pragmatic and there is evidence that these therapies are effective (eg Hogarty et al, 1974; Stein and Test, 1980; Gunderson et al, 1984).

In targeting problems associated with relapse prevention and management and social disability the aims of cognitive behaviour therapy are similar to most existing approaches. However, there are a number of important differences in the way this therapy is conducted. First, interventions to address these problems are not carried out as a didactic package intervention, but instead they are carried out as an aspect of a psychotherapeutic approach in which the client's subjective experience of psychosis is of primary importance. Second, the specific therapeutic strategies used are carefully tailored to an individualised assessment and formulation of the problems presented. Third, it is not assumed that people will accept a traditional illness model of their problems. Within cognitive behaviour therapy it is still possible to continue to work, using the patient's own language and terms to describe their problems, even if the patient holds very strong delusional beliefs which are at odds with professional opinion. In such cases the aim is often to develop a 'good enough' set of self-regulatory strategies to manage relapse (or, using the patient's words, perhaps 'bad periods' or 'set-back'). This pragmatic approach focusing on 'doing what is possible' is characteristic of cognitive behaviour therapy. It may be best illustrated with a case example.

Cognitive behaviour therapy: a case example

We noted previously that Lawrence pointedly denied that he had a mental illness, and refused to describe his problems as schizophrenia. He would also refuse to take medication. Previous attempts to encourage him to accept that he had schizophrenia by the use of didactic psychoeducational strategies had been angrily rejected. He had become distrustful of health professionals, saying that they did not listen to him, and would not take his problems seriously. The collaborative approach of cognitive behavioural therapy offered a way of breaking this therapeutic impasse. The starting point for therapy was listening to Lawrence's point of view and gaining trust. At this stage the therapist and Lawrence 'agreed to disagree' about the nature of Lawrence's problems, but they agreed to work together, with both parties having open minds. There then followed a period of detailed assessment of Lawrence's subjective experience of psychosis, and discussion about the consequences of Lawrence's beliefs and actions. These assessments clarified that compulsory admissions and relapses tended to be preceded by Lawrence starting to act on his beliefs of a special mission, particularly when he experienced feelings of telepathic

contact and special powers. Lawrence agreed that this was the start of the 'set-back'.

Over a long period attempts were made to assist Lawrence to adopt a new way of viewing his experiences. Discussions focused on offering Lawrence different views about the nature of the psychotic experiences which provided the core of evidence for his delusional system, and discussion about the way that these beliefs had helped him to make sense of these experiences and his life in general. While attempting to address the delusions the therapist did not insist that Lawrence accepted that his problems were symptoms of schizophrenia. The process of therapy involved a lot of give and take, and willingness to discuss openly the reasons for disagreements about the nature of his problems. This type of work eventually helped Lawrence to develop an understanding of his problems that moderated the more distressing aspects of his beliefs, and provided a rationale for taking medication, but did not insist that he entirely gave up his delusional beliefs, or that he accepted that these were simply symptoms of schizophrenia. By using this strategy of working 'within' the delusional system, some progress was made in helping Lawrence to monitor his beliefs more reliably, and then to modify his behaviour at times of symptomatic relapse.

1.6 CONCLUDING REMARKS

In this chapter we have reviewed the problems of people with psychosis that constitute the targets for cognitive behaviour therapy. Cognitive behaviour therapy may play an important role in ameliorating distress and disability associated with psychotic symptoms. It can also provide a structured approach to the psychological management of a number of other salient problems presented by people with psychosis, including emotional disturbance, risk of relapse and social disability.

We believe that it is important for therapists to have a good understanding of the nature of psychosis, as well as a knowledge of practical therapy techniques. Our reading of the literature suggests that there is evidence that biological factors have an important influence on psychotic disorder and on the experience of psychotic symptoms. However, equally important is an analysis of the psychological processes which determine how individuals attempt to make sense of the subjective experience of psychosis, and how they may act to counter perceived threats which may derive from either biological or social origins. In the next five chapters we will discuss our assumptions about the nature of psychosis in more detail, and highlight their implications for the practice of cognitive behaviour therapy.