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THE IMPORTANCE OF EARLY RECOGNITION

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RATIONALE

The length of time between the onset of psychotic symptoms and the subsequent detection, diagnosis and commencement of treatment has been termed the Duration of Untreated Psychosis (DUP) and is conceptualised as a treatment lag. The average length of DUP has been found to be approximately one year (Barnes et al., 2000; Beiser et al., 1993; Hafner et al., 1994; Loebel et al., 1992; McGorry et al., 1996) (see Figure 1.1). This is a fairly robust finding and these studies have been replicated in different countries and health settings indicating that the finding is generalisable. However, these studies report the mean DUP, which may lead to overestimates. If the median DUP is examined, then this gives a lower figure of 12 weeks (Drake et al., 2000). This indicates that DUP for the majority is around three months but some statistical outliers substantially increase the mean. Therefore DUP now tends to be calculated using both the mean and the median.

A number of studies have found that a longer DUP is associated with poorer prognosis (Crow et al., 1986; Loebel et al., 1992) and one study found it to be the most important predictor of treatment response in a large group of first admission patients (Drake et al., 2000). There are concerns that the association between DUP and poor treatment response may merely represent a difference in the illness itself with longer DUP being associated with a more insidious onset and shorter DUP associated with an acute presentation. A recent review of DUP (Norman & Malla, 2001) found that there is some tentative evidence to suggest a relationship between initial response to treatment and DUP, although they found no evidence to suggest a relationship to longer-term outcomes.

However, the main clinical implication from these findings is that minimising DUP would be advantageous to the client, their family and the treatment team even if this

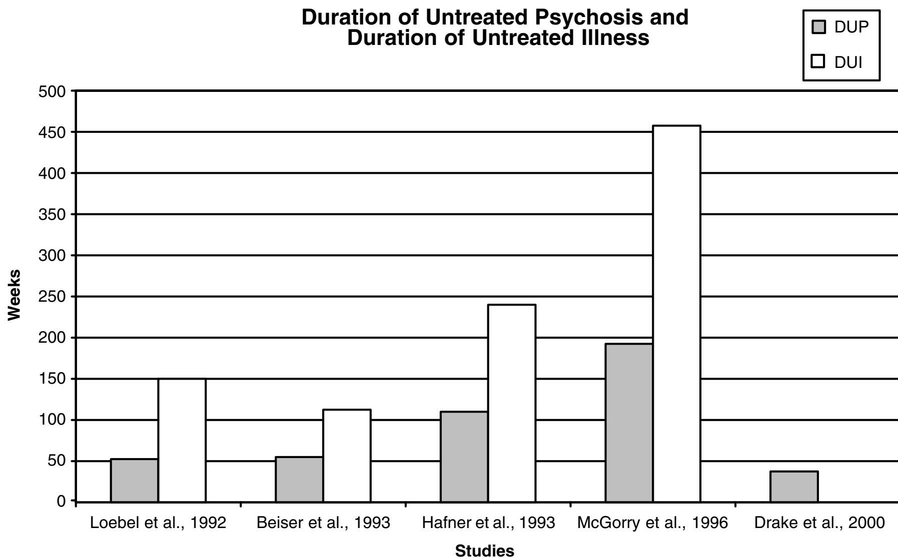

Figure 1.1 Duration of untreated psychosis and duration of untreated illness

were by a few weeks rather than months. Whatever definition is used, it is obvious that there are clear difficulties in being able to identify people who are in the early stages of psychosis, although a shorter DUP is associated with more frequent GP attendance in the six years before the onset of psychosis (Skeate et al., 2002). A recent study (Moller & Husby, 2000) interviewed people who had experienced their first psychotic episode and found that there may be factors associated with the symptoms themselves, which contribute to the DUP. In this study, two themes were found to be associated with a reluctance to disclose symptoms: one being a fear about disclosing symptoms because of what may happen; the second being that people become preoccupied with the symptoms and spend time encouraging them and engaging with them. Both fear and preoccupation can accentuate the DUP by preventing people from seeking assistance with these symptoms. However, it is not only the symptoms themselves which serve to prolong DUP. Unfortunately, as was found in the Northwick Park Study (Johnstone et al., 1986), if things are not managed in the early stages then deterioration continues until finally a crisis occurs, which frequently involves the police. This study found that people do try to access help for their symptoms, with an average of eight help-seeking contacts prior to appropriate treatment. Unfortunately, the police are often the final help-seeking contact, and it is often the police who act to initiate treatment. This will frequently involve taking the person for assessment, and this can often involve admission to hospital. These hospital admissions may be involuntary, requiring the use of the *Mental Health Act* in the UK. This whole process can be extremely traumatic for the individual, family and friends, and there is evidence

that such admissions can lead to the development of post-traumatic stress disorder (e.g. Frame & Morrison, 2001; McGorry et al., 1991).

The timing of the onset of psychotic illness is frequently within the second and third decades of a person's life. This period is when people are starting to make their way in the world, developing relationships and careers, and many people in this age range may be considering the possibilities of starting a family. However, not only can the stress and sleep disturbance involved with bringing up children play a role in the development of psychosis, but also the onset of psychosis could significantly impact upon a developing parent–child relationship. Therefore, the onset of psychosis has the potential to interfere at this crucial stage in a person's development with the ability to impact not only on the individual, but also on family and friends.

Significantly, when working with people with an established psychotic illness, many interventions are aimed at reintegrating social contacts, assisting families in understanding the nature of psychosis or getting the person back to work or college. Interestingly, in the group who are at risk but who have not yet developed florid psychotic symptoms, many of these factors are still intact. People are still engaged in college courses or work and frequently have a range of social contacts and family support. Many of these things may be in the process of breaking down, but the individual and their family are often highly motivated to prevent this from happening. This can frequently be easier than having to start from a position where the person has lost these things and their confidence and self-esteem has been affected. For the person who develops distressing psychotic symptoms and does not have access to treatment, deterioration in family and social life can occur very quickly.

Therefore, this period of untreated psychosis can significantly impact on the individual, interfering with their psychological and social development. Frequently, symptoms of isolation and social anxiety are associated with psychosis (in some cases this may be due to concerns about stigma). Traditionally, social anxiety would be considered to be a co-morbid disorder or related to negative symptoms. However, it can be conceptualised as being on a continuum, where someone can move from social anxiety (or culturally acceptable concerns about interpersonal threat) to psychosis, such as paranoia (or culturally unacceptable concerns about interpersonal threat). In the initial stages of the development of psychosis, a person may start to isolate themselves from their peer group and, over time, friends may stop calling. Symptoms of paranoia can develop and this can affect the quality of relationships to the point where they may break down, which obviously increases the loss of contact with family and friends. These relationships can be vital not only for the usual benefits associated with friends, but also as learning opportunities for understanding how to develop social skills and manage social interaction. Therefore, their loss can be extremely damaging. Increased isolation can lead the individual towards increased risk of depression and suicide. Clearly, if isolation persists over any period of time this will impact on the individual's confidence in their ability to initiate and maintain social contacts, which

can subsequently affect many aspects of their life. This can then become a secondary problem requiring treatment.

Another important area to consider at this point is how individuals may begin to cope with their emerging symptoms. Some people turn to alcohol or street drugs as a means of managing the distress they are experiencing, which can be a confounding factor. Unfortunately, most services tend to regard the drugs as being the cause of the psychosis. Therefore, they often believe that the drugs should be dealt with prior to the psychosis. It is certainly the case that drugs can induce psychotic experiences, although in our experience people frequently turn to drugs or alcohol as a means of reducing the distress or intensity of their developing psychotic symptoms (as a form of self-medication). Working with people with co-existing drug and alcohol use is, therefore, very important and the reasons for their use should be established rather than presumed.

All of these factors combine in the early stages of symptom development, conspiring to prevent early detection and treatment. However, as with many difficulties, the earlier a problem is identified and treatment is initiated, the easier it can be to treat. When symptoms are left for a long period of time they may become more resistant to treatment, and maintenance factors may become entrenched. Clearly, there are costs involved for the individual and family and an early identification approach could assist with some of these problems. Service providers and commissioners may be concerned about the costs of developing a proactive early detection and intervention service. However, they need to recognise that such a programme is likely to be cost effective (financially), as it is likely to reduce the number of people requiring admission to hospital (and such treatment is extremely expensive). Furthermore, it should be recognised that the personal and social costs of continuing with a reactive, crisis-driven approach to the recognition and management of psychosis is unacceptable (and the Department of Health guidelines (2001) suggest that this choice will no longer be an option in the UK). Working with individuals during the early stages of psychosis, in order to minimise the need for admission to hospital and coercive treatment, should be viewed positively by all concerned. However, it is important to offer a range of phase-specific interventions (Gleeson, Larsen & McGorry, 2003; Larsen, Bechdolf & Birchwood, 2003).

PREVENTION RATHER THAN CURE

The Duration of Untreated Illness (DUI) combines the initial prodromal period prior to the onset of psychosis and the DUP, with an average DUI being two years (see Figure 1.1). This indicates that there is a potential window of one year prior to the onset of psychosis during which people actively seek access to some form of help, often involving numerous unsuccessful presentations to services (Johnstone et al., 1986). Researchers in Australia have demonstrated that it is possible to identify people who

may be at this stage, in what is considered to be an ultra high-risk or prodromal group (Yung et al., 1996). In one of their studies, they found that 40% of their high-risk sample became psychotic over a period of one year (Yung et al., 1998), which clearly demonstrates a high transition rate. Further work is being undertaken to refine assessment strategies for identifying these high-risk individuals (Klosterkotter et al., 2001; Miller & McGlashan, 2000; Morrison et al., 2002) in an effort to impact further on the ability to predict the onset of psychosis.

The idea behind the early identification of psychosis as a preventative strategy is not a particularly new one (Falloon, 1992; Sullivan, 1927). However, the Kraepelinian concept of psychosis, a rather hopeless view that has predominated for many years, has meant that researchers and services have been extremely slow to embrace the early intervention paradigm. Recently, the concept of a 'critical period' has been introduced which proposes that the early stages of the illness may offer an opportunity to maximise the effectiveness of our interventions (Birchwood, Todd & Jackson, 1998). In the UK, this approach is now considered a vital component of services for people with a psychotic illness (Department of Health, 2000, 2001). However, those people charged with supplying the funding for these types of innovative services are still struggling to provide what they consider core services such as community mental health teams or inpatient facilities. Unfortunately, there appears to be little recognition that if this approach was adopted it could significantly impact upon the need for these perceived core services. An early intervention strategy should be considered as one of these core services, which could then identify people earlier and offer preventative strategies with the potential to reduce some of the burden experienced by secondary services and the risk of iatrogenic damage to clients. Despite this, there are still some people who have their reservations (for a review of the arguments see the recent debate between Pelosi & Birchwood, 2003). The potential benefits of this approach would include: improved recovery (Birchwood & Macmillan, 1993); more rapid and complete remission (Loebel et al., 1992); better attitudes to treatment and lower levels of expressed emotion/family burden (Stirling et al., 1991); and less treatment resistance.

This book describes strategies developed to identify people at high risk of developing psychosis, and psychological interventions that have been developed in an attempt to prevent the transition to psychosis. The terms 'high risk' or 'at risk' will be utilised throughout the text as opposed to 'prodrome' or 'prodromal'; this is because the term 'prodrome' emphasises a pathological, as opposed to normalising, conceptualisation of the onset of psychosis, and it also implies that people are going to become psychotic (whereas the data would suggest that this is only accurate for a substantial minority).