

Family interventions in early psychosis: specificity and effectiveness

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The first episode of psychosis frequently occurs during adolescence and early adulthood, and is associated with high levels of trauma, affective disturbance and suicide. The social networks of service users often decrease significantly following the first onset, although many will remain in close contact with some family members particularly during the early phases. However, the negative impact of psychosis on families and their relationship with the identified service user are well documented. Family intervention is a recommended and evidence-based treatment in later psychosis. In this paper, we review the literature on family interventions in early psychosis in the context of new evidence for its efficacy and its routine incorporation in early intervention services for psychosis.

Background

Schizophrenia spectrum psychoses rank among the most disabling conditions of modern times (World Health Organisation, 2001). The personal and financial costs are considerable and well documented (Knapp, Mangalore & Simon, 2004). The first episode of psychosis frequently occurs during adolescence and early adulthood with an average delay of 22 weeks to 3 years before individuals begin formal treatment (Norman & Malla, 2001; Stefan, Travis & Murray, 2002; Norman *et al.* 2004). The initial episode, including the period of untreated illness, often coincides with a time when individuals are already encountering changes in their role and peer relationships, and are negotiating transitions to independence and responsibility (Mackrell & Lavender, 2004).

A critical period – the first 5 years

For service users, the onset of psychosis is commonly associated with a broad range of feelings, including shock, confusion, fear, distress and despair. The literature suggests that the first 5 years constitute a critical period for treatment and outcomes (Birchwood, Todd & Jackson, 1998; Lieberman & Fenton, 2000). We know, for example, there are high levels of trauma, depression and anxiety in people presenting to early psychosis services (Koreen *et al.* 1993; Birchwood, Spencer & McGovern, 2000; Birchwood, 2003; Mueser

& Rosenberg, 2003; Jackson *et al.* 2004). Suicide levels are elevated in psychosis, but particularly so in the early illness years (Caldwell & Gottesman, 1990; Robinson *et al.* 2010). Aggressive behaviour is common, with recent figures suggesting that about 40% of service users engage in aggressive acts at first episode (Dean *et al.* 2006). Rates of co-morbid substance abuse disorders and problematic drug misuse are also high in first-episode groups (Green *et al.* 2004; Van Mastricht *et al.* 2004; Lambert *et al.* 2005). In contrast, adherence to prescribed pharmacological treatments is poor (Coldham, Addington & Addington, 2002). While remission from positive symptoms is often rapidly achieved following the first episode (Lieberman *et al.* 2003; Schooler *et al.* 2005), social dysfunction is a significant issue from the very early phases (Addington *et al.* 2008). Service users tend to become isolated very quickly after onset and their social contacts may become restricted to paid mental health professionals and a few close family members (Macdonald, Hayes & Baglioni, 2000; Macdonald, Sauer, Howie & Albiston 2005; Horan *et al.* 2006; Berry, Wearden & Barrowclough, 2007; Stanghellini & Ballerini, 2007).

Effects on families

A large body of literature confirms that the negative impact of psychosis extends beyond the service user; families are also adversely affected. In general, many service users maintain regular contact with their families. This is the case particularly during the early phase, when they are more likely to be living with their families of origin (Fisher *et al.* 2008). During this period, families play an active and key role in ensuring

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the care, well-being and recovery of service users. At the onset, they are often instrumental in initiating treatments and in helping the service user to engage with services and interventions (de Haan *et al.* 2002). However, the early illness phase can be a particularly challenging period for families as they struggle to make sense of the problems faced by their relative, including odd, unusual and embarrassing behaviours that may not always seem to be illness related. Carers spend a lot of time worrying about their relatives' well-being and future care (Tennakoon *et al.* 2000; Barker, Lavender & Morant, 2001). They often face uncertainty about diagnosis, prognosis and the effectiveness of specific treatments. In addition, families must also adjust quickly to their new and unexpected role as 'caregiver', for which they often feel ill equipped and unprepared (Addington & Burnett, 2004; Bergner *et al.* 2008). Carers rarely 'choose' their new role (Kuipers, 2001; Sawatzky & Fowler-Kerry, 2003). Psychosis often has a deleterious effect on the social networks of carers, rendering them isolated and lonely, with feelings of stigmatization, particularly if their relative has been involved in anti-social behaviour (MacInnes, 2000; Ferriter & Huband, 2003; Magliano *et al.* 2005). It is not surprising, therefore, that research over a 50-year period has shown that carers are negatively affected by their role, with as many as 80% reporting a sense of burden and distress (Magliano *et al.* 2002; Kuipers & Bebbington, 2005; Parabiaghi *et al.* 2007). Indeed, at least one-third of carers are clinically depressed (Dyck, Short & Vitaliano, 1999; Kuipers & Raune, 2000; Lowenstein, Butler & Ashcroft, 2010). Compared with those faced with the effects of more established illnesses, the carers of people attending early psychosis services tend to report equivalent or higher levels of distress and lower levels of positive caregiving experiences (Addington *et al.* 2003; Onwumere *et al.* 2008). Such carers often report levels of loss and grief similar to those seen in physical bereavement (Patterson, Birchwood & Cochrane, 2005). Many mourn the loss of their relationship with the service user and of their plans for the future. They report feelings of guilt and blame for various reasons, for example, feeling that they failed to help their relative soon enough, that they missed key signs and symptoms indicative of illness, and even that they played a role in causing the illness (McCann *et al.* 2009). Sadly, as part of their role, many carers experience verbal and physical aggression (Loughland *et al.* 2009). Almost 25% of homicides occur during the first episode, with close family members, particularly females, most likely to be victims (Nordstrom & Kullgren, 2003a, b; Nielszen & Large, 2010). Approximately one-third of carers report reactions indicative of post traumatic stress

disorder (PTSD) (Barton & Jackson, 2008; Loughland *et al.* 2009). We know that early psychosis carers are likely to have limited previous experience of mental health. One consequence is that carers often engage in less adaptive (avoidant) styles of coping, in themselves, associated with impact of care and poorer outcomes (Raune, Kuipers & Bebbington, 2004; Onwumere *et al.* in press). Moreover, indices of strained family relations, identified in terms of high-expressed emotion, are already present in at least 50% of first episode carers (Bachmann *et al.* 2002; Raune *et al.* 2004). In summary, service users and their families have considerable and varied needs during the early phases.

Family interventions

Given the ubiquitous negative impact of psychosis on service users and their families, and the evidence for a critical early period, international clinical guidelines recommend family-focused interventions during the early illness phases (International Clinical Practice Guidelines for Early Psychosis, 2005), as delivered by specialist early intervention teams such as the flagship services in Melbourne, Birmingham, London and Calgary. The exact format and approach varies, but evidence-based family interventions include psychoeducation, stress reduction, emotional processing, cognitive reappraisal and structured problem solving. These are designed to support family carers in their role, improve adaptive coping and minimize the risk of relapse and readmission (Falloon, Boyd & McGill, 1984; Barrowclough & Tarrier, 1992; Kuipers, Leff & Lam, 2002; Addington *et al.* 2005; Bertolote & McGorry, 2005).

Overall, the evidence for the efficacy of family interventions is strong, with more than 50 controlled trials that have assessed service user outcomes (Cuijpers, 1999; Pilling *et al.* 2002; NICE Schizophrenia Update, 2009; Pharoah *et al.* 2010, 2009). Family interventions can be cost effective (Mihalopoulos *et al.* 2004). They significantly reduce rates of readmission and relapse in service users, and improve their social functioning (Pharoah *et al.* 2010). The interventions have been linked to improved adherence with pharmacological interventions (Mari & Streiner, 1994; Pilling *et al.* 2002). In terms of carer outcomes, we also know that family interventions improve the experience of care and the commitment to the caregiving role (Berglund, Vahlne & Edman, 2003; Giron *et al.* 2010).

It is clear that family intervention is effective. However, very few of the controlled trials have involved patients in the early stages of psychosis, and results have so far been equivocal. Moreover,

where studies have been undertaken, family interventions have not been assessed independently. Thus, they have tended to be evaluated as part of an integrated approach to early intervention, making it difficult to assess the specific contribution of family intervention to service user and carer outcomes (e.g. Grawe *et al.* 2006). In a widely cited study, Linszen *et al.* (1996) examined 76 first episode families in receipt of individual psychosocial interventions. They recorded no benefits on relapse rates in families who received an additional 18 sessions of a year-long behavioural family intervention. Disappointingly, families with low expressed emotion (EE) actually became worse following the intervention. However, 5-year follow-up data indicated that family interventions reduced the length of time service users spent in hospital when compared with the standard individual interventions (Lenior, Dingemans & Linszen, 2001). In 106 families, Leavey *et al.* (2004) compared a brief, seven-session family intervention with standard care. The authors observed no differences between the two groups in readmission rates and carer satisfaction. In a study covering only male service users, Zhang *et al.* (1994) recorded positive effects of family interventions on relapse rates and social functioning over an 18-month follow-up, when compared with standard outpatient provision. Interestingly, a recent meta-analysis and systematic review demonstrated that family interventions in early psychosis significantly reduce relapse and readmission rates (Bird *et al.* 2010).

As there are still relatively few well-controlled randomized trials of family intervention in early psychosis, there is a clear need for additional studies (Askey *et al.* 2007, 2009; Alvarez-Jimenez *et al.* 2009). Further work is also required to identify the key mediators of change, and to determine the most effective format and timing of interventions. It is unclear as to whether concepts relevant to longer-term carers have similar weight in early psychosis. High EE, for example, has proved a useful framework for understanding relationships and is a robust predictor of poor functioning and relapse in longer-term groups (Bebbington & Kuipers, 1994). It has therefore been an important target for family interventions (Kuipers *et al.* 2002). However, the role and predictive qualities of EE have been less clearly established in early psychosis (Butzlaff & Hooley 1998). Recent evidence from Gleeson and colleagues suggest that following positive symptom remission, effective interventions offer a combination of individual cognitive behaviour therapy (CBT) for service users and family work for carers, and specifically target relapse prevention (Gleeson *et al.* 2009). However, there is a paucity of literature on whether interventions are more effective when offered to single families, to multiple families or to a combination.

A cognitive model of caregiving in psychosis

In our recent cognitive model of caregiving, we described the main types of caregiving relationships in psychosis and the proposed family interventions (Kuipers, Onwumere & Bebbington, 2010). In a climate of limited resources and of training and implementation difficulties with clinicians (Fadden, 2006, Kuipers, 2007), it is important that services have clear methods for identifying those in need of family interventions in early psychosis. However, evidence on how families successfully adapt following the first episode remains limited (Gleeson *et al.* 2010).

Triaged interventions?

Our clinical observations would suggest that, similar to longer-term groups, not all early psychosis families need full family intervention, particularly as we know that offering intensive interventions when they are not indicated may be harmful (Linszen *et al.* 1996). Given the range of issues they report, it seems likely that some early psychosis families might require only low-intensity interventions. These might offer clear and flexible opportunities for psychoeducation and social support. In the future, they might also use internet facilities to enhance the information provided (e.g. mentalhealthcare.org.uk – a website for carers and friends of those with psychosis; Rotondi *et al.* 2010). In contrast, intensive interventions are probably most suitable for families where there were previous as well as ongoing difficult relationships or when service users have persisting symptoms or frequent relapses or when carers have complicated grief reactions (Kuipers *et al.* 2010). We have argued that it may well be helpful to offer carers an individualized support service in their own right, as they are a seriously neglected group with needs of their own (Kuipers 2010).

Conclusions

A large number of people in need of early intervention for psychosis will still be in contact with their family of origin. These families will be caught up in the caring role. As in families dealing with longer-term illness, there will be a variable range of issues, but grief, loss and shock are likely to be salient. Not all families will need intensive support, and in fact, this may be harmful to those who have good relationships and who intuitively cope well. However, there will always be some families whose problems are not easily resolved. We argue that all families need basic support, but not all will benefit from the intensive support found helpful for longer-term groups and recommended by

schizophrenia treatment guidelines (e.g. NICE, 2009; PORT, 2009; Kreyenbuhl et al. 2010). Offering intensive intervention as part of routine care may be problematic, and is most likely to be resourced and available in early intervention teams. Family intervention in early psychosis may well be preventative, and may also improve engagement with services in the longer term (Bird et al. 2010). However, it seems unlikely that all families will need it: some may require only low-intensity intervention. Acknowledging this would ensure that the intensive form of family intervention is targeted at those who really need it.

In summary:

- (1) Psychosis can have a negative impact on service users and their families, and this is evident during the early illness phases.
- (2) We need to know more about what support is required in particular family circumstances.
- (3) It is likely that tailoring support to the individual family's needs will maximize both therapeutic benefit and the use of resources.
- (4) The rational deployment of family intervention resource is likely to form a major component of secondary prevention.

Declaration of Interest

None

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