Delivering Cognitive-Behavioural Family Interventions for Schizophrenia

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Background: In 1993, Kavanagh and colleagues outlined outcomes from a training programme designed to equip mental health practitioners to deliver evidence-based cognitive-behavioural family interventions within routine care. The authors highlighted how the training had not been able to deliver notable increases in the numbers of families being seen by the trained clinicians. There were significant issues in the translation and provision of family interventions within clinical settings, specifically difficulties with the integration of family interventions and caseload demands, and insufficient time within job plans and service settings to undertake the work. The authors posed the question: what can the matter be? Interestingly, the same question was being asked over a decade later.

Objective: The current article provides a narrative review of the issues on implementation of family interventions in psychosis.

Results: Current evidence suggests that while there exist pockets of good practice and provision for family interventions, it was a mistake to assume that care coordinators would be able to include these family interventions as part of their role, effectively to add duties without significant modification to their current roles and duties. It also seems to have been an underestimate of the skills required for delivering family work in psychosis and the ongoing requirements for high-quality supervision.

Conclusion: We argue for carer specialists to be involved in mental health teams, particularly early intervention teams, and for a triage system to offer families a range of evidence-based support, as well as family interventions for more complex problems and presentations.

Key words caregivers; family interventions; implementation; psychosis; schizophrenia.

What is already known on this topic

1 Informal caregiving relationships can facilitate better service user outcomes.
2 Family interventions for psychosis have a strong and long evidence base and are recommended treatments in several countries.
3 Family interventions are acceptable interventions to service users and carers.

What this paper adds

1 In different countries, difficulties with service implementation and provision of family interventions have persisted for the last two decades.
2 Innovative service models utilising a triage approach and targeting specific needs and presentations seem to have value.
3 Raising the expertise of all levels of the workforce, and providing good-quality training and supervision for formal family and carer interventions are required. The need for greater evaluation of their impact remains.

Introduction

Schizophrenia affects more than 21 million people worldwide (World Health Organization, 2015) and has long been identified...
as a globally burdensome condition (Rossler, Salize, van Os, & Riecher-Rossler, 2005; Whiteford et al., 2013). The high social and economic costs linked to schizophrenia spectrum disorders (psychosis), particularly those considered treatment-resistant, are widely reported (Kennedy, Altar, Taylor, De吉tar, & Hornberger, 2014). For example, approximate annual treatment costs across Europe and America are estimated at 29–100 billion dollars (Eaton et al., 2008; Gustavsson et al., 2011; Kennedy et al., 2014; Wu, Shi, Birnbaum, Hudson, & Kessler, 2006). Epidemiological data confirm that psychosis conditions can affect anyone, with their first onset typically observed during late adolescence and early adulthood. The common symptoms of hallucinations, delusions, and thought disorder, along with marked disturbances in social functioning, affect, and cognition, can often mean it will be a long-term condition with fluctuating periods of remission and relapse during recovery (Cooke, 2014).

There are high levels of psychiatric and physical health comorbidity in psychosis. We know, for example, that rates of suicide and substance misuse are often elevated in people with psychosis (Hartz et al., 2014). Emotional dysfunction, including depression, anxiety, and traumatic stress (Freeman & Garety, 2003; Krabbendam & van Os, 2005; Smith et al., 2006), and a history of bullying and victimisation experiences can be common (Catone et al., 2015). Mortality rates and general physical health outcomes are significantly poorer in psychosis, with individuals dying approximately 15–20 years earlier than the general population (Moore, Shiers, Daly, Mitchell, & Gaughran, 2015). People living with psychosis experience high levels of stigma, unemployment, and social isolation, even at first episode (Harley, Boardman, & Craig, 2012; Pescosolido et al., 2010; Sundermann, Onwumere, Bebbington, & Kuipers, 2013).

In the last 50 years, the care and treatment of service users with psychosis have witnessed a transfer from institutional-based care to community-based provision, where families and close relatives have taken on a significant role in treatment and recovery plans (Chan, 2011). Service users with informal caregiving relationships compared to those without can report better health outcomes, including self-reported levels of quality of life (Stowkowy, Addington, Liu, Hollowell, & Addington, 2012). In addition, informal caregiving relationships can reduce the need for and length of inpatient admissions (Norman et al., 2005). Carers will often play an important role in securing access to, and receipt of, relevant services particularly during the initial illness phases and at relapse (Bergner et al., 2008; Fridgen et al., 2013; Herts, 2000). Recent evidence taken from 10-year follow-up data of first-episode psychosis service users suggests that mortality rates are much improved for those with informal carers. Cases of unnatural death in service users with psychosis were reduced by 90% in those with input from their families on initial contact with services (Revier et al., 2015).

**Caregiving Experiences**

Although carers can positively input into service user outcome, there is a strong body of evidence illustrating the impact of caregiving and the service needs they can generate. Carers can spend the equivalent of a full-time job in caregiving activities and provide high levels of unpaid care (Flyckt, Lothman, Jorgensen, Rylander, & Koernig, 2013). The financial burden experienced by carers of people with psychosis is well documented (Goboth, Witt, Villa, & O’Gorman, 2015), with their economic value estimated at 1.24 billion per annum (The Schizophrenia Commission, 2012). Carers in employment can lose approximately 12.5 working days each year to undertake care-related duties, and a smaller proportion will permanently relinquish their paid role to carer for their relative (Mangalore & Knapp, 2007).

The rates of common mental disorders are raised in people in informal caregiving roles, once they provide 10 hr of care or more each week (Smith et al., 2014). Data spanning several decades confirm that caregiving in psychosis can be particularly stressful and burdensome (Boydel et al., 2014; Flyckt et al., 2013), with approximately 40% of carers reporting depression and emotional dysfunction (Dyck, Short, & Vitaliano, 1999; Hayes, Hawthorne, Farhall, O’Hanlon, & Harvey, 2015; Kuipers & Raune, 2000). The levels of psychological distress can show elevations during the initial illness phase and periods of inpatient admission, particularly compulsory detentions (Addington, Coldham, Jones, Ko, & Addington, 2003; Boydell et al., 2014; Boye & Malt, 2002; Jansen et al., 2015; Weller, Faulkner, Doyle, Daniel, & Goldston, 2015).

Carers also report feelings of burnout and emotional exhaustion, at equivalent levels to those reported by paid psychiatric staff (Angermeyer, Büll, Bernert, Dietrich, & Köpf, 2006). Reports of burden can also be found among carers in the early illness phase (Onwumere et al., 2015). Reports of loss and grief are often high in psychosis carers and not dissimilar to levels reported by those following bereavement (Lowenstein, Butler, & Ashcroft, 2010; McCann, Lubman, & Clark, 2011; Mulligan, Sellwood, Reid, Riddell, & Andy, 2013; Patterson, Birchwood, & Cochrane, 2005). As part of their role, many carers will be faced with difficult and problematic behaviours from their relatives, which may include violence (Onwumere, Hunter, & Kuipers, 2014), delusional and persecutory beliefs (Onwumere et al., 2008a), and negative symptoms (Dyck et al., 1999; Ukpong, 2006). The quality of life among psychosis carers can be poor (Hayes et al., 2015; Panigrahi, Acharya, Patel, & Chandrani, 2014; Zauszniewski, Bokchet, & Suresky, 2008), with over half reporting financial concerns (de Silva & de Silva, 2001). As a group, carers themselves can be isolated; recent figures suggest carers are nearly 10 times more likely to be isolated compared with matched non-caring samples (Hayes et al., 2015). They will also report poorer levels of social support compared with carers of other severe health conditions, such as brain injury (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006). Greater levels of social isolation in carers are linked to higher levels of distress and burden (Magliano et al., 2002). The difficult aspects of the caregiving role are universal and recorded in carer groups from all continents (Awad & Voruganti, 2008; Igerase, Morakinyo, Lawani, James, & Omoaregba, 2012; Ostman & Hansson, 2004; Svettini et al., 2015; Tang, Leung, & Lam, 2008).

These problems can have an impact on relationships. Informal caregiving relationships characterised by high levels of caregiver criticism, and/or hostility, and/or emotional over involvement, commonly described as high expressed emotion (EE), are predictive of a greater number of service user relapses and hospital admissions. In high EE households, relapse rates can run at
50%, which is more than twice the level recorded in low EE households (21%; Bebbington & Kuipers, 1994). Carer criticism has been proven to be the most predictive of relapse even after several years (Cechnicki, Bielanska, Hanuszkiewicz, & Daren, 2013), and is particularly linked to attributions that their relative is in some ways responsible for their difficulties and able to control their symptoms and behaviour, if they wanted to (Barrowclough & Hooley, 2003).

There is also a growing body of research effort focused on positive family processes and their implications for illness course and outcomes in psychosis (González-Pinto et al., 2011; Ierago et al., 2010; O’Brien et al., 2006; Tienari et al., 2004). In parallel to the negative aspects, we know that carers can also report positive aspects of the caregiving role and satisfaction (Bauer, Koepke, Sterzinger, & Spiessl, 2012; Hsiao & Tsai, 2014; Kulhara, Kate, Grover, & Nehra, 2012; Lavis et al., 2015). The evidence is clear that positive family interactions, such as reports and expression of care warmth, reduce relapse risk in individuals with psychosis (Bebbington & Kuipers, 1994; Lee, Barrowclough, & Lobban, 2014), including those considered at particularly high risk of relapse (Bertrand et al., 1992). The pattern of evidence suggests that carer reports of positive experience are linked to having supportive networks, being optimistic and hopeful about treatment outcomes, and having better meta-cognitive capacity (Boydell et al., 2014; Jansen et al., 2015; Onwumere et al., 2008).

Family Interventions—The Evidence Base

The large differences in relapse rates between low/high EE households, a greater understanding of caregiving experiences, and the interrelationships between family functioning and patient outcomes initially drove the development of evidence-based family interventions for psychosis (Flp). The interventions comprise key strategies including tailored information giving (psychoeducation), emotional and stress management, and improving positive communication and problem-solving skills. Although their formats and delivery modes differ, they share common underlying principles, namely the stress vulnerability framework for the ontogeny, maintenance, and exacerbation of psychosis (Barrowclough & Tarrier, 1992; Falloon, Boyd, & McGill, 1984; Kuipers, Leff & Lam, 2002; McFarlane et al., 1995). Treatment recommendations for family interventions have been included in schizophrenia treatment guidelines for more than a decade (e.g., Gaebel, Weinmann, Sartorius, Rutz, & McIntyre, 2005; Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2010; National Institute for Health and Care Excellence [NICE], 2003, 2009). The recent UK NICE (2014) psychosis and schizophrenia guidelines recommend that family interventions should be offered to families of service users with psychosis who are living with (or in close contact1), and include a minimum of 10 sessions over a 3- to 12-month period (NICE, 2014).

The evidence base detailing the efficacy and effectiveness for family interventions is well established and has been reviewed extensively (e.g., Bird et al., 2010; Pfammatter, Junghan, & Brenner, 2006; Pilling et al., 2002; Onwumere, Bebbington, & Kuipers, 2011). A Cochrane review of studies conducted worldwide confirm that family interventions can significantly reduce levels of relapse, hospital admissions, and high EE, and lead to measurable improvements in patient social functioning and treatment engagement (Pharoah, Mari, Rathbone, & Wong, 2010). The authors reported a fixed effects odds ratio of 0.55 for the interventions to reduce relapse at 12 months compared with standard treatment. The positive effects of the intervention can be enduring (Sellwood, Wittkowski, Tarrier, & Barrowclough, 2007), with recent data suggesting efficacy 14 years post-intervention (Ran, Chan, Ng, Guo, & Xiang, 2015). Interventions have proven efficacy during the early illness phases (e.g., Bird et al., 2010; Gleeson et al., 2010). Recent data have also offered encouraging data about the benefits of family interventions for at-risk psychosis groups (O’Brien et al., 2014). There are very early indications that brief interventions (five sessions or less) might confer some positive benefits for improving family understanding about psychosis (Okpokoro, Adams, & Sampson, 2014). Although it has not attracted as much focus as patient outcomes, the reported benefits of family interventions to carers have included significant decreases in reports of care burden and increased positivity about caregiving and willingness to continue (Berglund, Vahline, & Edman, 2003; Devaramane, Pai, & Vella, 2011; Lobban et al., 2013; Polo-Lopez, Salaberría, & Echeburua, 2015; Yesufu-Udechuku et al., 2015).

Family interventions have proven effective in real-world clinical services (Kelly & Newsstead, 2004; Ruggeri et al., 2015). Economic analysis confirm they are cost-effective (Christensen, Crane, Bell, Beer, & Hillin, 2014; Mihaiopoulous, Magnus, Carter, & Vos, 2004) and acceptable to families (Budd & Hughes, 1997; Nilsen, Frich, Friis, Norheim, & Rossberg, 2014; Stanbridge, Burbach, Lucas, & Carter, 2003). The perceived benefits, as reported by service user and carers, have included improved communication between family members and problem-solving skills (Nilsen et al., 2014).

The impressive evidence from many of the earlier intervention trials steered the initiative to support and train many frontline psychiatric staff (e.g., community psychiatric nurses) in psychosocial, including family-based, interventions (e.g., Bradshaw, Lovell, & Richards, 2000). Key questions relate to what degree training initiatives have transformed service provision of Flp.

Family Interventions, So What Is the Matter?

Access to evidence-based health interventions are problematic and are poorer for people with psychosis (Rowlands, 2004). Accumulating evidence confirms the surprisingly disappointing application, implementation, and provision of family interventions across the globe, despite the rhetoric about the need for and benefits of the intervention (Dixon, 1999; Fadden, 2009; Glynn, 2012; Krupnik, Pilling, Killaspy, & Dalton, 2005; Kuipers, 2010; Pytys, Garety, Jolley, Onwumere, & Craig, 2011). If we look at data from the UK, where much has been written about the practice of Flp (published at least two of the evidence-based manuals, and has been included as first line in national treatment guidance since the early 2000s; NICE, 2003), data suggest only 1.6% of those eligible are offered Flp and 1.1% received it (Haddock et al., 2014). This was the case despite records confirming that at least 44% of staff had been given training to deliver the therapy (Haddock et al., 2013, as
Delivering Family Interventions: Workforce and Organisational Issues

Much has been written on the development of family work training programmes, delivered at undergraduate and postgraduate levels with individual clinicians or whole clinical teams, to support the acquisition of specialist skills to work with families (Brooker et al., 1994; Burbach & Stanbridge, 2006; Fadden, 2006; Fadden & Heelis, 2011; Lancashire et al., 1997).

In a review of studies reporting on implementation rates of FIP post-training in the UK and Australia, implementation rates ranged from 1.4 families, as reported in Kavanagh et al. (1993), to 3.5 families in Bailey, Burbach, and Lea (2003; Mairs & Bradshaw, 2005). The pattern emerged that a greater proportion of families tended to be seen by a small subgroup of practitioners. For example, in the Kavanagh et al. study, 13% of the staff were recorded as having worked with 60% of the families. Likewise, Fadden (1997) reported that 8% of their sample provided family work for 40% of cases. The largest provision was reported by Burbach and Stanbridge (2006), where the picture is arguably more complicated, since the revisions and protected time. If we apply similar principles to FIP, where the picture is arguably more complicated, since the interventions often rely on having two staff members and out of hours work to support the attendance of family members, it could be argued that poor implementation post-training is attributable to laudable, but overambitious goals from service providers.

Delivering Family Interventions: Exploring New Ways of Working

New developments in the UK that have sought to redress the issue of poor access to FIP have responded to some of the aforementioned issues in their service models. Thus, as part of the new Increasing Access to Psychological Therapy for Severe Mental Health Illness (IAPT-SMI, http://www.iapt.nhs.uk/smi-), family interventions are delivered by clinicians trained at the expert level, receiving regular high-level supervision, but recruited to and working in dedicated therapy posts. The preliminary findings suggest much more promising results in significantly increasing access (http://www.iapt.nhs.uk/silo/files/slam--24-months-outcome-update.pdf).
It is increasingly argued that not all families will need, or indeed want, the full standalone FIp (Cohen et al., 2008; Kuipers, 2010; Onwumere et al., 2011). This may be due to a variety of reasons, including a perception by the family of the relevance of FIp to their own circumstances and needs, how well the family are managing at the time the therapy offer is made, and the extent to which the service user and/or carer wish to engage with offers of treatment. Further, there will be families where, typically, the service user is not at the stage where he/she is able to countenance a need for health professional support and treatment, despite his/her family being in need of support and willing to engage (Nilsen et al., 2015).

Cohen et al. (2008) have focused on triaging interventions and delivering the least intensive type of family work necessary to support families and help them feel less distressed. Consequently, only a small proportion require the full, multi-component family interventions, which form the basis of the evidence-based manuals (e.g., Kuipers et al., 2002), and require therapists trained to expert levels. Outside of the full family interventions, families and carers can benefit from less intensive, brief, and more targeted interventions, such as developing a relapse prevention plan or psychoeducation about psychosis. These brief interventions lend themselves to delivery by frontline mental health staff and are less dependent upon role and/or service redesign to undertake the work (Roddy, Onwumere, & Kuipers, 2014). Pilot data from a recent family work service initiative in South London, UK, offered a stepped care approach to working with families with encouraging results (Grice, 2014). The service was predicated on a family inclusive approach. It was based on a system of triaging brief and longer forms of family and carer only supportive interventions. The approach actively enabled the more highly trained staff to focus on delivering Fip, and those in coordination roles to deliver brief, standalone interventions; the latter still required agreement for dedicated and protected time to undertake the work and access supervision (Grice, 2014).

Digital and technological interventions are gradually playing a significant role in mental healthcare provision, including for families (e.g., www.mentalhealthcare.org.uk; http://www.futurelearn.com/courses/caring-psychosis-schizophrenia). They may offer far more cost- and time-efficient approaches to meeting the needs of service users with psychosis and their families and improve accessibility. We have seen recent developments, including early indications of positive impact, from online provision of family work (Glynn, Randolph, Garrick, & Lui, 2010; Rotondi et al., 2010) and carer education (Haley et al., 2011). Similarly, the benefits of family-led and peer-supported interventions are also attracting attention (Duckworth & Halpern, 2014).

Conclusions
Family interventions in psychosis were described nearly 20 years ago as effective but underused interventions (Anderson & Adams, 1996). Thus, we know it works, we know it is acceptable to service users and families, and we also know, as seen with other psychological therapies in psychosis, that the provision of FIp remains lower than one would expect given the prevalence rates for psychosis (e.g., Haddock et al., 2014). Successful implementation does not seem to be dependent only on offering and expanding training initiatives; evidence dating back almost 25 years shows this clearly. More work is required on the formal evaluation, including the economic value, of new service models. Proposals for promoting time-efficient and cost-effective access to family interventions and delivering good outcomes are far from novel (e.g., Cohen et al., 2008). At the very least, we suggest that each psychosis mental health team should have access to at least one specialist therapist. This would be a highly trained, well supervised and dedicated therapist who delivered full FIp (within their job description), in combination with other therapists. The therapist could lead in supporting the main workforce or less specifically skilled workers to deliver discrete evidence-based interventions to all carers. In turn, more families would be able to access these evidence-based interventions, and outcomes would be improved, for both service users and carers of those with psychosis (Table 1).

Despite the deleterious effect of psychosis on social networks, many service users with psychosis will live with or maintain regular contact with informal carers, particularly in the early years following first onset. Informal caregiving relationships can optimise service user outcomes and support the work of mental health services. Supporting the specific needs of service users and their families remains an important priority for healthcare providers. Identifying the most time-efficient and cost-effective strategies for the workforce to deliver the range of evidence-based interventions to both service users and their families, and carers on their own, requires more than simply training more practitioners. Skills to deliver FIp need to be part of job descriptions and role expectations, and supported by structures that allow long-term access to high-quality supervision.

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Note
1. Although no specific criterion was offered, evidence in support of 10 hr per week or greater caring contact being indicative of a greater level of strain for carers has been reported in general caring population studies (e.g., Smith et al., 2014).
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