What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals

Ryan Askey, a Janet Holmshaw, b Catherine Gamble c and Richard Gray d

Introduction

The development of anti-psychotic medications and deinstitutionalization has shifted the primary focus of mental health treatment from hospital to the community. As a consequence, carers have become an integral part of the care system (Thornicroft and Tansella, 2005). Historically, interventions for families with people with psychosis have tended to focus on service user outcomes that attempt to reduce or prevent relapse (Askey et al., 2007). As a consequence, carers often feel ignored or marginalized by services (Shepherd et al., 1995; Beck and Minghella, 1998; Henwood, 1998). This problem has recently been recognized, and it has been highlighted that there is a need for more involvement with carers of clients with mental illness (DoH, 1999). However, there continues to be a lack of knowledge about carers’ needs and how professionals specifically meet carers’ needs (Chambers et al., 2001). This article presents the results of a study aimed at exploring the views and experiences of carers, service users and professionals with regard to what carers of people with psychosis need from mental health services. It will initially review the literature on carer burden and needs, as well as interventions such as family intervention and carers’ assessments/care plans which have been developed to address carer needs.

a High Intensity Worker, Haringey Teaching Primary Care Trust Improving Access to Psychological Therapies (IAPT), London. Email: ringo.askey@hotmail.co.uk.
b Senior Lecturer, Middlesex University, UK.
c Nurse Consultant, South West London and St George’s Mental Health Trust, Springfield Hospital, London, UK.
d Professor of Research and Deputy Associate Dean for Research, Faculty of Health, School of Nursing and Midwifery, University of East Anglia, UK.

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Carer burden

The concept of carer burden was defined by Platt (1985) as the presence of problems, difficulties or negative events that influence the life of a family member when taking care of the client. Factors affecting burden include a number of client illness variables, such as severity of symptoms, length of hospitalization, number of previous hospitalizations and length of illness (Dyck et al., 1999). Other factors such as carers’ causal attributions have also been linked to increased carer burden and relapse for service users (Weiner, 1980). For example, if carers perceived service users’ negative symptoms as being controllable and were highly critical and hostile towards them, there was a higher chance of relapse (Barrowclough et al., 1994).

It is estimated that up to 1.5 million people in the UK may be caring for a service user with a mental illness (Maher and Green, 2002). Fifty-seven per cent of carers of service users with psychosis living within an inner city have regular contact with their relative, and 33 per cent of carers actually live in the same household (Garety and Rigg, 2001). Unless the amount of care provided by statutory services increases substantially, it is likely that there will be greater pressure for support to be provided by carers (Maher and Green, 2002). This pressure is increased by the growing incidence of psychosis within inner cities. The reported incidence has doubled since 1970 with rates of 40 per 100,000 (Boydell et al., 2003).

The effects on carer burden with a relative affected by psychosis have been reviewed extensively since mental health services have become more community focused. Such burden frequently results in psychosocial distress, reduced quality of life, and significant impacts on the health and functioning of the caregiver (Hoenig and Hamilton, 1966; Fadden et al., 1987; Maurin and Boyd, 1990). A better understanding of carer burden can contribute towards mental health services improving practice to meet carer needs (Lowyck et al., 2004). Carer burden has been considered in terms of objective and subjective factors (Fadden et al., 1987; Schene et al., 1994; Magliano et al., 1998). Objective burden refers to the client’s behaviour and the respective consequences on carers’ financial, health and leisure activities. Subjective burden refers to the psychological reactions faced by carers such as feelings of loss, anxiety and embarrassment. Higher levels of objective and subjective burden have also been found to be associated with high expressed emotion, which in turn increases the risk of relapse in psychosis (Kavanagh, 1992).
The relationship between mental health services and carers can be uneasy, with relatives often expressing criticism of the relationship with health professionals (MacInnes, 1998). Cohen and Thomas (1996) reported that families receive too little information from mental health services about psychosis, which increases carers’ sense of burden and distress. There has been a call for an improvement in the level and quality of information that carers receive from professionals (Pryjmachuk, 1996).

Carer needs

It is recommended that professionals become more proactive in assessing and meeting the emotional needs of carers (Chambers et al., 2001). Factors that have been found to increase carer burden are perceived lack of information and skills, and lack of emotional support, respite breaks and financial support (Chambers et al., 2001; Rose, 1999, Schneider et al., 1999).

A key tension between carers, service users and professionals seems to be around sharing information and confidentiality. Carers often feel marginalized by professionals, despite government initiatives that recognize the importance of the caring role. Evidence suggests that details of treatments, symptoms and long-term care are frequently not shared with them (Simpson, 1999; Pinfold et al., 2004; Repper et al., 2005). A recent survey suggests that carers feel confidentiality is used as a reason for professionals not to share information (Rethink, 2003). However, carers may also be reluctant to share information with professionals in fear of breaking family loyalty, the reprisals of close relations, and hospital admissions of their relative (Rapaport, 2002). Pinfold et al. (2004) carried out a substantive study to understand more about information sharing between professionals and carers of service users with psychosis in an attempt to improve good practice. Carers often felt disappointed by the attitude of professionals and the support services provided. They also describe feeling that professionals did not take them seriously and viewed them negatively.

A number of studies have highlighted that carers recall feeling despair and being unclear about what was happening to their relative in the early stages of psychosis, and being unsure what to do or who to turn to for support. As time went on, the carers reported that professionals did not recognize their role as the main source of support (Addington et al., 2001; Repper et al., 2005).
Family interventions

During the late 1960s and early 1970s, investigations were made as to whether family atmospheres could influence the course of illness in schizophrenia. It was found that service users living with relatives who displayed high levels of criticism, hostility or over-involvement relapsed more than service users whose families were less expressive of their emotions. These behaviours were named ‘High Expressed Emotion’ (High EE) (Brown et al., 1972). Expressed emotion does not tell us much about the causes of schizophrenia, but it can be a predictor of its course when someone with the illness lives with relatives. Low Expressed Emotion (Low EE) relatives tend to display higher levels of warmth and higher level positive coping strategies (Kuipers et al., 2002).

These early generation findings led to the development of Family Intervention (FI) approaches to reduce relapses. They aimed to increase service users’ social functioning, to reduce family burden, and to improve quality of life of service users and their relatives. FI is based on a broad psychoeducational and cognitive behavioural therapy (CBT) approach (Midence, 2006). It is acknowledged that educating families about the illness alone does not reduce levels of EE in families with High EE (Kuipers et al., 2002). However, working with them to tackle practical problems such as improving communication, effectively developing coping skills and helping families to attribute the symptoms to illness can decrease their critical or over-involved behaviours. These interventions can reduce relapses for this population (Kuipers et al., 2002). As awareness and knowledge increase, tension and stress throughout the family decrease, improving the quality of life for all concerned (Barrowclough and Tarrier, 1997). The reduction in families’ ambient and chronic stress levels and a reduction of face-to-face contact to fewer than thirty-five hours per week can enable the service user to cope better with unavoidable stressors and reduces their risk of relapse (Falloon et al., 1984).

The published results of early FI studies are unequivocal in demonstrating superiority over medication alone in preventing relapses (Goldstein et al., 1978; Falloon et al., 1982; Leff et al., 1982; Hogarty et al., 1986). The studies demonstrate that relapse rates can be reduced by 20 per cent if families receive FI (Addington and Burnett, 2004). However, Pharoah et al. (2003) suggest that there is insufficient data to definitively state that FIs are any more efficacious over standard care. They also note difficulties in assessing the efficacy
of FI. Within their meta-analysis, after reviewing twelve studies that were conducted in Europe, Asia and North America they found comparability and replication difficult due to the varying treatment models used. They concluded that it is unclear if the positive effect of FI may be facilitated by a change in the frequency or quality of contact between service users and mental health professionals in general. Results indicated that family intervention might reduce the risk of relapse and improve concordance with medication. However, data were often inadequately reported. As this package of care is widely employed they suggest that further studies be conducted to properly clarify several of the short-term and long-term outcomes.

Carer support services

The government now recognizes that carers have needs in their own right and has therefore set out a number of policies and legislative frameworks in an attempt to identify and meet their needs. Under the Carers (Recognition and Services) Act (1995) carers gained the right to a separate assessment of their own needs (DoH, 1995). The Carers and Disabled Children Act (2000) indicates that carers have the right to assessment even if their relative refuses to be assessed or accept services (DoH, 2000a). Standard six of the National Service Framework for Mental Health (1999) focuses on carers of service users who have mental health issues. It states that people providing regular care for a service user under the Care Programme Approach should have an assessment of their caring, physical and mental health needs repeated on an annual basis (DoH, 1999). The government suggests that these policies and legislation have improved resources for carers’ support by £5 million (DoH, 2004). The NHS Plan (DoH, 2000b) set out a national target of employing 700 carers’ support workers before 2005, but this has not been fully implemented (DoH, 2004). It is also recognized that further research is needed to evaluate the benefits of carers’ breaks, support, education and training programmes (DoH, 2004). An important contribution to further understanding in this area is Mottaghipour and Bickerton’s (2005) ‘pyramid of family care’, which explores the provision of different levels of intervention to meet families’ needs. It is a useful framework in guiding professionals in involving families in their everyday practice. The pyramid outlines a minimum level of care for families and in hierarchical order builds on higher levels of care to specialist family interventions.

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It is estimated that carers save the government £57 billion a year, which is the cost of providing equivalent professional care; however, it has been highlighted that they are getting little return for their investment. Despite the recent policy changes, carers have argued that the progress in investment is too slow, with many still unaware of their rights, and some suggest there has been no positive change at all (Carers UK, 2003).

Training and supervision needs

A major theme from the literature is that FI trained staff feel frustrated that they could not systematically deliver FI due to reasons such as high caseloads, time pressures, lack of clinical supervision and minimal support from management (Kavanagh et al., 1993; Brennan and Gamble, 1997; Fadden, 1997, 2006; Mairs and Bradshaw, 2005). Moreover, it is also known that pre-qualification training for most professionals provides them with little or no contact with carers (Winefield and Burnett, 1996), and thus little opportunity for development of skills and expertise in this area, and many professionals are overwhelmed by the prospect of having to work with families (Goldstein and Miklowitz, 1994).

Evidence suggests that the rates of FI following completion of training courses are significantly low (Baguley et al., 2000; Bailey et al., 2003; Brooker et al., 2003; Mairs and Bradshaw, 2005). Mairs and Bradshaw (2005) reviewed six studies that investigated rates of FI being implemented following training courses. They found that following training, the mean number of families seen for a minimum of three sessions ranged from 1.4 (Kavanagh et al., 1993) to 3.5 (Bailey et al., 2003) per co-worker. This is also worrying as, in accordance with the NICE guidelines FI should be of at least six months in duration, with ten planned sessions, using two co-workers for significant change to take place (National Institute of Clinical Excellence, 2002).

In establishing FI services, the innovative Somerset service (Burbach and Stanbridge, 1998, 2006; Stanbridge et al., 2003) found that training is more likely to change practice if it is accompanied by backing and encouragement by management at all levels, with a formal strategy and a lead person to move it forward. Workplace issues also need to be addressed; for example, team managers must ensure that staff have manageable workloads and sufficient supervision (Stanbridge and Burbach, 2007). They found that in-house team-based training and ongoing supervision enabled the necessary
changes in culture and practice for service development (Quarry and Burbach, 1998; Burbach et al., 2002).

**Study aims**

Despite a considerable body of research involving carers, families continue to report that their needs are not being understood and met by mental health services (Repper et al., 2005). Although studies have provided important information about factors that affect carers, they have largely failed to provide professionals with a deeper understanding of how carers themselves experience the situation. This article presents findings from a qualitative research study comprising focus group discussions and interviews with carers, service users and mental health professionals. The aim of the study was to gain a broader understanding of the needs of carers of people with psychosis.

**Methodology**

A qualitative approach, using focus group discussions and individual interviews, was adopted for this study. The rationale for using this approach is that while there have been a number of randomized controlled trials (RCTs) of FI for people with psychosis there are still unanswered questions as to what a carer needs. The intention of qualitative research tends to be on the understanding of meaning embedded in participants’ experiences through open-ended, unstructured and subjective approaches (Lincoln and Guba, 1985). The present study sought to explore these experiences with the aim of developing a richer understanding of carer needs.

Qualitative approaches have provided important insights into participants’ experiences in similar areas. Notably, Stern et al.’s (1999) investigation of carers’ accounts of serious mental illness in a family member explored semi-structured interviews using a narrative analysis to uncover how carers make sense of their experiences by constructing life stories. Common themes were evident in carers’ stories and two types of narrative were identified: stories of reconstruction where experiences of their relative’s illness were transformed into meaningful phenomena; and stories of disruption where the illness was experienced as a series of random events. Such findings have considerable potential for aiding our understanding of carers’ experiences and for informing therapeutic work with carers, for example, around coping strategies, and also for FI.
A total of fifty-six participants took part in the study. All were recruited within two London NHS Trusts by advertising within the local mental health services and support groups. Ethical approval for this study was obtained from the relevant NHS Research Ethics Committees for the two Trusts and permissions gained from the Research and Development Committees of each of the Trusts. Informed consent was gained from all participants before taking part in the focus groups and interviews.

Six focus group discussions were held: three for carers, two for professionals and one for service users. These were supplemented by individual interviews with service users and carers who had expressed an interest in taking part in the study but who were not able to attend the focus groups. The inclusion criteria for the three groups of participants were as follows:

- **Carers**: self-defined carer of someone with psychosis currently in contact with local mental health services.
- **Service users**: people with a diagnosis of psychosis (aged 18–64) currently in contact with local mental health services.
- **Professionals**: members of different mental health professional groups currently working with people with psychosis in local mental health services.

A total of twenty-two carers took part in the study (fourteen in the carer focus groups and a further seven were interviewed). Their ages ranged from 35–67 (mean 51 years, std dev 9.3 years); sixteen were women; ten were currently living with the person with psychosis; and their length of time in this carer role ranged from one to twenty years (mean 7.6 years, std dev 6.3 years). Thirteen carers identified their ethnic group as white (nine as British, two as Irish, two as ‘Other’); three carers identified themselves as black (two as Caribbean, one as African); three as Asian (Indian, Bangladeshi and mixed), and there were missing data for three carers.

Twelve service users participated (five in focus group discussion and seven in interviews). Their ages ranged from 24–48 (mean 32 years, std dev 7.7); half were women; five were living with a carer; and their length of time in contact with mental health services ranged from one to thirty-two years (mean 7 years, std dev 6.1 years). Four service users identified their ethnic group as white (two as British, two as ‘Other’); three identified themselves as black (one as Caribbean, one as African, one as ‘Other’); two as Asian (Pakistani and Bangladeshi).
two as ‘mixed white and black Caribbean’ and one as ‘mixed white and black Asian’.

Of the twenty-two professionals who took part in the focus groups, all were qualified; fifteen were nurses and the rest were made up of roughly equal numbers of occupational therapists, social workers and psychologists. Nineteen worked full time; sixteen were women; and their length of time working in mental health services ranged from one to twenty-two years (mean 7 years, std dev 6.1). Fourteen professional participants identified their ethnic group as white (thirteen as British, one as Irish); six identified themselves as black (five as African and one as Caribbean); one as Asian, and there were missing data for one professional.

The focus group discussions lasted for about one-and-a-half hours. Participants in the focus groups were asked to generate statements focusing on the needs of carers of people with psychosis. These statements were written on a flip chart during the course of the discussion, and towards the end of the focus group the statements were reviewed with participants to ensure an accurate record of the discussion and whether there were any other key points they wanted to add. The individual interviews lasted for about thirty minutes and focused on the same question of carers’ needs. Notes were taken during the interviews and again these were checked by the interviewees at the end of the interviews.

The main challenges to qualitative research are around the data analysis process as researchers take a plethora of text-based data and attempt to reduce it to a manageable form while trying not to lose its meaning (Daley, 2004). In this way data tend to be analysed through an inductive, ongoing and evolving process of identifying themes within a particular context (Miles and Huberman, 1994). For the purpose of the present study a basic thematic qualitative approach was used to analyse the statements generated by all participants. Thematic analysis is a method of identifying, analysing and reporting patterns within data (Braun and Clarke, 2006). The type of coding and thematic analysis that was established was determined by the aims of the study, i.e. to understand the meaning of the participants’ views of what are the needs of carers of people with psychosis; therefore a rich description of the overall dataset was established rather than a particular aspect of the data. This rationale is supported by Braun and Clarke (2006) who highlight the advantages and disadvantages for both approaches. The main disadvantage for the chosen method is that some of the depth and complexity can be lost but that a rich overall description is maintained.
The notes and statements from all the focus groups and interviews were collected together and coded according to the key themes emerging from the data and the earlier literature survey. The coding and analysis was carried out at different levels. The first order coding enabled us to capture chunks of meaning from the statements that were purely descriptive. The second order coding allowed some interpretation of the meaning of the participants’ statements by capturing the meaning of larger segments of data into super ordinate constructs. The final level of coding enabled us to draw on the overarching themes within the data with specific examples of the statements. The themes that emerged from the statements were supported by a process of reading and rereading and comparing codes, constructs and emerging themes. This process was also supported by the researchers’ colleagues who independently found similar emerging themes when they analysed the statements. The rationale for including these additional analyses was to make the process more robust and reduce some of the subjectivity in the analysis.

**Results and discussion**

*Improving care for service users*

For carer participants, the main area of concern was around the care and services available for their relatives. This was seen in terms of both the consequences for the service users themselves and also for carers’ own sense of burden.

‘If service users are unstressed then carers are unstressed, which means professionals will be able to provide better care.’

(Carer)

A major source of anxiety, stress and physical and emotional burden was when their relatives were not provided with sufficient help when needed, or when the standard of care provided was poor. In particular, carers talked about the unacceptable standard of many inpatient services. This increased feelings of guilt, burden and stress for carers when their relatives were admitted. Ward environments were frequently experienced as frightening places that did not aid recovery, and where patients’ basic needs were not being met. Sometimes their relatives were admitted to places at a distance from their family home, which caused immense stress for both the carer and...
service user. The process of admitting service users to hospital was sometimes seen as traumatic and not useful for the service users or their families.

‘Carers require that the ward environment adheres to the basic standards such as good toilet facilities and privacy. Carers feel upset when the inpatient environment is unkempt.’

(Carer)

‘Sometimes the system can cause more trauma than the actual illness such as sectioning the person with the police at home where all the neighbours can see.’

(Carer)

Once in hospital, another source of concern for carers was around preparation for discharge. Most of the carer participants had experienced problems in this area, feeling that their relative had been discharged prematurely or with little notice, or that there had been insufficient discharge planning. They suggested that professionals should take more time in assessing service users’ functioning and mental state so that they would be more aware of their needs prior to discharge, and that people’s long-term needs should be taken more into consideration, especially regarding support for improving their daily functioning and social inclusion.

‘I’m happy as X is getting help but I would like him to do more outside activities. I’ve noticed he does well if he is doing more with his time which motivates him and seems to make him better within himself. When X is happy this makes me happy. When he’s down this makes me down and he seems to find it hard to get out of it. If he was offered to do more with his time this would help him.’

(Carer)

Carer participants also argued that services should have intervened earlier in the course of the illness as the delay in accessing treatment had caused families a great deal of distress. Most felt that initially getting access to care was difficult when they knew something was not right with their relative. Several carers indicated that they were upset and angry as they felt that professionals did not listen to them. Carers of service users with an early onset psychosis also argued that service should be more age-appropriate for young people.

A major difference between the three participant groups was that carers passionately argued that if their relative received improved care, then carers themselves would feel less stressed and burdened. To a lesser degree service user participants also argued that better care
for themselves would reduce burden for their carer. However, the professional groups only briefly touched on this subject but not in any specific detail. Within this study most carers suggested that it was impossible to separate the needs of carers and service users and that services should see them as being the same if progress was to be made. This is a different perspective to that found in the carers’ needs literature which tends to emphasize that carers and service users have very different needs (e.g. McFadyen and Farrington, 1997). While most of the literature does not directly focus on service users’ needs as an issue, it may be argued that poorer service user functioning can increase carer burden (Platt, 1985; Schene et al., 1998) and a better understanding of carer burden can contribute towards mental health services improving practice to meet carer needs (Lowyck et al., 2004). However, the literature does not argue that improved service user care will directly reduce burden for carers. The only study that has directly linked this to carer needs was by Repper et al. (2005). Their results concluded similar concerns expressed by carers in the present study, i.e. that there should be provision of adequate services for their relatives.

Carer involvement

There was solid consensus among the different participant groups about the importance of improving carer involvement in their relatives’ care. Carer participants voiced a strong wish to be more involved in the care of their relatives. They frequently felt that they were either excluded or that professionals did not take them seriously. They suggested that as they knew their relatives well and demonstrated expertise in their care delivery they should be seen as a part of the multi-disciplinary team and respected by professionals. All too often they found that confidentiality was used as a reason for professionals excluding them from information.

Carers also found it difficult to build trust with professionals as they frequently saw different members of the team.

“There is no consistency who’s in the team as sometimes you can see a different doctor every time. There needs to be more consistency. Once you’re in the system you’re too scared to drop out in case things get worse. X was discharged several times and this made things worse. Teams should hold on to service users for a longer time.’

(Carer)
The professional groups also acknowledged that there was an issue with continuity of care and that sometimes carers became confused about who were the main contacts within the team. They suggested more of an effort was needed to tackle this problem. Professional participants also wanted carers to be more involved within the care process, and for this to happen they suggested that they needed to improve their relationship with them and be more flexible and friendly in their approach. They indicated that carers were experts in their delivery of care and that they should be valued. Another issue the professionals raised was that carers could withdraw or stop being carers if they found the role too stressful.

‘Carers should feel safe at saying no to caring and not to feel judged by professionals.’

(Professional)

Similarly, the service user participants also argued that carers should be involved and kept informed of their relatives’ progress. They also highlighted that carers should be able to set limits with their relatives if they were becoming too stressed or burdened.

The theme of carers not being sufficiently involved is mirrored by the literature and there is a recommendation by the government to tackle this problem (DoH, 1999). Despite this there is a plethora of literature which suggests that carers still feel marginalized and excluded from the care process (Shepherd et al., 1994; Winefield and Harvey, 1994; Beck and Minghella, 1998; Henwood, 1998; Simpson, 1999; Arksey et al., 2002; Pinfold et al., 2004; Repper et al., 2005). However, when carers felt more involved in relationships with professionals there was an increased sense of satisfaction with services (Stanbridge et al., 2003; Noble and Douglas, 2004).

**Emotional and practical support**

Carer participants talked about needing professionals to listen to their needs and be generally supportive. They often felt that professionals did not have the time to talk with them, which caused them frustration and upset. Some carers talked about the emotional effects mental illness had on their own well-being and requested that professionals help them to deal with their sense of loss and offer them reassurance.

A common theme in the discussions was that carers did not receive help early in the course of their relative’s mental health condition and did not know who to contact for help during the initial stages.
‘In the past we did not know who to talk to about X’s problems and our worries and concerns. The GP didn’t listen. It would be useful to know who else to contact.’

(Carer)

A recurring theme for the carer participants was difficulty in accessing care in a crisis.

‘It’s not clear where to look when there’s a crisis especially out of hours. Crisis doesn’t have a specific time. There should be clearer information for everybody.’

(Carer)

Some carers felt that professionals relied on them too much in a crisis, which they found stressful and distressing. Others reported that they were only contacted by professionals in a crisis and not for their general needs.

Similar points were raised in the professionals’ focus groups; however, most of these statements were about practical support rather than about carers’ emotional needs. Again the theme of crisis and risk emerged. Professionals believed that carers needed to know the risks service users could pose and how they could access services to reduce risk. They argued that twenty-four-hour care was paramount and that carers should be aware of the crisis and contingency plans.

The service user participants also raised the issue of crisis intervention and especially of carers’ views being taken seriously by professionals.

‘Carers should be able to get help when in a crisis as teams often don’t get back to them.’

(Service user)

Service users also felt that professionals should engage and support carers throughout the time that their relatives were in contact with mental health services, whereas from their own experience they saw that professionals tended to only contact their carers if a crisis developed.

The theme of crisis is prevalent within the literature. Carers wanted to learn skills for dealing with their relatives’ symptoms (Noble and Douglas, 2004) and not just to be contacted in a crisis (Repper et al., 2005). Carers wanted earlier professional intervention to avoid crises (Winefield and Harvey, 1994), and Kuipers et al. (2002) discuss the aim of FI, which is to enable families to build a repertoire of coping skills to reduce burden and relapse.
To be treated with respect

Throughout the focus groups and individual interviews the theme of respectfulness recurred. Carers argued passionately that professionals and services should be more respectful and listen more to what carers were saying. They believed that some professionals acted as if they did not care and were frequently critical of them. They also found that professionals frequently assumed what carers were thinking which made them feel angry.

‘Sometimes the professionals don’t listen and understand what’s actually happening with X. They should listen to what carers are saying more. It makes me feel frustrated.’

(Carer)

The professional groups also raised this issue of respectfulness. They stated that they should be more understanding and listen to carers’ points of view and that they needed to improve their relationship with them and appreciate the work that carers do. They continued by highlighting that professionals should concentrate on the carers’ strengths and holistic needs.

The theme that carers do not feel listened to by professionals about their needs is evident within the literature (Shepherd et al., 1994; MacInnes, 1998). This also fits well with Forrest and Masters’ (2004) finding that both carers and service users valued the process of the interventions over the actual outcome of FI. In other words, they valued the qualities of the professionals and the sense that they were being listened to.

Information, education and training needs

A major theme emerging from the carer participants was around information-sharing and educational material. Carers found that having information about the illness and treatments was really useful, but that more attention was needed in how to impart such information. Some carers received little or no information from professionals, while others were given too much at one go, which they found overwhelming, especially during the initial phases of the illness. Some of the carers had also received conflicting and confusing information from different members of the multi-disciplinary team, which they found difficult and stressful.

As well as information on specific treatments, carers also wanted information and education about how to understand early warning
signs and how to prevent relapse, and also on how to deal with
difficult behaviours that their relatives sometimes presented with.

‘Carers need to know when to help their relative and know what to say to them.’
(Carer)

‘Carers should be given advice in how to diffuse difficult situations with their
relative.’
(Carer)

One of the main concerns raised by the professional groups was
around confidentiality and information-sharing with carers.

‘Carers should be aware that not all information needs to be shared with them.’
(Professional)

However, they also believed that it would be useful if carers received
information about psychosis and treatments available, and that this
should happen during the initial stages of the illness and throughout
the time that they were in contact with services. Professionals were
aware that it could be very distressing for families to be told that their
relative has psychosis and that this should be done in a very sensitive
manner. The issue of legal information was raised and how this can be
confusing and frightening for carers.

The service user participants also highlighted the importance of
providing carers with information on psychosis, and also that it would
be useful for carers to receive training to provide them with strategies
in dealing with service user distress and understanding more about
early warning signs and relapse prevention. While they thought that
the main purpose of giving carers information and training would be to
reduce their burden it was felt that this would also ease the stress on the
service users, as at times they found the carers’ behaviours unhelpful.

‘Carers need to be strong people because if I said leave me alone or I would get
angry they would have to be able to take it. If they got angry this would make me
worse. Professionals should give advice and tell carers that this behaviour doesn’t
work. Carers need to be able to take a step back.’
(Service user)

‘My sisters didn’t understand about the illness and would shout and blame my
mother for my illness. Professionals should be able to educate them about the illness
and how it happens.’
(Service user)
These themes are again echoed within the literature and support the importance of offering FI (Kuipers et al., 2002). Issues around confidentiality as a barrier to giving information are also well documented (Rethink, 2003; Pinfold et al., 2004). Interestingly, service user participants in the present study felt that carers should be involved throughout the care process and did not see confidentiality as a barrier to this. This finding is different to Pinfold et al’s (2004), who found that a high percentage of service users did not want information passed on to carers.

Conclusion

The overarching theme from the findings is that carers and service users do not believe that service users’ basic needs are being met, which causes them a great deal of distress and anger towards services and increases carer burden. Carers asserted that the needs of service users and carers are interconnected and should not be seen as separate. Furthermore, carers felt strongly that professionals tend not to listen, involve or respect them in the care of their relatives, which in turn increases carers’ sense of burden and distress. All three stakeholder groups agreed that it would be useful if carers received training in coping strategies and more information on psychosis and the course of the illness. However, there were differences in opinion between the three different stakeholders. Carers and service users argued for consistent information, while professionals raised the issue that concerns about confidentiality would override information-sharing with carers. All three stakeholder groups asserted that families should be given more support and information at the earliest possible opportunity as this could reduce overall distress for the family at a time when things are stressful for all significant others. Similarly, it was felt that education and training for carers could be immensely useful, with service users in particular believing that training carers in dealing with difficult behaviours would help to reduce stress within the household.

The main concern arising from these findings is that most of these issues have been described and argued within the carer literature over the past twenty years and not much has changed in spite of increased government activity and policy in these areas. Carers and service users still feel disempowered despite these acknowledgements. As services are not able to offer FI to all families, how can services develop to meet carers’ needs? One option is to embed family-inclusive routine
practice within existing services. Despite the well-documented difficulties in implementing FI it is important to take note of the innovative but complementary projects in Somerset (Burbach and Stanbridge, 2008). First is the well-established FI in psychosis service, where they have sustainably implemented FI for psychosis services. The second is where they have started to develop family-inclusive mainstream mental health services. This aims to ensure that families are involved as ‘partners in care’ and that families’ basic needs for information and support are routinely met by all mental health teams/services (Burbach and Stanbridge, 2008). Similarly, incorporating the ‘pyramid of family care’ set out by Mottaghipour and Bickerton (2005) would offer a useful way of structuring family-inclusive services that uses a hierarchical framework for targeting different levels of care. However, for family interventions to be successful and to sustain good standards of delivery, manageable workloads and sufficient supervision are key requirements (Stanbridge and Burbach, 2007). In-house training and supervision contribute towards the necessary changes in culture and practice for service development, which needs the backing and encouragement by management at all levels (Stanbridge et al., 2003).

References


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