**Exploring the impacts of a carers’ psycho-education group: personal insights from the family of people with early psychosis**

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**Abstract**

Introduction:

Carers (family and friends) are simultaneously impacted by a loved one’s experience of psychosis and influential in supporting recovery from psychosis. This study examines carers’ experiences and perceived impacts of a psycho-education group within one Early Intervention in Psychosis (EIP) service in England.

Methods:

Semi-structured, face-to-face interviews were conducted with seven carers who had attended a psycho-education group. Interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA) for which a small sample is recommended.

Results:

Participants highlighted the importance of carers’ early access to information and of working around barriers to attendance at psychoeducation groups. They perceived that their attendance at the group had enhanced their confidence and independence in supporting loved ones with their symptoms, encouraged greater involvement in care planning, and overall improved carer wellbeing. Further, sharing experiences had increased their understanding of psychosis and helped with tackling stigma and feelings of shame. Implications and areas for further research are discussed.

**Introduction**

Psychosis can be extremely debilitating and lead to high rates of inpatient admission, physical health problems, and lower levels of social functioning. Intervening in the early stages of psychosis is vital to improve prognosis (NHS England et al., 2016). Early intervention services for psychosis (EIP) in England are designed to promote recovery and aim to reduce relapse rates by providing a range of evidenced interventions such as cognitive behavioural therapy, education and employment support, physical health assessments and family interventions including psychoeducation for carers (NHS England et al., 2016).

Carers, defined here as family members, partners or friends who provide unpaid informal care to somebody with mental health difficulties, are simultaneously impacted by a loved one’s experience of psychosis and influential in supporting or shaping their recovery from

psychosis (Hannan, 2013). First episode psychosis (FEP) typically occurs during adolescence and early adulthood and carers are often family who have an essential role in facilitating access to EIP and sustaining engagement and recovery. Supporting family to understand and respond to psychosis has been shown to reduce relapse rates by 40% (Knapp., et al, 2014).

The Schizophrenia Commission (2012) state carers save £1.24 billion of public funds per year. Providing statutory support to carers is essential to help them continue to support the person experiencing FEP and also to support their own health and wellbeing. Research has shown that caring for people with mental health problems can have a detrimental impact on family relationships, emotional wellbeing and physical health (Broady & Stone, 2015). Several studies highlight the burden and stress on carers of people with recent-onset psychosis, including stigma, difficulty accepting diagnosis, and internalised feelings of blame (e.g. Vasconcelos et al., 2017). A study investigating carer burnout in first episode psychosis (Onwumere et al., 2018) concluded that carers felt exhausted, inadequate and expressed overall negative appraisals of caregiving, highlighting the need for targeted interventions for carers during the early phase of psychosis.

Previous research has identified carer priorities: routine identification of carers and delivery of support, information and training at the right time (Carers UK, 2018). One way of providing support to carers is through the provision of psychoeducation groups. In their review of carers’ experiences of FEP, Dillinger and Kersun (2019) link psycho-education and increased interaction with facilitators with improved carer wellbeing. Psycho-education appears to improve carers' mental health knowledge, including understanding recovery and relapse prevention (Petrakis et al., 2013) as well as their understanding of navigating NHS services (Riley et al., 2011). Provision of carers psychoeducation as a routine part of care within mental health services can facilitate carer involvement in care planning by supporting carers to identify and communicate symptoms of concern (NICE, 2015).

Group settings are linked to improvements in wellbeing and appraisal about caregiving (Riley et al., 2011). Further benefits include a sense of collective experience, and the opportunity to feel heard, reduced public stigma and enhanced skills in supporting the service user (Petrakis et al., 2014). Group settings for psychoeducation are thus recommended for therapeutic effectiveness as well as economic and resourcing advantages (Day et al., 2017; Breitborde et al., 2009).

***Barriers to carer involvement in psychoeducation groups***

Carer concerns about psychoeducation groups include any potential negative consequences of being involved, issues around privacy and confidentiality in group settings, discomfort with group participation, being or feeling unable to physically attend, and low expectations of the helpfulness of the group (Riley et al., 2011). Professional barriers include limited training opportunities in family work, and confidentiality concerns (Landeweer et al., 2017). Organisational barriers include limited time and resources to meet carer schedules, which suggests a need for organisational support and practice development strategies to implement programmes for carers (Sin et al., 2014).

Findings from previous research thus pose the question of how to facilitate support and care-plan involvement for carers which is diverse and accessible. Although group psychoeducation provision for carers is recommended and established in clinical guidelines (Petrakis et al., 2013; NHS England et al., 2016), there is little specification on timing, format, and content. Given the importance of support and psycho-education for carers, this study addressed the question, ‘What are family and friends’ experiences of a psycho-education group within an EIP service, and what is the perceived impact of the group?’

**Materials and methods**

The current study aimed to explore carers’ subjective experiences of a psychoeducation group programme run by the EIP service in one city in the West Midlands. In particular the study aimed to explore carers’ decision-making in accepting the invitation to the group to explore potential barriers to participation, and also what they perceived to be the advantages and disadvantages of attending, both for themselves and for the person with FEP.

***Design***

In line with these aims a qualitative research design was selected as this enabled the collection of rich data in which carers could share their views, experiences and opinions (Padgett, 2008) of the group and their perceptions of its impact on themselves and their loved one with psychosis. As this was exploratory research, the study was designed with data analysis to be undertaken using Interpretative Phenomenological Analysis (IPA) (see below). A small, purposive sample was thus recruited as a sample size of 3-6 participants is typically recommended for IPA (Hefferon & Gil-Rodriguez, 2011).

Owing to the sensitive nature of the subject, individual semi-structured interviews were completed face-to-face in a location of the carer’s choosing. This was expected to make the carer feel most at ease, help to build rapport with the researcher, and thus produce a fuller account of their perspectives. Semi-structured interviews supported participants to share their subjective views as this method ensured core questions were asked of all participants whilst still allowing participants to raise points not covered by the topic guide but which were felt to be relevant to the area of study (Green & Thorogood, 2018).

The research was undertaken by the first author in her role as a master’s degree student; the second and third authors provided academic and clinical supervision respectively. The researcher was also a social worker in the EIP at the time, however none of the participants were carers of service users on her caseload thus the researcher was not known professionally to the carers. Approvals were obtained from an NHS Research Ethics Committee (reference: 18/NW/0143), the NHS Health Research Authority (HRA) and the research and development office in the NHS Trust in which participants were recruited.

***Service setting and intervention***

The research took place within a county-wide multi-disciplinary NHS EIP service. The programme was based on Worcestershire Relatives Group and incorporated ideas from the Meriden Caring for Carers Programme (Fadden et al., 2018; <https://www.meridenfamilyprogramme.com/>), but had been adapted for the service. The programme facilitated information sharing, coping strategies and support whilst covering: experiences of mental health in the family; experiences of caring; information on assessment, treatments and local services; communication in families and with professionals; problem solving; dealing with crisis and relapse; recovery and hope; and self-care. The structure utilised some aspects and principles of Behavioural Family Therapy (see Campbell, 2004).

The 10-week programme involved a commitment of two hours, one weekday evening every week to attend the group. A monthly, two-hour follow-up group was also held for those carers who had completed the 10-week programme and wanted to maintain a support group. Carers, identified by service users and care coordinators, were sent information about the programme and invited to attend an introductory session. Participation was voluntary. The research was initiated after two completed programmes, the first of which comprised of 15 attendees at the first session followed by 12 regular attendees. At the second programme there were 9 attendees at the first session, followed by 9 regular attendees. The average number of sessions attended was 9 (out of 10). Thus, programme drop-out rates were low.

***Recruitment***

Carers who had attended at least six out of 10 sessions of the psycho-education programme were eligible to take part in the study, if their loved one was still accessing the service and if all parties were aged over 18 years. Letters were sent by the group administrator to every member of the most recent group informing them about the study and asking those interested to return a signed consent to contact form. Owing to initial low take-up, the researcher attended the follow-on monthly support group to introduce the study and open up recruitment to this group. Recruitment commenced in March 2018, with data collection undertaken in spring/summer 2018.

***Procedures***

Carers who completed consent to contact forms were contacted by the researcher and a date and time for interview arranged. Interviews took place at the participants’ home or an EIP clinic room dependant on participant preference. Interviews lasted 50-70 minutes and were audio-recorded (with consent).

Interview questions were designed to gain an understanding of carers’ experiences of the group. The schedule asked participants: how they were approached about the group; for a description of the group and their experiences within it; their experiences and impact of being a carer; for any noticed changes since attending the group; about relationships formed in the group; any changes in support received; for their hypothetical advice to a friend supporting someone with FEP who was invited to the group; and their advice to facilitators of the group.

The researcher allowed topics to be diverted by participants to explore experiences pertinent to them and followed up with further questions on participant-initiated subjects.

***The sample***

Seven participants volunteered, four male and three female, and none dropped out. Each has been randomly assigned a pseudonym to maintain their confidentiality. Six participants were each caring for their son who was aged 20-30. Chris shared his experiences of supporting his son who had accessed EIP approximately a year prior to interview. Pete shared his experiences of supporting his son who had been accessing EIP for two years prior to interview, as did Annie and Mitchell who chose to be interviewed together and shared their experiences of supporting their son since he accessed EIP two years prior. Elise’s son had also accessed EIP two years prior. Susie’s son had been accessing the service for four years prior to interview. Henry shared his experiences of caring for his wife, aged 60-69, who began accessing EIP three years prior to interview and had experienced three episodes before he received information about the group. Two participants identified as Black Caribbean, one as Indian British and four participants identified as White British.

***Analysis***

Interviews were transcribed verbatim and anonymised by the first author. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). Recognising the personal journeys of carers and how, if at all, the group impacted on this journey was congruent with the epistemological position of IPA. IPA operates with a double hermeneutic, as ‘the researcher is trying to make sense of the participants trying to make sense of their world’ (Smith, 2004: p.40). The researcher began analysis by transcribing and repeatedly reading each transcript to become immersed in the data, before coding line by line, noting descriptive, linguistic and conceptual patterns in the data to thus develop emergent themes (Smith et al., 2009). Themes were clustered according to content and meaning, and superordinate and subthemes were identified (Smith, 2011). An in-depth account was produced for each case (participant), before determining areas of convergence and divergence across the dataset (ibid.). Where a prominent theme emerged within only one transcript, it was included in the results in line with the focus on meaning within context as opposed to frequency and numeration of the evidence (Smith et al., 2009). It is important to highlight that the double hermeneutic of IPA can only result in a tentative and subjective analysis; the end result is only an account of how the researcher ‘thinks the participant is thinking’ (Smith et al., 2009).

During data analysis, supervision was utilised to check codes, challenge initial interpretations and develop a narrative. An independent coding of data by the first author was reviewed by the co-authors to discuss ideas leading to a more interpretative account (Smith, 2004). The researcher reflected, both independently and with co-authors, on their own personal and professional biases to mitigate their views being imposed onto participants’ narratives (Larkin et al., 2006). The study aimed to create a credible insight into lived experience that is grounded in participants’ accounts.

**Results**

Four super-ordinate themes and ten sub themes emerged from the interview data, illustrated in Table 1 below.

Table 1: Summary of super-ordinate and sub-ordinate themes

|  |  |  |
| --- | --- | --- |
| Super-ordinate themes | Sub-ordinate themes | Number of participants contributing to the theme (of 7) |
| Theme 1: Stepping out of isolation | * Initial feelings of loneliness and uncertainty prior to the group * Deliberation about attending the group | 7  5 |
| Theme 2: New-found empowerment in the carer role | * Increased independency in recovery management at home * Increase of day-to-day input in care planning * Change of communication with loved ones | 6  5  5 |
| Theme 3: Change of perspectives through shared experiences | * Learning from other people’s experiences * Different stages of a coping journey * Validation from other group members | 7  5  5 |
| Theme 4: Enhanced psychological wellbeing | * Growth and hope * Finding new ways of being | 7  7 |

***Theme 1: Stepping out of isolation***

*Initial feelings of loneliness and uncertainty prior to the group*

Participants did not know anyone experiencing similar problems prior to attending the group and described difficulty with retrieving information about additional carer support, or knowing what was best to do to support their loved ones experiencing psychosis. Participants explained that they had needed answers which were hard to find about how to support their loved ones and understand their symptoms as exemplified by Mitchell:

*“Everybody has got a little thing that they’re thinking about but don’t know enough about and then just knowing who to turn to… a lot of people who are suffering don’t know who to turn to.”*

The group introduced carers to others in the same position which seemed to be experienced as providing some relief from the fear about what was happening to their loved ones, and the isolation attached to this, as exemplified by Susie:

*“…you felt as though you were the only person that had got a loved one with psychosis, so it was quite frightening really…when you met other people, they were all going through the same as me...”*

This relief appeared to be a consistent experience for most participants; irrespective of length of time between access to EIP and group attendance.

Carers also explained that their loved one had changed in their behaviour which created a new relationship dynamic and emotional distress but hearing how other people in the group managed this was important as explained by Henry who experienced a longer timeframe between diagnosis and group attendance and was “clutching” for support:

*“For somebody to then become no longer that person it’s quite a big thing to take on. And so I dealt with it but it would have been good to understand how other people deal with it. I was clutching for something at the time...” (Henry)*

Carers suggested that the earlier the group came in the recovery journey, the better:

*“I think it’s being made aware at the first stages of what’s out there and available and there needs to be more out there and available because obviously at the beginning, this course wasn’t out there and we were lucky really that we were suggested it quite early on.”* (Elise)

*Deliberation about attending the group*

Despite yearning for support, carers deliberated about whether to attend the psycho-education group. Their accounts suggested they didn’t want sympathy; they wanted proactive advice and were concerned that this would not be the case. Frustrations about wanting care to remain focussed on their loved ones rather than themselves emerged.

*“Well at the beginning I’ll be honest, I thought, I don’t want anything that’s going to be self-pity.” (Annie)*

*“I was thinking – I wish our son could have 2 hours a week for 10 weeks, him getting help, I don’t need help; that was my initial reaction.” (Pete)*

Participants also described feeling cautious about judgements from others:

*“I think with the stigma you find that…you don’t want to meet up with people knowing that you’ve got that in your family, so a lot of people that I can see that came were sort of looking around and were a little bit nervous about what could be said.”* (Mitchell)

It was also practically more difficult to attend the group when loved ones were experiencing an episode of psychosis.

*“And when I received that letter, (loved one) had probably just started her fourth episode and it was quite a hectic time for us and so I wasn’t really taking a lot of notice.” (Henry)*

However, participants described how the need for information and support out-weighed worries about attending the group and in fact all participants suggested they would, owing to their experiences, encourage other carers to attend a future group.

***Theme 2: New-found empowerment in the carer role***

*Increased independency in recovery management at home*

With attending the group, participants reported they better understood psychosis and how to manage situations at home, thus improving their confidence in their own abilities and subsequently reducing their reliance on services:

*“The more we attended the course, the more we were able to deal with the problems…almost taking the position of the help you were seeking.”* (Mitchell)

*“If by making me more knowledgeable, more capable, more able, more confident, it means that I can keep (loved one) out of hospital…isn’t that a great boost to society and to the NHS?”* (Henry)

*Increase of day-to-day input in care planning*

With increasing knowledge and confidence, participants described feeling empowered to play a bigger role in the care-planning process.

*“I’m aware more of the kind of therapies, the kind of planning, that can go on in terms of early warning signs…I can demand it more.”* (Henry)

Participants recognised the importance of their role in informing the care plan, as demonstrated by Pete:

“*You didn’t want to push him too far if he wasn’t ready to and so I had doubts as to whether I was qualified enough…he’s coming out of himself but actually feeding that back which perhaps the care coordinator comes and has an hour with them and perhaps wouldn’t see.”*

The participants recognised they were closest to their loved one and suggested attending the group had empowered them to feedback to professionals about their loved one’s progress.

*Change of communication with loved ones*

Participants described learning communication skills to help them respond to their loved one which combatted not knowing the best way to approach conversations and maintained relationships in the home. For example, learning:

*“…things like wordings and how to approach the situation because sometimes things could get quite quiet and you didn’t know what to say, if you were going to say the right thing, how you were going to say it. Going to the group helped with that.”* (Elise)

*“…exercises that you did with other group members about how to make constructive criticisms and how to make helpful suggestions and how to deal with problem behaviour.” (Pete)*

Participants also highlighted that improved communication skills helped them get back to their normal routine.

*“…when it first happened it was really rough, we moved every sharp object out of the house and all the alcohol out of the house, and it’s hard for us to get back to normal. And I think the group sort of helped [us] transition back to normal…I [had] stopped going out with my friends, stopped drinking because of avoiding the conversation, but the groups taught me you have to get back to normal so…the groups taught me to have conversations with him and talk about alcohol rather than avoiding the issue.”(Chris)*

**Theme 3: Change of perspectives through shared experiences**

*Learning from other people’s experiences*

Increased understanding of psychosis was in part facilitated through learning from other group members’ experiences. The diversity of experience in the group showed carers that psychosis can occur for a variety of reasons.

*“It makes you realise that there are different ways of getting psychosis … you tend to think schizophrenia and psychosis just comes from within that person rather than it actually being an injury, I’d never thought of that before.”* (Susie)

Participants highlighted how hearing each other’s experiences helped them understand their own difficulties and they discussed ideas together about what worked to help their loved ones and themselves.

*Different stages of a coping journey*

Participants highlighted the importance of hearing about other people’s experiences and stages of recovery, as Chris states,

*“It was good to hear from other people: …there are people in [a] worse position than us, there’s other people who are coming out of it, there’s people who they’ve been where (loved one) was and they are a lot further down the road so it gave you hope. But, the negative side of it was there’s people there whose kids or partners or whoever weren’t getting any better and it was a very long road so… that brought you down to earth as well, that this might be a long journey...”*

This helped group members understand the diversity of each person’s recovery journey and prepared them for what might happen in the future.

*Validation from other group members*

Participants described opportunities to say what they were feeling and thinking to people who understood them. These were crucial moments of validation which provided reassurance and a safe space to normalise difficult topics arising from their shared experiences.

*“I think that’s partly the strength of the situation itself, the fact that you know that other people will understand and that helps you be relaxed about what you want to talk about and be open.” (Henry)*

Participants also described validation for their own behavioural responses to their loved one based on shared experiences; highlighting a trust placed in other group members’ opinions.

*“Family don’t really understand. I’d be running around after (loved one) doing lots of things and they’d say ‘oh you shouldn’t be doing that, let him do it himself’, but then when you’re speaking to other people at the group, they’re the same.” (Susie)*

**Theme 4: Enhanced psychological wellbeing**

*Growth and hope*

Information learned through the group appeared to have facilitated hope due to a change in perception of long-term recovery outcomes.

*“I became a lot more hopeful that there would be a future for him, and he could come out of it...I had begun to think ‘well what a waste of life’. We became more hopeful, more cheerful, and so then we’d sit and have a chat to him.”* (Pete)

The group describe developing a collective strength as Annie demonstrates:

*“That’s what I like about that group, they are all very strong minded, we are looking after somebody but we’re not going to lie down and let it all swallow us up.”*

*Finding new ways of being*

Participants explained how the group helped them transition to feel more empowered to champion for their loved ones in society and talk about what it’s like to face mental health difficulties.

*“I understand it…and I want you to understand it and I want you to realise that actually it’s bad enough for us to see how she’s behaving in that unusual manner that we don’t realise and recognise but can you imagine what it’s like for her.”* (Henry)

Annie showed that she felt less guilt about her son’s diagnosis. The psycho-education helped to create an explanation for the diagnosis and reduced feelings of blame among carers.

*“I mean it’s inevitable that you start to blame and think it was your fault … [but] it’s just an illness that’s happened and it just could be a bucket load of stress and it sets things off…it doesn’t matter who you are these things can happen.”*

Participants suggested that the group encouraged them to consider their own wellbeing, which some wouldn’t have considered if it hadn’t been highlighted to them directly. Pete stated:

*“The behavioural family therapy is more about the impact on you which I’d never thought about.”*

Some group members became more at peace and accepting of what was happening:

*“It’s helped us help him. It’s helped me be less stressful especially when he’s away at university, and accept some things are going to happen.”* (Chris)

Group members found new ways of being: unashamed, hopeful for the future, advocates for mental health, and mindful of their own wellbeing.

**Discussion**

Interviews with seven carers about their experiences of attending a psycho-education group in one EIP service identified a number of obstacles to attending the group and a host of perceived benefits from attending. The findings supported previous research around the caring role being difficult for carers of those experiencing FEP in particular the associated isolation (Petrakis et al., 2014); with this research emphasising negative experiences of not knowing how to help the individual they’re supporting. However, participants reported deliberation about attending the group which emphasises the importance of identifying and working around barriers. Potential barriers were identified as worry about judgements from others, surmising that the focus would be emotional support mostly and unhelpful for the person they care for, and practical difficulties such as finding the time to attend sessions.

The research concurs with Riley et al (2011) in suggesting that, through attending the group, carers increased their understanding of psychosis and treatment. Participants described starting to request specific NICE-recommended treatments for their loved ones, due in part to a new found confidence and also positivity about recovery, highlighting potential cost-effectiveness benefits of psychoeducation such as increased carer involvement in care-planning for relapse prevention.

Whilst it may be intuited that carers would become more independent the longer they experienced caring for somebody with psychosis, this does not account for the variety of coping experiences that participants spoke of, and the importance of learning from others through the group, in addition to the support and sense of belonging that they described.

Participants highlighted how they found new perspective in hearing about other people’s recovery and sometimes assuming the coping strategies of group members. Participants also spoke of how the group diverted them from emotional exhaustion by facilitating support from people who understood their experiences, which is particularly notable in light of research suggesting that 78% of carers report high burnout, including emotional exhaustion (Onwumere et al., 2018). In addition, validation from other group members’ experiences combated feelings of shame and guilt highlighted to be a common difficulty among carers (Vasconcelos et al., 2017).

The group appeared to be beneficial as a means of helping to problem-solve members’ concerns, and findings indicated the importance of a psycho-educational focus with problem solving as opposed to unstructured group support. Practising communication skills also positively impacted on their relationships with their loved ones (see also Salinger et al., 2018). It reinforced problem-solving behaviour, rather than dependant behaviours, as exemplified by the participants’ increased independence in managing symptoms at home.

***Implications for policy and practice***

This study appears to support the recommendation that routine identification and clear support referral pathways for carers are important (NICE, 2015), as is access to information supporting carers to understand symptoms early in the recovery journey. By doing this, care systems may be able to better support carers and the service users they support in their recovery from psychosis. Psycho-education groups for carers are one seemingly accepted way of supporting carers to understand the mental health conditions of their loved ones and to understand and manage their own responses and wellbeing. There is certainly an advantage for health services in delivering multi-family groups as more families can be seen at one time and they clearly articulate the benefit of group processes. If services are to offer such groups, barriers to attendance should be considered. A key factor for carers in this study was being provided with thorough and accessible information about the content of the group at invitation, whereby they recognised the group would provide practical and problem-based help for supporting their loved ones. The introductory session also seemed beneficial for some to experience a taster prior to signing up for the programme.

Psycho-education groups appear to help carers facilitate the recovery of their loved ones (the service users) and thus indirectly help services to mitigate limited resources. An influential component of the group was regular peer support from other group members, highlighting the importance of group interaction. Carers described becoming more involved in care planning and feeling better able to manage their loved one’s symptoms as a result of attending the group. This, in turn, could reduce dependence on, and hence cost to, the NHS; demonstrating the potential cost-effectiveness of such support and the need for a cost-effectiveness study of psycho-education groups for carers before this could be recommended or mandated for resource-strapped services.

***Limitations***

The research was undertaken with seven carers accessing a psycho-education group in one EIP service in England. Results are therefore not representative of all mental health carers’ needs. Although this study had a small sample size, a figure of 3-6 participants is typically recommended for IPA given the focus on detailed experience (Hefferon & Gil-Rodriguez, 2011). This was a qualitative study exploring carers’ experiences of the psycho-education group; it was not designed to be an evaluation of the particular psycho-education programme. Quantitative research measuring any impacts of group psycho-education for carers on the recovery outcomes of loved ones and of carer wellbeing and behavioural changes is recommended.

Most participants were recruited from the monthly follow-up group and therefore, by virtue of continuing attendance, were likely to have mostly positive experiences of the group. The study thus was unable to explore why other carers had not attended or continued to attend the psycho-education group; this is worthy of investigation in future research.

The lead researcher was also a social worker in the EIP team. However, none of the carers involved in the study (nor their loved ones) were known professionally to the researcher and the researcher had no prior experience of carer psychoeducation groups.

**Conclusion**

This study set out to explore carers’ experiences of a psychoeducation group for carers of people experiencing psychosis in England. Qualitative interviews with seven carers identified that despite feelings of isolation, participants described initial concerns about attending a carer psycho-education group, emphasising the importance of identifying and working around barriers to attendance. Carers identified that increased access to information that supported carers to understand symptoms of psychosis early in the recovery journey was crucial.

They described a change of perspective through group shared experiences and noted improvements in their own psychological wellbeing, including increased confidence to support loved ones at home and thus reduce demand on the NHS. Participants noted they would recommend the psycho-education group to others supporting a loved one with first episode psychosis.

Key implications arising from the study include providing carers of people experiencing psychosis with information about the condition and about any available support, and addressing barriers to accessing carer support. This could in part be achieved through carer psychoeducation groups through which carers can learn with, through and from the experiences of others, whilst developing a support network and challenging internal stigma, and improving their confidence and knowledge such that they feel better able to support, care-plan, and advocate for their loved one. This in turn could reduce demand on NHS services for both the service user with psychosis and their carer. A cost-effectiveness study of psycho-education groups for carers is recommended alongside quantitative investigation into any impact on service user recovery outcomes.

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