

Views of Young People in Early Intervention Services for First-Episode Psychosis in England

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Objective: This study described the views over time of young people referred to early intervention services (EIS), particularly as they relate to the importance of relationships. **Methods:** A cohort of people aged 14 to 35 enrolled in a large multisite study of EIS for psychosis in the United Kingdom were recruited for a qualitative, longitudinal study in which they were interviewed within six months of admission to EIS and 12 months later. Transcripts of the interviews were analyzed using Charmaz's constructivist grounded-theory methodology. **Results:** A total of 63 individuals were interviewed during the six months after their first service contact, and 36 (57%) were interviewed 12 months later. Service users generally viewed IES key workers as supportive and youth sensitive, but up to one-third felt that the three years of sustained engagement expected was too intensive. Family support was highly valued by service users, and key workers and families worked well together to support the young people as they recovered. A significant minority of service users, however, reported feeling the emergence of a new self-identity, often associated with a sense of loss of the person they had felt themselves to be before becoming ill. **Conclusions:** EIS for young people should provide not only the right type of engagement but also the right amount, recognize the very important role of families in giving both practical and emotional support and in liaising with key workers, and take into account the relatively rapid change in perceptions of personal identity that accompany illness. (*Psychiatric Services* 62:882–887, 2011)

Psychosis is a serious and potentially life-changing condition. Although some people make a full recovery, many develop a lifelong illness (1,2).

Early intervention services (EIS) for young people with a first episode of psychosis were introduced into the health care systems of many countries, including the United States and the United Kingdom, starting in the early 1990s. The motivation for this reform included significant and sustained dissatisfaction among users and their families with existing service structures (3), recognition of a link between the duration of untreated psychosis and poorer long-term prognosis (4), and an understanding of the importance of the outcome of the early phase of psychosis in predicting longer-term recovery (5). More recently, EIS have been shown to decrease relapse and rehospitalization (6), and they appear to be cost-effective (7).

In the United Kingdom, the Department of Health's *Mental Health Policy Implementation Guide* (8) states that EIS should be targeted at people aged 14 to 35 with a first presentation of psychotic symptoms and should be continued during the first three years of the illness. Services are community based and multidisciplinary and focus on providing appropriate youth-sensitive care in settings of low stigma. A key feature includes the need to develop mean-

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ingful and sustained engagement with the service user and the family or other caregivers.

Even though young people's engagement and satisfaction with services are seen as key outcomes for developing services, there has been little research on service users' views of EIS and their wider views of how life has changed since becoming ill. Previous relevant qualitative work exploring the views of service users with psychosis, often at a later stage in the illness trajectory, has focused on assertive community treatment (9), community mental health teams (10), and primary care (11,12).

This study explored in depth the value of EIS over time from the perspective of service users. To enable a better understanding of the service users' evolving experiences, we chose a longitudinal study design that collected qualitative data in interviews conducted one year apart (13). The study focused particularly on service users' relationships during that time period, both within and beyond the services, an issue considered important by service users in a qualitative study conducted previously by the authors (14).

Methods

Study setting and participants

The sampling frame for this study was the cohort of service users recruited into National EDEN, a national evaluation of early intervention for psychosis services. National EDEN was a large multisite cohort study funded by the English Department of Health between 2006 and 2010 that aimed to explore the impact of EIS on a range of qualitative and quantitative service-user outcomes. Service users in this study were recruited from five geographically diverse sites across England using a maximum variation sampling strategy that captured the range in age, gender, and ethnicity of the group. Participants took part in in-depth interviews about the services.

Procedure and topic guide

Service users were approached between January 2006 and January 2008 by a trained research associate at each site who was dedicated to the National EDEN study and not involved in providing clinical care. Participants

were asked to provide written informed consent after receiving a complete description of the study. Interviews continued until January 2009.

Two semistructured interviews, lasting about one hour, were conducted either in the service user's home or at a mutually convenient location by the same research associate. The first interview was carried out within six months of admission to an EIS site. A topic guide listed subjects to be covered, including views of services and relationships with service providers and with families. At the second interview, 12 months later, topics were personalized to recognize and reflect changes in an individual's circumstances and in response to analysis of the first interview.

Analysis

Interviews were tape-recorded and fully transcribed. Analyses of all transcripts from individuals who participated in interviews at both times were undertaken jointly by two of the researchers and conducted using Charmaz's constructivist grounded-theory approach (15,16). We used the constant-comparison method to make comparisons between data to advance our conceptual understanding. Initial coding of themes was developed after studying each transcript line by line. Other members of the research team developed more focused codes by gathering together, describing, and verifying the initial codes. As coding became more focused, it became not just a descriptive tool but a means to synthesize the data into analytical and, finally, core categories.

Disconfirming evidence was actively sought throughout (17). Interviews continued until data saturation was complete. The quotations from the interviews included in this study were chosen on the grounds of representativeness.

Ethical approval was given by the Suffolk Local Research Ethics Committee.

Results

During the data collection period, 491 young people consented to take part in the National EDEN study, which included 1,027 people by

study's end. Sixty-three people agreed to take part in an interview, and of those, 36 (57%) agreed to a follow-up interview. Demographic characteristics of the study population and the entire EDEN cohort are shown in Table 1.

Three main themes of direct relevance to young peoples' experience of EIS emerged from the data: relationships with key workers, the value of family support, and changing self-identity.

Relationships with key workers

Most (N=24) of the 36 service users described EIS in positive terms, as offering activities and services that were "youth friendly" and that made sense to young people. For example, they were contacted by e-mail and texting, rather than by letter; activities were focused on sports and pop music; and education included up-to-date information technology (IT) training. Appointments with key workers were kept in local community venues or at the service users' homes rather than in secondary-care hospital settings.

Services helped users come to terms with their illness, working with them, over time, to identify triggers and early warning signs and to understand why they had become unwell. For example, one individual said of a key worker during a first interview, "I talk and he sort of chats back with me and sort of goes through it all—so he explains it all to me and my family. Now I know it's more to do with me trying to learn to cope with my anxieties."

In particular, service users highlighted the positive nature of the relationships with their key workers and the benefits of being able to develop a long-term relationship with one individual. The positive personal characteristics of key workers, such as apparent genuineness and support, were frequently discussed. Asked to describe the relationship with a key worker in the first interview, one participant said, "I'd say very positive . . . it picks me up each week. Every time I see [name of key worker], it's another pick-me-up." After 12 months, another participant said of the key worker, "I see her every two weeks. I don't know what I would do without her, to

Table 1

Characteristics of individuals who completed a 12-month follow-up while enrolled in the National EDEN study of early intervention services

Characteristic ^a	12-month follow-up (N=36)		Total (N=1,027)	
	N	%	N	%
Sex				
Male	24	66	709	69
Female	10	28	318	31
Race-ethnicity				
White, British	25	68	721	70
White, other nationality	1	3	6	1
Irish	1	3	6	1
Pakistani	3	8	102	10
Indian	2	6	56	6
Black Caribbean	1	3	35	3
Mixed race	1	3	43	5
Black African	—	—	23	2
Black, other	—	—	13	1
Education				
GCSE, GNVQ, A level, or foundation degree ^b	23	64	660	64
University qualification	5	14	99	10
No qualification	5	14	245	24
Employment				
Employed	5	14	188	18
Unemployed	21	59	591	58
Voluntary work or student	7	19	208	20
Homemaker	—	—	22	2
Living arrangements				
With parents	25	68	649	63
Alone	3	8	130	13
In hospital	1	3	—	—
With partner	1	3	108	11
Other	4	10	137	13
Age at admission (M±SD)				
Men	21±4.86		—	—
Women	23±3.83		—	—

^a Data were missing for race-ethnicity (N=8), education (N=11), employment (N=11), and living status (N=11) in the 12-month follow-up group.

^b GCSE, general certificate of secondary education; GNVQ, general national vocational qualification

be honest with you. She's such an amazing person to have in my life at this time."

At both time points, most people stated that they appreciated the flexible approach to the amount of care received. Service engagement was negotiated and reduced when agreed upon during their treatment. For example, at the 12-month interview one participant explained, "If I feel particularly upbeat and that, she might say, 'Well, shall we leave it three weeks?' but, then, if she thinks that maybe I need a bit extra, she says, 'Okay, well, I'll come and see you in the week.'"

However, approximately one-third of those interviewed described an overemphasis on engagement with EIS to the point of feeling that the

visits from key workers were too frequent. Yet this complaint was often associated with having had a number of different key workers because of staff turnover during the 12-month study period. As a result, participants often were expected to repeat personal stories and received the same advice. Even within six months, one participant complained, "We agreed that 'C' would see me weekly, and then 'D' came instead and started repeating things, and then I started seeing 'E.' I had 'V' come up for a bit, and she was alright, but then of course she left."

Another participant said at the second interview, "Each change was disruptive. I was continually having to get to know different people and to

tell my story, and it takes a whole load of time to build up trust in someone."

Overengagement became a more prominent issue in the follow-up interviews, perhaps because the first interviews were based on expectations and on relatively limited contact. By the time of the second interviews, service users' comments were based on actual experience. For some service users, the continued regular presence of their key workers after 12 months reminded them that they were still, at least in the eyes of EIS, a patient in need of treatment. Yet, they had reached a point in their recovery at which they were keen to resume their lives, to be as one said, "free from everything and move on."

In the following exchange, a user of services complains of seeing the key worker too much.

Service user: As I've got better it's not nice having somebody come in all the time, because it constantly reminds me that you're suffering from an illness. They seem to ask the same questions all the time.

Interviewer: Right, so do you feel it's too much, then?

Service user: At the moment I do.

Value of family support

Family support was described as critical by the majority of service users at both time points. Families were relied upon not only to provide practical help in terms of money and accommodation but also to serve as someone to talk to and to offer emotional security. Parents and other family members provided an informal help network, looking after an adult child at a time of crisis as they would have when the child was younger. Many parents reportedly took on tasks that they had previously relinquished, such as shopping and laundry.

Over the 12 months, most service users—even the minority of participants who had been living independently but were again living with their family—felt that family support had increased and described feeling closer to their parents. The family had usually gained a better understanding of the illness over time from frequent contact with key workers in EIS. Many families had also become increasingly involved in advocating for

treatment and in helping the service users cope with symptoms, for example, by encouraging them to work with the key worker to develop and use relapse plans. They were also often actively involved in making and maintaining contact with the key workers and wider team.

At the first interview, one participant said, "Well it's helped since I've told my mum. I only told my mum about how I've been feeling a few months ago, so it's just really changed since she's known. She was really supportive and could understand that it's an illness and that you need to get some help. [I didn't tell her before because]... I felt ashamed, and I was just worried about how she would feel."

Later, at the second interview, the participant continued to express gratitude for the mother's understanding.

Interviewer: And has your relationship with your mum changed, do you think, over the course of the last year?

Participant: Yes, definitely, yes it has. I'm more willing to say, 'This is what I'm experiencing,' without feeling ashamed or seeing it as a weakness. I was scared about her getting worried and things like that. But she's been great.

Changing self-identity

During the first interview, most service users talked about psychosis as an illness from which they would recover simply through time and medical help. By the second interview, however, a significant minority of service users had begun to express an emerging acceptance of a new identity, created by the illness and often associated with a sense of loss of their old self. They talked about their current situation in negative terms compared with their old selves and situations. One said, at six months, no less, "I used to be a normal person you know... you feel so alone, and you feel jealous of normal people."

A more negative self-identity was reinforced for some by changes in physical appearance, such as weight gain secondary to medication use and by episodes of perceived stigma involving work, friends, or wider society. Only 15 of the 36 service users were back at work or in school at the time of the second interview, which

further emphasized a sense of feeling different from their old friends and their former selves. One said at the second interview, "I see quite a lot of people I used to know but because I've put on a bit of weight, and I look a bit different, they don't recognize me. I would have said, 'Hey it's me!' but now I'm glad they don't recognize me any more. . . . I wouldn't know what to say."

EIS key workers, however, were seen as important allies in recovering a positive sense of self, through providing therapy-based coping strategies and enabling participants to meet and share experiences with other service users. One participant at six months said, "It's been all right. I'm quite proud of the activities we do. We play pool in George Street, and they're a laugh. And my key worker's helping me with computer classes."

Discussion

This qualitative study has described in detail how users of EIS viewed their relationships over a 12-month period with key workers, with family, and with images they held of their former selves. A recent article describing qualitative studies of services for a first episode of psychosis (18) found 27 discrete studies, but only one, in Denmark, was longitudinal in nature, and it involved only 15 individuals (19). Longitudinal study seems particularly important when exploring an evolving illness with a cohort of young people.

The literature suggests that up to one-third of individuals with serious mental illness who have had some contact with the mental health service system disengage from care (20). Early disengagement from mental health services can lead to devastating consequences for individuals with schizophrenia, including exacerbation of psychiatric symptoms and suicide (21). Part of the rationale behind EIS is the need to actively engage people early in the course of the illness and to sustain engagement through a number of approaches, including offering frequent visits from key workers in low-stigma settings, using a youth-centered approach to engagement, and providing activities that are age appropriate.

Most service users in this study described their key workers as having very positive personal qualities, as being someone they could trust, and as being supportive and warm, highlighting the importance of relationality in EIS. Relationality, defined as our lived relation to other human beings, is an underresearched issue, but its role in promoting engagement in services warrants study. EIS may empower parents and other family members to help individuals maintain a therapeutic relationship (22), in stark contrast to examples in which parents seeking help for children with first-episode psychosis encountered many problems, particularly difficulties accessing psychiatric care (23). Positive therapeutic alliances, themselves a positive predictor of engagement, appeared to occur among EIS participants in this study (24,25).

The interpersonal nuances of trust and respect built up between individuals over time are perhaps even more important among service users whose illness may cause them to be considered different by wider society. Yet among a significant minority of the young people we interviewed at the 12-month follow-up, the notion of sustaining engagement for up to three years was seen as too intensive. On the other hand, those most likely to complain of overengagement were also those who perceived less continuity with key workers, suggesting that concerns about overengagement may only emphasize the importance of a positive therapeutic alliance. This study, in the context of the established and emerging literature, therefore suggests that it is important to negotiate not only the right type of EIS for young people but also the right amount of engagement in services and to review them regularly.

This study also supports findings of a previous study, that many parents of young people with psychosis appear to take on caring responsibilities they had previously relinquished as their child reached adolescence (26). Additionally, this study suggests that service users found the family environment very supportive. Indeed, an unanticipated reward of caregiving in some circumstances was that many service users described having a more

open and deeper relationship with their families than they did before their illness (27). This finding challenges the notion lingering from Brown's work in the 1950s that parents can exert a negative influence on people with psychosis after they return home after hospitalization (28). Brown found that people with psychosis living with their parents were more likely to be readmitted to a hospital than those living with siblings or in hostels.

The study also captured the evolving process by which service users came to terms with their illness. It suggests that from an early stage, some service users experienced a disruption in their sense of self, accompanied by a feeling of loss. For many, this new sense of self was linked to changes in physical appearance, often linked to the side effects of medication, which increased perceptions of stigma. This finding is consistent with Festinger's social comparison theory (29), which proposed that people have the drive to evaluate and assess their abilities and opinions by comparing themselves with others they consider similar.

In a development of this theory, called temporal comparison, Albert (30) argued that when people engage in self-evaluation, they also compare their current selves to who they had been at earlier points in time. One of the basic hypotheses of temporal-comparison theory is that such comparisons help individuals to maintain a sense of identity and continuity over time, which in turn allows them to evaluate and adjust to changes. Compared with research about social comparison theory, there is limited empirical research to document the use of temporal comparisons (31). Comparisons with past selves, especially among young people, according to Ross and Wilson's theory of temporal self-appraisal (32), tend to be rewarding because, in general, skills tend to improve with age and experience and people tend to regard their current selves as better. In general, images of oneself in the distant past are more likely to be derogated, whereas images of oneself from the more recent past are more likely to be enhanced.

In this study, however, service users

saw themselves in a less positive light compared with their past selves, a finding that is consistent with a study by Dinos and others (33) in which 12 individuals diagnosed as having schizophrenia compared themselves negatively with their former selves. Most studies that have explored temporal comparisons, however, were conducted in the absence of threatening events or focused on acute threats that were no longer present (34). Experiencing a first-episode psychosis is a different type of threat that has the potential to cause ongoing problems. These findings suggest that the theory of temporal self-appraisal be elaborated to include people who have and continue to experience major life changes, such as service users with a first episode of psychosis.

This study had several limitations. Most of the caregivers were family members, making the data less generalizable to use of EIS when caregivers are not family. There was also significant but expected attrition between the first and second interviews; we do not know if the individuals who agreed to the second interview were more or less likely to hold particular opinions about or perhaps have different experiences of EIS. Also, we were able to conduct follow-up interviews of service users at only one time point.

Conclusions

The study findings suggest several conclusions. First, there is a need for greater flexibility in service provision, so that service users can be engaged at the level they need for as long as they need. Engagement should not be regarded as synonymous with highly intensive contact. The ability to be flexible and reflexive to individual service users' needs in early intervention may be a better marker of the quality of services than are uniformly high levels of service engagement.

Second, family support was seen as critical by service users, and families were an important link with services. Involving and supporting families is part of the policy-implementation guidance for EIS, but this study suggests that their role in providing both practical and emotional support and in liaising with key workers may be

more important than previously thought. Families may also provide a means of engagement with service users.

Third, because a diagnosis of first-episode psychosis is accompanied by major changes and continuing readjustments in many areas of an individual's life, consideration of temporal comparisons is important. EIS may need to develop even more recovery-focused strategies that take into account the relatively rapid change in service users' perceptions of their personal identity. Providing therapy and stigma-challenging activities in particular seem to be key in supporting service users as they gradually develop a new self-image. Understanding the nature of service users' adaptation to such an intensive therapeutic approach over time and the way in which their sense of self is challenged and can be protected is critical in further developing the EIS model.

Acknowledgments and disclosures

This work was supported by a grant from the U.K. Department of Health Policy Research Programme. The authors thank the service users for sharing their time and thoughts and the National EDEN research associates at each site for undertaking the interviews.

The authors report no competing interests.

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