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Service users' views of moving on from early intervention services for psychosis:

a longitudinal qualitative study in primary care

Abstract

Background

The role of primary care for young people with psychosis, and transitions between specialist mental health services and primary care, are underexplored areas, both clinically and in research terms.

Aim

To explore service users' perspectives of early intervention services and primary care, in-depth and over time.

Design and setting

Longitudinal qualitative methodology in five geographically diverse sites across England.

Method

Semi-structured interviews with 21 young people with first-episode psychosis at two time points.

Results

Early intervention services are highly prized by service users; however, the 'gold standard' nature of the care is difficult to replicate in other services and may lead to unrealistic expectations. Flexibility in terms of the timing of discharge does appear to be happening in practice, but continuity is not always well established before discharge. Primary care seems to be under-utilised, both as a location of care during time with the early intervention service and as a skill set, particularly for physical health problems. Service users expected GPs to advocate for and navigate the health system, particularly at times of crisis or relapse.

Conclusion

Early intervention services should focus on actively establishing relationships between service users and either the community mental health team or the GP in the months leading up to discharge, and ensuring that service users' expectations about access and availability of care are 'realistic'. Primary care could be better utilised, even when service users are actively engaged with early intervention services, to help ensure physical health needs are met from the start of treatment.

Keywords

continuity of care; health; primary care; psychoses; qualitative research.

INTRODUCTION

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

Early intervention services for young people with a first episode of psychosis were introduced into the healthcare systems of many countries across Europe, the US, and the UK from the early 1990s. The motivation for this reform included significant and sustained user and carer dissatisfaction with existing service structures,² the link between the duration of untreated psychosis and poorer long-term prognosis,³ and the importance of intervening early in predicting longer-term outcomes.⁴ In the UK, the Department of Health's *Mental Health Policy Implementation Guide* stated that early intervention services should be targeted at people aged between 14 and 35 years, with a first presentation of psychotic symptoms, and should be continued during the first 3 years of the illness.⁵ Services are community based, multidisciplinary (often including doctors, nurses, psychologists, occupational therapists, and social workers), and focus on providing appropriate youth-sensitive care in low-stigma settings. Discharge from early intervention services has been far less

mandated in guidance or explored through research. The policy implementation guide suggests that, if stable and well, the service user should be discharged to primary care, and that mental health team follow-up should be arranged in all other circumstances. Ideally, transition should be a planned, orderly, and purposeful process of change, taking into account both personal and illness-specific needs.

The role of primary care for young people with psychosis is also an underexplored area, both clinically and in research terms. Some of this is related to a relatively low incidence, with an individual GP having no more than six young people in early intervention services at one time. However, in terms of lifetime health and social care needs and service use, this group is an important part of the primary care population. People with a psychotic illness (schizophrenia and bipolar disorder) die up to 25 years earlier than members of the general population.⁶ Two-thirds of the premature deaths result from cardiovascular, pulmonary, and infectious diseases. Those aged 25 to 44 years with psychosis are 6.6 times more likely to die prematurely than members of the general population.⁷ A variety of factors have been implicated in these findings, including the

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How this fits in

Psychosis is a serious and potentially life-changing condition. Service users' views of discharge from early intervention services are unknown. Primary care could be better utilised when service users are actively engaged with early intervention services, to help ensure physical health needs are met from the start of treatment. After the acute crisis, primary care clinicians have an important role to play as system navigators and physical health champions.

illness itself, drug side-effects, lifestyle choices, and GP attitudes and actions, including fewer screening and health-promotion activities.⁸

This study aimed to explore service users' perspectives of early-intervention services and primary care in depth and over time, with a particular focus on the role each could play and on the transition process itself.

METHOD

In this study, the concept of the 'patient career' was used to frame service-user accounts of their experiences of early intervention services and primary health care, including the systems in place to help transitioning. The study followed Hughes' definition of a career as a series of movements between stages in a sequence,⁹ and its use in relation to patient experiences in mental health institutions.¹⁰ For Hughes, the career is 'the moving perspective in which the person sees his life as a whole and interprets the meaning of his various attributes actions and the things which happen to him'. The career therefore becomes an individual's interpretation of their relation to and place in society. This concept has been used in a number of studies in mental health settings, to highlight the relationships that are formed and changed as individuals negotiate the system.^{11,12} Methodologically, a longitudinal qualitative approach was chosen since this reflects the study's conceptual framework and enables a better understanding of evolving experiences.¹³⁻¹⁵

Study setting and participants

The sampling frame for this study was the cohort of service users recruited into the National EDEN study of early intervention services. [National EDEN [Evaluating the development and Impact of Early Intervention Services in the West Midlands] is a large multisite cohort study funded by

the English Department of Health [2006-2010] in five sites across England that aimed to explore the impact of early intervention services on a range of qualitative and quantitative service user outcomes.) Service users were recruited from five geographically diverse sites across England, using a maximum variation sampling strategy (age, sex, and ethnicity) for more in-depth interviews on their views of services.

Procedure and topic guide

Service users were approached by a trained dedicated study research associate in each site, who was not involved in providing clinical care in either an early intervention service or primary care setting, between January 2006 and June 2007. The first interview was carried out within 6 months of inception into a service. Participants were then contacted from January 2009 to June 2010 for follow-up interviews within 6 months of discharge from early intervention services.

Semi-structured interviews, lasting about 1 hour, were conducted in either the service user's home or a mutually convenient base, and were led by the same research associate at each time point, wherever possible. The topic guides (which were piloted with three service users prior to the main study) focused at time 1 on their career as a user of early intervention services and at time 2 on the transition from early intervention services to primary care and the role of primary care.

Interviews were tape recorded and fully transcribed. Analyses of all transcripts from individuals who participated at both time 1 and time 2 were undertaken jointly by two of the researchers (a GP and health services researcher, and a health services researcher) and conducted using Charmaz's constructivist grounded theory approach.¹⁶ This approach applies the strategies of traditional grounded theory within a constructivist paradigm, rejecting notions of emergence and objectivity. The constant comparison method was used to make comparisons between data to advance the researchers' conceptual understanding. The analysis began with initial coding after studying each transcript line by line. Initial and then more focused codes were gathered together and described and verified by other members of the research team. Coding then became more focused, moving from using coding as a descriptive tool to using it to help synthesise the data. This led to the development of analytical and, finally, core categories.

Disconfirming evidence was actively sought throughout.¹⁷ Quotations have been chosen on the grounds of representativeness and are coded using the site and participant number and baseline (BL) or follow-up (FU) interview. Where relevant, paired quotations are presented to demonstrate changes in views over time.

RESULTS

Sixty-three people agreed to take part in an initial interview and, of these, 21(33%) agreed to a follow-up interview 3 years later. At this point, 10 were being seen only in primary care and 11 still had regular contact with a community mental health team. At time 1 the mean age was 23 years (range 18–33 years); 16 described themselves as white British, 15 were unemployed, 14 were male, and 13 lived with their parents. Service-user demographics in this study and in the entire National EDEN cohort are shown in Tables 1 and 2.

There were three major themes that were relevant to the study aims: 'gold standard' early intervention services, barriers and facilitators to good transitions, and the under-utilisation of primary care.

'Gold standard' early intervention services

The majority of service users were very positive about their contact with early intervention service staff, often talking about them, at follow-up, as providing gold standard care which they felt other services found hard to match. They valued their key

worker as someone they could access easily, talk to, and trust, and stressed the value of good interpersonal continuity of care. Above all, key workers appeared to provide certainty at a time of great uncertainty:

'I think when I went to them, I didn't really want to let anything out and I was hiding things from my parents like I was hearing voices and that and seeing things. I wasn't telling anyone and once I was there with the EIS [early intervention services] team they explained what was going on and what I was going through and I knew that I could finally show everybody. I could tell them what was really going on and they understood.' (7–4, BL)

'It was really good. They were really available and willing to work quite in depth with me. If there was something I wasn't sure of they would sort it out for me or tell me where I could go to get help or refer me to people who could help. They helped me move out of my home which was quite a big step. I wish I could go back under them. I don't think I fully appreciated it having been on the other side of it. Yeah, it was definitely a lot better than anything I've had since.' (7–4, FU)

'They helped me with medication, associating with other people, going to clubs, snooker clubs, making me go outside, doing activity, making new friends.' (1–2, FU)

Table 1. Demographics of service users

Site number ^a	Service user number	Sex	Age, years	Ethnicity	Living arrangements	Employment status
1	1	M	20	Pakistani	With parents	Unemployed
1	2	M	18	Asian-Indian	With parents	Unemployed
1	3	M	18	Indian	With parents	Student
1	4	F	23	Bangladeshi	With partner	Unemployed
4	1	M	21	White British	With partner	Unemployed
4	2	M	33	White British	Single	Unemployed
4	3	M	27	White British	With parents	Unemployed
4	4	M	33	White British	Alone	Unemployed
5	1	M	22	White British	With friends	Unemployed
6	1	F	32	White British	Alone	Working
6	2	F	28	White British	With partner	Working
6	3	M	23	White British	With parents	Student
7	1	M	24	White British	Long-stay accommodation	Unemployed
7	2	M	19	White British	With parents	Unemployed
7	3	F	23	White British	With parents	Unemployed
7	4	F	19	White British	With parents	Working
7	5	M	23	White British	With parents	Unemployed
7	6	F	19	White British	With parents	Unemployed
7	7	M	23	White British	With parents	Unemployed
7	8	F	23	Mixed-white/black African	With parents	Unemployed
7	9	M	18	White British	With parents	Working

^a1 = Birmingham. 4 = Lancashire. 5 = Norfolk. 6 = Cambridge. 7 = Cornwall.

Table 2. Characteristics of individuals who completed a 36-month follow-up while enrolled in the National EDEN study of early intervention services

Characteristic ^a	36-month follow-up (n = 21)		Total (n = 1027)	
	n	%	n	%
Sex				
Male	14	66	709	69
Female	7	33	318	31
Race-ethnicity				
White, British	16	73	721	70
White, other nationality	0	0	6	1
Irish	0	0	6	1
Pakistani	2	10	102	10
Indian	2	10	56	6
Black Caribbean	0	0	35	3
Mixed race	1	5	43	5
Black African	0	0	23	2
Black, other	0	0	13	1
Employment				
Employed	4	19	188	18
Unemployed	15	71	591	58
Student	2	10	208	20
Homemaker	0	0	22	2
Living arrangements				
With parents	13	62	649	63
Alone	3	14	130	13
With partner	3	14	108	11
Other	2	10	137	13

^aIn the National EDEN cohort, data are missing for employment (n = 18), ethnicity (n = 22), and living arrangement (n = 3).

'In EIS, I was seeing my key worker every week or two which was very good but with [the community mental health team worker] ... not so much. I understand that she deals with other people but I've hardly seen her at all recently.' (7-7, FU)

Most were also very positive about the functions of the early intervention service itself. They felt that the early intervention service promoted recovery through engendering a sense of hope for the future at a point when they felt they were missing out on life. This was achieved through practical help such as organising training and employment opportunities, and in accessing benefits, and psychological help through discussions of illness signatures (particular patterns of symptoms) and relapse-prevention planning:

'I was confused but when I was on medication it opened up my mind and it made me think more differently and it made me feel what happened in the past was the past and now this is the future so I have to look ahead.' (1-2, FU)

'I get to see that other people with mental health problems aren't just lying in bed all

day feeling sorry for themselves. They get me more active. They encourage me to be interested in things and to think that I have a future. I thought my life was coming to an end and they kind of encourage me to see that there is life after psychosis.' (6-1, BL)

Early intervention services also enabled most service users to talk with others about their perceived changes in identity and with people who understood what it was like being on the receiving end of negative stereotypes of mental illness. Some of these changes appeared linked to side effects from medication, such as weight gain:

'We're just painted with the same brush but just because you can't see it, it doesn't mean it's not happening. I've met quite a few people with similar problems to me and it's helped because we've discussed how we're different and tried to suggest ways that can sort of help each other or help ourselves.' (7-4, BL)

Barriers to and facilitators of good transitions

Discharge experiences were generally positive, although a minority (about a quarter of the service users the researchers spoke to) described more difficult transitions. The most positive experiences shared a series of common characteristics, particularly in terms of timing. Ensuring the service user themselves felt ready to move on and recognised their ability to self-manage seemed particularly important:

'I think if I'm honest I was sort of starting to perhaps become a little bit dependent on them. I mean I remember R saying to me "you need to think of me as a kind of friend" but I went away thinking "but I don't want a paid friend, I want real ones". Which is what I've got now. So in some ways I'm sad about leaving [EIS] but in another sense I'm glad because it means I've moved on.' (6-1, FU)

Good transitions were planned and expected, but with a strong sense of personalisation that enabled flexibility over the timing of discharge. Positive experiences were also grounded in previous strong and trusting relationships. Good communication between the current early intervention service key worker and service user and the two sectors involved in the transition were also important, so that service users felt both in control and cared for:

'I stayed on a little bit extra; they extended my time so that when I was discharged I felt fine about it because that was the natural thing

to come to an end. During the last 8 months we worked on a lot of things so that was useful as a way of bringing everything together.' (6-2, FU)

'And then obviously time was coming to an end. In fact they let me stay on with them for an extra few months because I had a bad time ... Then I was involved in the decision making and we had a meeting of the new and my old CPN [community psychiatric nurse] and we met up together and it was just to kind of ease it over.' (7-6, FU)

'My GP called me to go in and see him a few weeks ago. The doctor from the EIS had contacted him and so he wanted to like follow-up to see how I was and just blood pressure and stuff like that.' (4-3, FU)

'I had been apprehensive I guess, but I spoke to her [new CPN in the community mental health team] on the phone and she said "look we've been told that you're ready to be discharged do you mind me coming round?" So she came round and I'm glad because I was left thinking she's definitely the right person for the job, nice and really non-judgemental.' (7-1, FU)

The minority of service users who had expressed more ambivalent feelings about their transition described commonalities of experiences, including a sense of unexpected and abrupt endings, even though all knew that early intervention services were not set up as ongoing permanent services. There were also stories of poor information sharing between the two sectors or services involved in the transition, which left service users feeling helpless and on their own. This was contrasted with the help and support they had previously experienced from early intervention services. The language used was also interesting in this respect, including a sense of being passed on or over:

'The day I was told I'd got my new accommodation, that's when my CPN turned round and went "oh good luck in the future. I might see you in the future". And sort of hugged me in the street and then walked away. It was very strange. I knew it was going to happen but I wasn't given a confirmed date. A firm date would have been much better and a bit nicer than "oh good luck you've done it" and that's it.' (7-4, FU)

'The time came when they passed me onto somebody else. It meant me trying to get used to somebody else when I'm already

used to the EI [early intervention] team and the people that come round to see me.' (4-4, FU)

Under-utilisation of primary care

All service users had seen their GP since discharge from the early intervention service, usually for medication and intercurrent physical health problems. However, it was notable that although GP involvement at the point of diagnosis was relatively frequent, most had not then seen their GP or used primary care during the 3 years they were in contact with the early intervention service. This appeared to be related to the intensity of support from early intervention services, which meant that service users felt little need to use primary care:

'The first time I was ill, I saw my GP. They wanted me to take a tablet but I didn't want to take the tablet so they called an ambulance and I was sectioned into hospital.' (1-2, FU)

'No — it'll be a few years ago since I last saw my GP. My GP's not very much involved because mental health is covered by EI and I look after my own physical health.' (1-1, FU)

Following discharge from early intervention, service users particularly valued the ease of access to primary care, as they had with early intervention services, and good continuity in terms of the same GP knowing them over a long period of time (often pre illness). This created a sense of trust, once again echoing the gold standard of early intervention services. However, now the service user was in control of any future changes in the relationship, for example by leaving the practice:

'It's basically a 2 minute walk that way, so if I do need to go and see him it's not like I have to travel a great distance or anything like that, I just nip up the road and go in and see him.' (4-4, FU)

'We do get on really well and I trust her [the GP] ... I felt like, you know, if I felt the early signs, I'd go to my GP and between me and the GP we've organised different things. I trust her and we've got a really good relationship.' (7-3, FU)

GPs who knew them well were often seen by service users as advocates, able to stand up for them within the wider health system. From a service user perspective, GPs didn't have to possess detailed knowledge about psychosis, but did need to recognise when

help was required and know how to access it quickly and effectively.

'GPs can't have training in everything. They can have like a snapshot of all these different things so it's more about how they can use other sources of information that's important rather than them having it all in their head.' (6–2, FU)

'The ones here have known me since I've lived in Cornwall and they know everything and if something's not happening or they're not happy with something, they have been known to phone up and shout at the mental health team and in fact I was in the same room with one of them once when one of them did that and it was quite something to see! ... They've always gone with what my needs are and if I needed more then they sort of fought my case for me.' (7–2, FU)

It was particularly interesting to note that within this small sample of young people, seven had already experienced significant physical health comorbidities such as obesity, diabetes, or heart disease. However, there was little recognition from the majority of service users of the potential physical health problems in store or of the need to actively address them with their GP. Indeed, with the exception of weight gain secondary to medication (see below), discussions about physical health were noticeably absent both during contact with early intervention services and after discharge. The following quotations demonstrate a rare example of proactive care from primary care and an example of premature cardiac morbidity:

'Dr Z [GP] is a really nice doctor. I've not seen him for some time but he was concerned with my weight gain and he wrote to Dr M [psychiatrist] and then he was concerned too, so they're now both taking notice of the fact my shape's changing and stuff with the medication.' (7–3, FU)

'Since I had my heart attack they sent me to kind of like a rehabilitation class, it's just to get you to do gentle exercise. To be honest I'm a 36-year-old guy in a room full of 65 and 70 year olds. I felt so out of place — like an idiot you know doing yoga with a 70-year-old man and stuff like that ... It's only been 9 months since I had my heart attack so I'm still basically getting used to this new life.' (4–2, FU)

DISCUSSION

Summary

This paper suggests that the intense nature

of early intervention services is highly prized by service users; however, the 'gold standard' nature of the care is difficult to replicate in other non-early intervention services and may lead to unrealistic expectations. Flexibility in terms of the timing of discharge does appear to be happening in practice, but continuity is not always well established before discharge. Well-managed transitions highlighted the importance of professionals personalising transitions and situating them in the context of service users' daily life.

Primary care seems to be under-utilised, both as a location of care during time with the early intervention service, despite valued characteristics such as access and continuity, and as a skill set, particularly for physical health problems. Although service users did not expect GPs to know everything about psychosis, they did expect them to be able to advocate for and navigate the health system, particularly at times of crisis or relapse.

Strengths and limitations

Transition, at least in the context of mental health, is often discussed but rarely examined and this paper is, the authors think, the first to report service users' views of discharge from early intervention services. Most focus has been on engaging people into services as early as possible, with much less emphasis on discharge planning. The data also highlight the significant physical health challenges faced by such young people, and the potential role of primary care in helping them address them. Although it was felt that data saturation was reached, this is a relatively small study of 21 young people at two time points [42 interviews], although generalisability in qualitative research is linked more to transferability of concepts than study size.¹⁸ The interviews were based on service users' recall of events, making the data subject to recall bias. The background of one of the interviewers as a GP may also have influenced the analysis of the data, although all coding was agreed jointly with non-GP researchers. It is also not known whether those who declined to engage with the study at follow-up were different from the 21 who did engage. In terms of demographic variables, the interviewees were very similar to the wider National EDEN cohort.¹⁵ However, bearing in mind the small numbers in this study, the data presented here are less applicable to the experiences of those from ethnic minority communities. Low follow-up rates were largely related to problems in accessing

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Competing interests

The authors have stated that there are none.

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contact details after discharge from early intervention services rather than individual refusal to participate further.

Comparison with existing literature

The accounts of these service users resonate with a number of other studies that have focused on people with a serious mental illness.^{12,19,20} Previous qualitative studies in the UK have found that service users emphasise the importance of building a long-term relationship with a professional and express frustration at having to repeatedly review their medical histories during transition periods.¹⁹ In the US, qualitative data from interviews with adults with psychosis (mean age 48 years) found that competent trustworthy doctors were most valued, and when the 'fit' with clinicians was good, ongoing relationships over a period of time led to better illness and medication management. In the UK ECHO (Experiences of Continuity of Care and Health and Social Outcomes) study, Jones and colleagues explored continuity of care in mental health services for service users with serious mental illness, and highlighted the difficulties of definition, fragility of continuity, and importance of professionals personalising transitions.¹² They also suggested that face-to-face communications between community mental health teams and GPs were facilitators of informational continuity.²¹ However, transitions between early intervention services and primary care do appear to be better than other transition points in a mental health service user's illness career. For example, Singh and colleagues found that for the vast majority of service users, transition from children's

mental health to adult mental health services was poorly planned, poorly executed, and poorly experienced.²² The physical health needs of people with psychosis are well documented,^{23,24} and reflected in English national guidance.^{25,26} However, this paper suggests that both primary and secondary care health services and service users themselves have yet to respond fully to the physical health challenges posed by the condition, lifestyle, and treatments.

Implications for research and practice

This study suggests that early intervention services should focus on actively establishing relationships between service users and either the community mental health team or GP in the months leading up to discharge, and also ensuring that service users' expectations are 'realistic' in terms of access to and availability of care. Primary care could be better utilised when service users are actively engaged with early intervention services, to help ensure physical health needs are met from the start of treatment. In the UK, the pay-for-performance scheme (the Quality and Outcomes Framework) now includes a series of discrete annual physical health indicators such as body mass index, smoking habits, blood pressure monitoring, and glucose and cholesterol testing, which mean that primary care is now well placed and financially rewarded to implement a series of physical-health-screening interventions.²⁷ It will be interesting to see if the introduction of such measures leads to better cardiometabolic outcomes for future service users.

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