Original Article

First episode psychosis in the over 35s: is there a role for early intervention?

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Abstract

Aim: The early intervention (EI) model appears to improve outcomes of psychosis for younger people, and there is now interest in implementing it in older groups. In the UK, the National Institute of Clinical Excellence advised that EI should be accessible to all individuals with first episode psychosis (FEP). We aimed to explore the likely impact on EI workloads and clinical populations of extending age range.

Methods: Data were collected on all patients aged 36–65 years who were referred to an inner London EI service from 2011–2014 using the MiData 2 tool at entry and at 1-year follow up.

Results: People aged between 36 and 65 represented 30% of all referrals to the service. There were high levels of recorded past trauma in the sample (62.5%), half had dependent children (58.3%) and just under half physical comorbidity (48.6%). Duration of untreated psychosis was less than a year for the majority. At 1-year follow up, inpatient admission rates were lower than in previously studied younger EI populations, but only 15% experienced a single episode with full remission.

Conclusions: These findings indicate that admitting over 35-year-olds to EI results in a substantial increase in workload. A large proportion had become unwell relatively recently, indicating that the concept of EI may not be redundant in this age range. Evidence is needed on EI effectiveness in this group.

Key words: early intervention, older patients, outcome, psychosis.

INTRODUCTION

Significant benefits have been established for the early intervention (EI) model, with improvements in recovery rates and reductions in relapse, suicides and overall costs.[1–6] Guidelines (e.g. IRIS,[7] Mental Health Policy Implementation Guide,[8] Orygen[9] and STEP[10]) have recommended a youth focus, with for example 35 the usual upper age limit in the UK. This reflects a recognition of specific difficulties associated with early disruption of personal and social development by psychosis, and an aim to engage young people by tailoring services to their needs and interests and making them feel accessible and acceptable, for example through group activities with similar aged peers.

However, a concern for equity has resulted in debate about whether EIS should be extended to older age groups. This is especially relevant to women, who on average present later.[11] It is also recognized that many of the interventions delivered by EIS are in practice not age specific.

Potential arguments against extending EIS age range include that older groups will have significantly different needs from the population EIS was set up to treat, so that benefits cannot be assumed to generalize. For example, organic factors may be more prominent, requiring different expertise in assessment and management than presentations in younger people. Older people may have been ill for longer and may be beyond the 'critical period' hypothesized as being crucial for long-term outcomes.[12–14] The different life stage of this group, having already achieved adult roles, may mean that they do not need the intensive occupational and functional support

that EIS provide. An important potential adverse effect of extending the EIS age range is dilution of the youth focus.

We have found only one recent paper that examined clinical characteristics by age. Selvenrdra *et al.*[15] found that over 25 s in an Australian cohort were more likely to have depressive psychosis and had more metabolic morbidity than under 25 s. Beyond this, little relevant literature is available to inform service planning for the over 35 s. In England, this is a particularly pressing need, as the latest update of National Institute of Clinical Excellence Guidelines for psychosis and schizophrenia in adults [16] (1.3.1.1) recommends that EI be available across the age range. The English experience is also of interest for other countries where issues of equity have been raised in relation to EI services.

Aims

In this paper, we will aim to

1. Describe the numbers and characteristics of over 35 s referred to an EI service which since 2011 has accepted people aged 18 to 65.
2. Make a preliminary assessment of the extent to which there may be scope to intervene early in this group to improve the course of their illness, including examining the stage of illness at which they present, whether they already recover well without an intensive intervention, and whether a service that is socially as well as clinically focused appears relevant to them.

METHODS

Setting

The EI services in Camden & Islington cover a diverse inner-city population with a combined total population of 435 800 individuals.[17] Local rates of new presentations with psychosis are high.[17] The area was one of the earlier ones in England to be served by an EIS, established in 2003. However, over the study period, caseloads were very high (at times over 30 per care coordinator) because of a combination of local resource constraints and large numbers resulting from the extension of the age range. There was also an inadequate supply of specialist family, psychological or vocational interventions during this period. The local consensus was thus that the EI model was no longer being delivered with adequate fidelity at this time. Outcome data reported here

should not thus be seen as reflecting what could potentially be achieved by a good quality EIS.

Sample

Data were collected for all patients aged 36–65 years referred and accepted onto the caseload of Camden & Islington EIS, from the time when referrals to over 35 s opened in 2011 to January 2014. During this period, the local service policy was that all new cases of psychosis should be referred to EIS, and there was little indication of breaches of this guidance.

Measures

The Midata-2 tool was completed by local clinicians (S Joshi, A Gregorowicz) from review of electronic records, supplemented by some discussion with other clinicians to fill gaps (Appendix S1 shows the Midata-2 tool). Data were collected at point of EIS referral and 1 year later. MiData-2 is a new brief baseline and follow-up tool designed for collecting routine audit and service evaluation data in EI. Paper and Microsoft Access versions are available. It is a revised shortened version of the MiData standardized data collection tool developed by the London Early Intervention Research Network (LEIRN).[18] MiData-2 includes sociodemographic and clinical data (symptoms, duration of untreated psychosis (DUP), pathways into care, social functioning, substance misuse, service use and course of illness).

MiData-2 includes assessment of DUP with a revised version of the Nottingham Onset Schedule.[19] Service DUP was defined as months between the appearance of the first positive psychotic symptom and date of referral to EIS. ICD-10 (International Classification of Diseases-10)[20] diagnosis at 1-year follow up was as confirmed by the responsible consultant psychiatrist and grouped as non-affective psychosis (codes F20–29), manic psychosis (F30.2, F31.2 or F31.5), depressive psychosis (F32.3, F33.3 or F39) and other.

Ratings for overall course of illness were adapted from Bebbington *et al.* (2006)[21] and Lambert *et al.* (2006),[22] and the symptom and functioning components were based on respective sub-scales of the Global Assessment of Functioning (GAF-S and GAF-D).[23] The categories of illness course were (i) single episode with full remission; (ii) single episode with partial remission; (iii) repeated episodes with full remission; (iv) repeated episodes with partial remission; (v) continuous illness (in the same episode as when presented to EIS); and (vi) not known. An episode was defined as a period of continuous

positive and/or negative psychotic symptoms that interfere with thinking and/or behaviour. Partial remission was defined as residual positive and/or marked negative psychotic symptoms that still have some impact on thinking/behaviour (GAF-S > =31), but sufficient improvement meaning individuals can function safely in the community (with support) with some functional improvement (GAF-D > =31) but not able to hold down a job or study; while full remission required no evidence of positive symptoms and only minimal negative symptoms that do not interfere with behaviour (GAF-S > = 61), where the individual has good functioning (GAF-D > =61) and is capable of engaging in vocational activity.

Procedures

The study was approved locally in Camden and Islington NHS Foundation Trust under procedures for audit and service evaluation: it informed the further development of services for over 35 s. Descriptive tests were used to analyse and present the data.

RESULTS

The referral rate to Camden and Islington EIS for all patients between 2011 and 2014 was approximately 97 referrals per 100 000 population over 18 per year. For each 100 000 population, there were 68 new cases in the 18–35 and 29 in the 36–65 range.

During the study period, 75 patients were identified as having been accepted to caseload who were over 35. Data for three patients were excluded because of limited baseline data and lack of follow-up data, or because of patient non-engagement with the service from the point of acceptance. Therefore, data were available for a total of 72 patients aged 35 and over.

Baseline data

Sociodemographic characteristics

Both genders were equally represented (Table 1). The median referral age was 46 years. A wide range of ethnicities was represented, the largest groups being White British and Black African. Most had been employed in the past, but only a third during the year prior to EIS referral.

More than half had children: 58.1% of those with children under 18 lived with them. Nearly, half lived alone and very few with a partner. Most reported some social contacts.

TABLE 1. Baseline sociodemographic data on over 35 s from the Camden and Islington early intervention service

Characteristic	Frequency $N = 72$ N (%)
Gender	
Male	37 (51.4)
Female	35 (48.6)
Age mean (SD)	45.5 (7.5)
Ethnicity	
White	30 (41.7)
Mixed/multiple ethnic groups	5 (6.9)
Asian/Asian British	8 (11.1)
Black/African/Caribbean/Black British	22 (30.5)
Other ethnic group	5 (6.9)
Not known	2 (2.8)
Vocational information	
Ever undertaken any work	63 (87)
Paid work	57 (79.2)
Voluntary work	1 (1.4)
Type of work not known	5 (6.9)
Worked the last year	26 (36.1)
Children	
Has children	42 (58.3)
Has children age <18	31 (43.0)
Lives with	
Alone	32 (44.4)
Children <18 only	16 (22.2)
Children < 18 and partner	2 (2.8)
Partner	7 (9.7)
Parents	3 (4.2)
Another relative	7 (9.7)
Other	5 (6.9)
Type of accommodation	
Council or state funded	41 (56.9)
Private	17 (23.6)
Currently homeless	1 (1.4)
Not known	13 (18.1)
Social contacts	
Contact with others (Total)	62 (86.1)
Contact with others, supportive	42 (58.3)
Contact with others, unclear if supportive	20 (27.8)
Generally isolated	9 (12.5)
Not known	1 (1.4)

SD, standard deviation.

Clinical characteristics

Whilst initial referrals tended to come from primary care, the immediate source of the majority of referrals to EIS was from secondary mental health services (Table 2). Just under two-thirds had reported a history of significant trauma to clinicians. Half had known physical health comorbidity. A lifetime history of cannabis use was reported to clinicians by a third. About a quarter had a known history of a previous suicide attempt or self-harm prior to the time of referral, and a quarter had a known history of

TABLE 2. Clinical data on over 35 s from the Camden and Islington early intervention service

Characteristic	Frequency N = 72 N (%)
Referral to mental health services	
GP	33(45.8)
GP and A + E	5 (6.9)
GP and counsellor	2 (2.8)
A + E	18 (25.0)
A + E and police	2 (2.8)
Police/criminal justice system	4 (5.6)
Counsellor	2 (2.8)
Other	5 (6.9)
Not known	1 (1.4)
Referral to EIS	
Community mental health team/mental health assessment team	33 (45.8)
Inpatient ward	20 (27.8)
Crisis team/crisis house	12 (16.7)
Primary care	0 (0.0)
Police	0 (0.0)
Other	7 (9.7)
History of trauma (as reported to clinicians)	45 (62.5)
Childhood abuse	15 (20.8)
Experience of war	7 (9.7)
Unexpected/traumatic bereavement	6 (8.3)
Domestic violence	6 (8.3)
Other serious sexual/violent assault	2 (2.8)
Traumatic labour	2 (2.8)
Other childhood adversity	6 (8.3)
Unknown	1 (1.4)
Physical health comorbidity	35 (48.6)
Cannaboids (ever used)	
Yes	25 (34.7)
No	37 (51.4)
Not known	10 (13.9)
History of suicide attempt or self-harm prior to referral	19 (26.4)
History of some form of violence prior to referral	18 (25.0)
DUP of less than 1 year	31 (43.1)
DUP of more than 3 years	13 (18.0)

DUP, duration of untreated psychosis; EIS, early intervention service.

TABLE 3. One-year follow-up data on over 35 s from the Camden and Islington early intervention service

Characteristic	Frequency N = 72 N (%)
Case status	
Patients remaining on the caseload	67(93.1)
Patients discharged	5(6.9)
Patients who had face to face contact in the last 6 months	58(80.6)
Formal CBT (past year)	14(19.4)
Worked (past year)	16(22.2)
Social contacts	
Contact with others (Total)	61(84.7)
Contact with others, supportive	47(65.3)
Contact with others, unclear if supportive	14(33.3)
Generally isolated	8(11.1)
Not known	3(4.2)
Clinical diagnosis	
Non-affective psychosis (including schizophrenia and schizoaffective disorder)	47(65.3)
Manic psychosis	11(15.3)
Depressive psychosis	10(13.9)
PTSD	2(2.8)
Organic psychosis	1(1.4)
Drug induced psychotic disorder	1(1.4)
Course of illness	
One episode of psychosis with full remission	11(15.3)
Single episode with partial remission	21(29.2)
Repeated episodes with full remission	4(5.6)
Repeated episodes with partial remission	16(22.2)
Continuous illness	19(26.4)
Not known	1(1.4)
Inpatient admission, after referral to EIS	8(11.1)
Total inpatient admissions at 1 year (including prior to EIS referral)	35(48.6)
Physical health comorbidity	36(50.0)
Patients taking regular antipsychotic drug	43(59.7)
Risk information	
History of suicide attempt or self-harm over the last year	2(2.8)
History of some form of violence over the last year	4(5.6)

CBT, cognitive behavioural therapy; EIS, early intervention service.

perpetrating some form of violence. Median service DUP was 11 months (range 0–251 months).

One-year follow up

Nearly, all patients remained on caseload (Table 3). Less than a quarter were known to have worked in the last year. There was no change in the distribution of living arrangements or social contacts between entry to EIS and 1-year follow up. There was also no change in the number of patients with known physical health comorbidity over the course of the ear.

The most frequent primary diagnosis was of a 'non-affective psychosis' (65.3%), followed by 'manic psychosis' (15.3%) and 'depressive psychosis' (13.9%). The course of illness was equally distributed between categories, but at 1-year follow up, very few had had only one episode of psychosis with full remission.

Almost half had inpatient admissions either at point of referral to EIS or within the first year of EIS care. More than half were taking regular antipsychotics at follow up. Only a fifth were known

to have undertaken formal cognitive behavioural therapy with the service. The number of patients who had self-harmed or attempted suicide or were known to have perpetrated an act of violence during their first year on the EIS caseload was extremely small.

DISCUSSION

Ours is the first study to describe the characteristics of patients over 35 presenting with FEP and their 1-year outcomes following referral to a specialist EIS.

Referrals for people aged between 36 and 65 represented 30% of total referrals to the service after extension of the age range. Thus, the additional needs for EI services and impact on overall caseload size were considerable. The only directly relevant data for comparison with younger populations are from the MiData project, a cohort of 533 under 36 year-olds presenting with FEP across London, assessed with similar procedures and an overlapping set of measures.[18] Unlike our sample, men predominated in this younger cohort (68% vs 52%). Such gender differences have previously been documented,[1,24] with gender balance evening out in later presenters,[15,25] when there is also a recognized later life peak in incidence in psychosis in women.[11] Thus, gender as well as age discrimination is an issue when considering the EIS age limit.

Our sample was similar to the younger MiData cohort in ethnic distribution, with more than half from black and minority ethnic (BME) groups. The same number (58%) in each cohort reported that they had social relationships that were a significant source of support. More of the older cohort had been employed at some stage (87% vs 63%) and more had children (58.3% vs 11%), in our older cohort. A larger number was living alone than in the younger cohort (44.4% vs 17%).[18]

Clinical characteristics

At 11 months, the median DUP for our cohort was substantially longer than the median DUP of 4 months among younger Londoners in the previous MiData study.[18] Thus, as predicted, there were larger numbers than in younger groups who had been ill for a considerable period. However, the majority had a DUP of less than 1 year at time of referral, so there were a substantial number for whom intervention could realistically be described as early.

When compared with the MiData younger cohort[18] in terms of clinical characteristics, there were higher rates of past suicide or self-harm in our group (26.4% vs 14%) but similar rates of past history of violent behaviour (25% vs 29%). Lifetime cannabis use reported to staff was lower in our sample (34.7% vs 58%) than in the younger cohort.

Half our sample had physical health comorbidity of some type. Recorded morbidities were wide-ranging without clear predominance of metabolic morbidity, which was particularly highlighted in the Australian paper looking at late-onset presenters.[15] However, metabolic morbidity was not explicitly asked about in our study, and it may not have been well screened for in the service.

The majority had reported a history of trauma to assessing clinicians. This is in keeping with accumulating evidence on trauma and psychosis,[26] especially in relation to childhood adversity. Thus, the recent National Institute of Clinical Excellence guidelines recommendation that all patients presenting with psychosis should be assessed for post traumatic stress disorder (PTSD)[16] (1.3.3.2) certainly appears relevant for this group. We cannot comment on how this compares to the younger EI population. However, further research in this area does support higher levels of reporting of childhood abuse in women with psychotic illness, than in men.[27] The gender makeup of our sample (more women than in the younger MiData group) could therefore be one factor influencing the level of trauma reporting in this older age group.

One-year follow up

Relatively few of the cohort were working at the point of referral, and the proportion was no higher at follow up, suggesting a potential unmet need. During the study period, resources for psychological and social interventions were very limited, and the team lacked a dedicated vocational worker. The relatively low levels of vocational recovery and the frequently continuous or recurrent pattern of illness suggest that early intervention to optimize social recovery and prevent future decline is a relevant goal.

Primary psychiatric diagnosis amongst the over 35 group was consistent with findings from the recent Australian Paper looking at older onset psychosis,[15] and previous studies of younger patients with psychotic disorders.[18]

Almost half our sample had an inpatient admission within 1 year (including index admissions prompting the initial EIS referral). This is lower than in a recent study by Mann *et al.* (2014)[28] looking at rates of inpatient admission in the first year following referral to mental health services, across four EI services

(including London). Their data showed rates of 63.2%, for the same time period.

Strength and limitations

The large increase in caseload without increase in resources meant that the team was unable to deliver a high fidelity model of care with a full range of psychological and social interventions and may well also have affected outcomes.

The sample was derived from two ethnically and socioeconomically diverse inner-city London boroughs,[17] a setting not demographically representative of England, which limits generalizability. Additionally, the findings were based on extracting clinician recorded data from electronic patient records to complete the MiData-2 audit tool rather than directly elicited patient data. However, data were collected for the complete cohort of over 35 s taken on by the service during the study period and not selected. One of the questions this paper does not answer is about the impact on the youth focus, and whether the more diverse age range has affected the accessibility and acceptability of an EIS for younger patients. The sample methodology is predominantly descriptive, but description of a complete cohort of early intervention service users over 35 is of considerable current interest in the current context where changes in age range are contemplated.

Our study focuses on patients who were assessed as having FEP and taken onto the team caseload following initial contact with the service. Only one diagnosis of organic psychosis was recorded in this group (Table 3). However, a study limitation is that we do not have precise data regarding numbers screened out as having psychosis of organic origin either prior to referral to EIS or during the initial EIS assessment prior to acceptance onto the caseload. It is also possible that some organic conditions remained undetected at 1-year follow up in this cohort. Thus, it is possible that organic psychoses are less rare in this age group than our findings suggest.

Clinical implications

Increasing age range of early intervention services will significantly increase referral rates and case load numbers.

Our results suggest there may be scope for improving outcomes in people between 36 and 65 years presenting with psychosis through implementation of a full EI model, perhaps with some adaptation to our service. People in this age group presented in substantial numbers with psychosis and while some illnesses appeared very longstanding most were of more recent onset. The range of diagnoses was not strikingly different to younger people. Most had persisting or recurrent difficulties, with just 15% having a single episode with full remission, and most had not made a good occupational recovery at a year, despite the majority having worked in the past. Almost half were admitted in their first year of contact with services, although recorded levels of violent and suicidal behaviour were relatively low. Thus, there is considerable room for improvement in the outcomes obtained in this service, which was of low fidelity at the time of the study.

The study findings also suggest some areas, which may be particularly important for this age group, with implications for staff skills and training. Many of this age group have dependents, so support with parenting, considering children's needs, young carers and addressing safeguarding issues is likely to be a substantial role in working with this group. The high numbers of patients with comorbid physical health problems suggest that expertise and support around physical health assessment, monitoring and specialist prescribing is likely to be important. Although probably a common need for all services caring for patients with psychosis[16] adequate psychological support and staff training in trauma and psychosis and PTSD likewise seem to be important in tailoring services to this group's needs. An important recognized part of EI care is targeting welfare, vocational and occupational support to the needs of the group. With regard to occupational recovery, the task in a group who have in the main worked previously may involve supporting a return to previously established career trajectories rather than establishing a working life or educational pathway afresh. The low numbers working during the year after initial service contact in this cohort suggest a role for specialist vocational input.

Research implications

An assessment of the profiles of older people with psychosis based on researcher-recorded data is desirable, as is data from a more representative range of areas. To establish more conclusively the case for EI in over 35 s, further research should investigate whether an EI model for people over 35 is effective and cost-effective compared with standard care from generic psychosis services, as previously available. Impact on younger groups of widening the age range should also be investigated: we need to establish whether including older groups results in less acceptable and engaging care for younger groups.

Investigation of the optimal ways of addressing the needs of families where a parent develops psychosis and of supporting older people in re-establishing careers would also be valuable.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's website:

Appendix S1. Ia. MiData-2 baseline assessment. 1b: MiData-2 follow-up assessment.