Pathways to care for first-episode psychosis in an early detection healthcare sector

Part of the Scandinavian TIPS study*

JAN OLAV JOHANNESSEN, TOR K. LARSEN, INGE JOA, INGRID MELLE, SVEIN FRIIS, STEIN OPJORDSMOEN, BJØRN RISHOVD RUND, ERIK SIMONSEN, PER VAGLUM and THOMAS H. McGLASHAN

Background Early detection programmes aim to reduce the duration of untreated psychosis (DUP) by public education and by prompt access to treatment via active outreach detection teams.

Aims To determine whether those with first-episode psychosis in an early detection healthcare area with existing referral channels differ from those who access care via detection teams.

Method Those with first-episode psychosis recruited via detection teams were compared with those accessing treatment via conventional channels, at baseline and after 3 months of acute treatment.

Results Patients recruited via detection teams are younger males with a longer DUP, a less dramatic symptom picture and better functioning; however they recover more slowly, and have more symptoms at 3-month follow-up.

Conclusions After establishing low threshold active case-seeking detection teams, we found clear differences between those patients entering treatment via detection teams *v.* those obtaining treatment via the usual channels. Such profiling may be informative for early detection service development.

Declaration of interest Supporters included Lundbeck Pharma, Eli Lilly and Janssen-Cilag Pharmaceuticals; full details in Acknowledgements.

*Paper presented at the Third International Early Psychosis Conference, Copenhagen, Denmark, September 2002.

Today, the duration of untreated psychosis (DUP) is long in most western countries (Johannessen *et al*, 1999; McGlashan, 1999; Norman & Malla, 2001). The reasons for this are varied. Four restrictions to earlier detection and intervention have been identified: (1) the patients themselves; (2) the patients' families; (3) the primary healthcare system; and (4) the specialised psychiatric services. This results in patients receiving treatment unnecessarily late in the illness development, with its inherent subjective suffering and negative consequences for the individual's psychosocial adaptation and development. Long DUP may also have a negative impact on the individual's long-term prognosis, although this has not been conclusively demonstrated (Altamura *et al*, 2001).

We know little about how organisational structures in the health services influence important parameters, such as DUP. In Germany, Fuchs & Steinert (2002) found that patients with a first-episode psychosis who came to treatment via a general practitioner had the shortest DUP. However, only 24% of the patients entered psychiatric services via this route. In Australia, Lincoln *et al* (1998) reported that 50% of people developing a first-episode psychosis experienced psychotic symptoms before approaching any service. The general practitioner played a key role, with 50% of people having had this contact at some point prior to commencing effective treatment. Where an individual's own efforts to seek early help failed, the role of relatives and others was subsequently vital. DUP via these different pathways is not accounted for in that study. de Haan *et al* (2002) carried out a survey on European families concerning their priorities and satisfaction with the services provided in a first-episode psychosis. The respondents emphasised the need for early intervention through outreach. Drake *et al* (2000) found that longer DUP results from a pattern of symptoms and social functioning that reduces the concern of the sufferer and relevant others. Long DUP was predicted by poor insight and social isolation but preserved basic coping skills.

In a previous study on pathways to care for first-episode psychosis (Larsen *et al*, 1998) we found that patients with a long DUP (>1 year) were young males with a poor social network, social withdrawal and a more deteriorating course, compared with patients with a short duration of untreated psychosis (<1 year).

In this paper we review those patients with first-episode psychosis obtaining treatment in a healthcare sector with an established early detection system of public education about psychosis and easy access to care through active outreach. We also investigate the differences, at first admission and following 3 months of acute treatment, between those patients obtaining treatment via the teams and those obtaining help via existing referral systems.

METHOD

Setting

The TIPS project (Early Identification and Treatment of Psychosis) is a four-site prospective clinical trial in Norway and Denmark designed to investigate the effect of the timing of treatment in first-episode psychosis. Two healthcare sectors (Stavanger and Haugesund, comprising Rogaland County, Norway) are experimental and have developed a system for early detection, aimed at reducing DUP. Two other sectors (Ullevål, Norway, and Roskilde, Denmark) are sectors used as comparison and rely on existing referral systems for first-episode psychosis. The study ultimately will compare early detected patients with those detected via conventional routes. This paper discusses only the experimental sector.

The experimental sectors are characterised by a comprehensive education and detection system designed to enhance knowledge about early signs of psychosis among the general public, schools and health professionals. Early detection teams have been established in the experimental sectors in order to lower the threshold of entry to specialised psychiatric services, and to recruit appropriate patients as early as possible in the illness course. The teams comprise psychiatrists, psychologists, psychiatric nurses and social workers. They are on call from 08.00 h until 16.00 h,

https://doi.org/10.1192/bjp.187.48.s24 Published online by Cambridge University Press

Monday to Friday. The teams are mobile and work with a dynamic outreach attitude. Details of the programme have been described elsewhere (Johannessen *et al*, 2001; Larsen *et al*, 2001). The active period of inclusion was 1997–2000, with follow-up planned at 3 months, 1, 2, 5 and 10 years.

In the early detection area, mean DUP was reduced to 25.3 weeks (median 4.5, s.d.=61.7) in the period 1997–2000, compared with 114.2 weeks (median 26.0, s.d.=173.6) before the project started (1993–1994) (Larsen *et al*, 2001). These results indicate that the early detection strategies are successful in changing the attitude to obtaining help.

Study population

The sample consists of patients recruited to first treatment in the early detection sectors, Rogaland County, Norway in the TIPS study. The population of the County is 370 000.

Our clinical hypothesis is that the lowered threshold to treatment and active case-seeking, as carried out by the detection teams, would facilitate the help-seeking process for those patient groups that we had earlier found to be recruited into treatment late in the illness development. These are usually young males with a long DUP, a weak social network and a less dramatic symptomatology (Larsen *et al*, 1998). As a result we would expect a higher percentage of such patients among those recruited through the teams.

The criteria for inclusion were: (a) a first episode of a non-affective psychosis, i.e. schizophrenia, schizophreniform, schizoaffective and delusional disorder, brief psychosis, affective disorder with mood incongruent, delusions, and psychotic disorder not otherwise specified; non-narrow schizophrenia or spectrum disorder (non-NSSD); (b) living in the catchment area; (c) age 15–65 years; (d) IQ > 70 and (e) a first episode of psychosis. The exclusion criteria were a history of an earlier treated first psychosis, receiving adequate prior neuroleptic treatment and organic or substance-induced psychosis. Written informed consent was obtained from all the individuals and the study was approved by the Regional Committee for Medical Research Ethics and the Data Inspectorate.

Instruments

Diagnosis was identified using the Structured Clinical Interview for the DSM–IV Axis I Disorders (SCID–I; First *et al*, 1995). Symptom levels were measured with the Positive and Negative Syndrome Scale (PANSS; Kay *et al*, 1987). Global functioning was measured by the Global Assessment of Functioning Scale (GAF; American Psychiatric Association, 1994), the scores were split into symptom scores (GAF–S) and function scores (GAF–F) to improve psychometric properties. The DUP was measured as the time from the first onset of positive psychotic symptoms (the first week with a PANSS score of 4 or more on Positive Scale items 1, 3, 5, 6 or General Scale item 9) to the start of first adequate treatment of psychosis, i.e. admission to the study. Multiple sources, including personal interviews with patients and relatives, were used to ascertain the length of this period. Premorbid functioning was measured by the Premorbid Assessment of Functioning Scale (PAS; Cannon-Spoor *et al*, 1982). Drug and alcohol use was measured by the Clinician Rating Scale (Drake *et al*, 1990). Social functioning (number of friends and participation in meaningful activities) during the year before the start of treatment was measured with the Strauss–Carpenter scale (Strauss & Carpenter, 1974).

All raters were trained in the use of study instruments by rating pre-prepared case notes and audio/videotapes before entering the study assessment teams. The rating of essential variables, such as diagnosis and DUP, was achieved by consensus with experienced clinical researchers. Reliability for the PANSS scores was measured by the rating of videotaped interviews of patients with first-episode psychosis by all raters. Reliability for diagnosis, GAF and DUP was measured by the rating of actual case notes by masked raters with long clinical research experience. Reliability of measurements was fair to very good (for details see Friis *et al*, 2003). For the PAS, a test–retest was carried out with a masked rater in 1993–1994. As it showed good reliability with intraclass correlation between 0.84 and 0.87, no specific reliability test was carried out for the PAS in the TIPS study, but all raters were experienced.

Statistics

Analyses were performed with the Statistical Package for the Social Sciences (version 11.0) for Windows. Mean values are reported with standard deviations in parentheses, and median values are reported for skewed variables. The *t*-test is used for comparison between groups, with dichotomised data the χ^2 test and the Fisher's exact test were used. Non-parametric tests are used for data without normal distribution. All tests are two-tailed. As noted in several other studies, DUP is not normally distributed, although its natural logarithm has a normal distribution. All analyses that include DUP are thus non-parametric where possible. In parametric analysis, the DUP has been transformed to its natural logarithm. In order to determine which characteristics contributed to the patients being identified by the detection teams, a logistic regression analysis was performed.

RESULTS

Referrals to the detection teams 1997–2000

A total of 203 study-appropriate patients with first-episode psychosis were identified by early detection in Rogaland County. Of these, 78 made their first contact via the detection teams (38%) and the remainder (125, 62%) via existing channels. The detection team patients were more reluctant to join the TIPS project. Of these, 22 (28%) refused to participate in the study compared with 20 (16%) of the non-detection team patients (χ^2=4.36; d.f.=1; P<0.05). Consequently, 56 team and 105 non-detection team patients gave informed consent, and form the sample for further comparisons.

For the 4-year period of active inclusion, the contacts with the detection teams were about one per day. Out of 1921 contacts, 107 individuals had a first-episode psychosis (Table 1).

The pattern of referral for treatment in the early detection sector changed, with about 50% of the referrals coming from the patient's family, or the patients themselves via the detection team. This is in contrast to before the project began, when all the referrals were made by general practitioners.

Patient characteristics at baseline

The samples recruited via the detection teams *v.* conventional channels did not differ at baseline diagnostically (i.e. percentage schizophrenia, schizophreniform disorder, schizoaffective disorder, psychotic disorder not otherwise specified, mood incongruent affective psychosis, delusional

https://doi.org/10.1192/bjp.187.48.s24 Published online by Cambridge University Press

Table 1 Referrals to the detection teams 1997–2000

	n	Possible first-episode psychosis (%)
Total contacts with the detection teams	1921	
Anonymous contacts	423	
Possible first-episode psychosis	986	
PANSS interviews	802	81
First-episode psychosis[1]	107	11
Study-appropriate patients	78	8
Refusers	22	
Included in TIPS[2]	56	6

PANSS, Positive and Negative Syndrome Scale.
1. Includes patients who are not study-appropriate, such as those with drug-induced psychosis, living out of catchment area, low IQ and inability to speak the native language.
2. Twenty-nine per cent refused to participate in the study.

Table 2 Comparison between included patients recruited through the detection teams and non-detection teams at baseline

	Detection teams (*n*=56)	Non-detection teams (*n*=105)	*P*
Age at start of treatment	22.5 (5.4)	26.3 (8.6)	0.001
Gender (% males)	73	53	0.02
DUP in weeks: mean (median, s.d.)	53.4 (18.0, 97.3)	31.9 (4.0, 126.0)	0.001
Drug misuse	2.1	1.7	0.03
Alcohol misuse	2.0	1.9	0.1
Treated as out-patients	25.0	7.6	0.002
Global assessment of functioning			
Function	37.6 (9.8)	32.2 (9.8)	0.001
Symptom	33.6 (5.6)	29.9 (6.6)	0.001
PANSS at hospitalisation			
Positive	18.1 (4.5)	18.9 (5.2)	0.3
Negative	14.3 (5.9)	14.2 (6.3)	0.9
General	31.7 (8.0)	32.3 (8.3)	0.7
Total symptoms	64.1 (13.0)	65.4 (15.7)	0.6

DUP, duration of untreated psychosis; PANSS, Positive and Negative Syndrome Scale.

Table 3 Comparison between included patients recruited through the detection teams and non-detection teams at 3-month follow-up

	Detection teams (*n*=51)	Non-detection teams (*n*=96)	*P*
Global Assessment of Functioning			
Function	48.4 (11.1)	52.3 (13.8)	0.08
Symptom	46.1 (11.4)	52.2 (15.1)	0.01
PANSS at 3 months			
Positive	12.8 (5.0)	11.2 (4.7)	0.06
Negative	13.9 (6.0)	12.2 (5.4)	0.08
General	27.5 (8.7)	24.3 (7.1)	0.02
Total symptoms	54.2 (16.4)	47.7 (14.5)	0.02

PANNS, Positive and Negative Syndrome Scale.

disorder, brief psychosis), premorbidly (PAS), neuropsychologically (executive function, verbal learning, working memory, impulsivity), or functionally according to the Strauss–Carpenter scale (work, meaningful activity, friends and hospitalisation in the past year, and symptoms in the past month). Differences between the samples recruited via the detection teams *v.* existing channels are shown in Table 2.

We found the detection team sample to be younger with a mean age at start of treatment of 22.5 years (s.d. 5.4) (males 21.8; females 24.3) as opposed to the non-detection team sample with a mean age at start of treatment of 26.3 years (s.d. 8.6). The teams recruited more males (73%) as opposed to non-team patients (53%).

DUP was longer in the detection team sample, with a median of 18.0 weeks (mean 53.4; s.d. 97.3) *v.* median 4 weeks (mean 31.9; s.d. 97.3) in the non-team sample. The detection team sample had a higher score on drug use, but no differences on alcohol use.

At admission, the detection team group was found to be better functioning as measured by the Global Assessment of Functioning Scale (GAF). On the Positive and Negative Symptom Scale (PANSS) there were no significant differences between the two groups.

Patient characteristics at 3-month follow-up

A higher percentage of the detection team sample was treated on an out-patient basis: 25% in the team group *v.* 7.6% in the non-team group. Although there were no differences on admission, the non-detection team patients had a total PANSS score of 47.7 after 3 months, the detection team patients 54.2. This difference was also apparent as measured on the GAF, with the non-detection team group showing a much higher degree of symptomatic improvement after 3 months, and also a higher level of social functioning at 3 months (GAF–S 52.2 *v.* 46.1, and GAF–F 52.3 *v.* 48.8) (Table 3).

DISCUSSION

The overall DUP was significantly reduced in the early detection sector during 1997–2000. Detection teams received about one referral per day, in a population of about

https://doi.org/10.1192/bjp.187.48.s24 Published online by Cambridge University Press

380 000, and about half of these referrals were screened for psychosis by a full PANSS interview. One out of eight of those screened had symptoms of first-episode psychosis. The initial concern by practitioners in specialised psychiatric services that they would be overwhelmed by referrals proved not to be the case. The referral pattern changed significantly from the period before the project began, with more than half the referrals being made by non-medical individuals, such as the patient's close family members.

A major aim of the early detection sector is to make the entry to treatment more straightforward for people developing psychotic disorders. After 4 years' experience with detection teams, we found that the teams recruited young males with longer DUP, who had better functioning but more substance misuse. They were also more frequently treated on an out-patient basis. However, they proved to be less responsive to treatment during the acute phase. This could be interpreted as the non-detection team group showing a more dramatic spectrum of symptoms resulting in more conventional admission, whereas the detection team group had a more insidious onset, with a symptom profile that did not alarm the patients and/or their relatives sufficiently to initiate contact with the treatment system via the usual channels. It appears that detection teams may be required in order to net patients with fewer symptoms and longer DUP.

At 3-month follow-up, the detection team group was characterised by social withdrawal to a higher degree than the non-team group, which probably is one of the basic characteristics of these patients. The main factors associated with their less robust response to treatment appears to be longer DUP and younger age. The patients identified by the teams seem to be similar to the patients with a long DUP found in our previous study (Larsen *et al*, 1998). We have since reported that those early detected patients as a group are less ill at the start of treatment (Larsen *et al*, 2001). This also seems to be the case for the patients with a long DUP. Is the poorer response to treatment in the acute phase for the detection team group in this study a result of long DUP, or is DUP only a confounding factor? We hope that we will have more information about this when we report the long-term follow-up results from the TIPS study.

CLINICAL IMPLICATIONS

- The use of active outreach detection teams is an effective instrument in lowering the threshold for treatment for patients with first-episode psychosis.
- The specialised psychiatric health service is not overwhelmed by referrals when the threshold for treatment is lowered for patients with first-episode psychosis.
- The use of detection teams appears to identify patients with a less dramatic symptomatology, i.e. young men with a long duration of untreated psychosis (DUP).

LIMITATIONS

- The study does not indicate the relative contribution of detection teams *v.* the information programmes to the overall shortening of DUP in the early detection sector.
- The study does not provide conclusive evidence for why the detection team group recovers more slowly.
- The cost-effectiveness of an early detection programme has not been established.

JAN OLAV JOHANNESSEN, MD, TOR K. LARSEN, MD, INGE JOA, RN, MSc, Division of Psychiatry, General Hospital of Rogaland, Stavanger; INGRID MELLE, MD, SVEIN FRIIS, MD, STEIN OPJORDSMOEN, MD, Ullevål University Hospital, Oslo; BJØRN RISHOVD RUND, PhD, Institute of Psychology, University of Oslo, Norway; ERIK SIMONSEN, MD, Roskilde Psychiatric University Hospital Fjorden, Roskilde, Denmark; PER VAGLUM, MD, Department of Behavioural Sciences in Medicine, University of Oslo, Norway; THOMAS H. McGLASHAN, MD, Yale University School of Medicine, New Haven, Connecticut, USA

Correspondence: Dr Jan Olav Johannessen, Division of Psychiatry, General Hospital of Rogaland, Armauer Hanssens vei 20, 4000 Stavanger Norway. E-mail: jojo@sir.no

The main advantage of a detection team is rapid response and a high level of mobility, including the possibility of visiting the patients in their homes, schools, etc. The teams have a relaxed attitude towards patients using drugs, which could be a possible explanation why the detection team patients have a higher level of substance misuse than those accessing the treatment system via existing channels.

To our knowledge, this is the first study to measure the characteristics of patients contacted by detection teams in an early detection programme. For a population of about 400 000, a team comprising four people appears to be adequate for detection and screening purposes, depending on geography and communications.

Our findings suggest that early intervention systems that include outreach case-seeking structures with easy access to treatment will recruit a younger but more chronically disordered subgroup of patients with first-episode psychosis. This is an important and often difficult to reach group. This is also reinforced by our finding that patients contacted by a detection team were more reluctant to join the TIPS project with its comprehensive treatment programme. Understanding the different patterns of response to specific early detection system elements can aid in the construction of effective early detection and intervention public health systems.

ACKNOWLEDGEMENTS

This paper is part of the TIPS project with the following research group: Thomas McGlashan, MD (principal investigator), Per Vaglum MD (principal investigator), Svein Friis, MD, Ulrik Haahr, MD, Jan Olav Johannessen, MD, Tor K. Larsen, MD, Ingrid Melle, MD, Stein Opjordsmoen, MD, Bjørn Rishovd Rund, PhD, Erik Simonsen, MD.

From the Department of Psychiatry, Yale University, New Haven, Connecticut, USA; Ruskide County Psychiatric Hospital Fjorden, Roskilde, Denmark; Rogaland Psychiatric Hospital, Haugesund Hospital, Ullevål University Hospital and the

https://doi.org/10.1192/bjp.187.48.s24 Published online by Cambridge University Press

Departments of Psychiatry, Psychology and Behavioural Sciences, University of Oslo, Norway.

This study was supported by the Norwegian National Research Council (nos 133897/320 and 154642/320), the Norwegian Department of Health and Social Affairs, the National Council for Mental Health/Health and Rehabilitation (nos 1997/41 and 2002/306), Rogaland County and Oslo County (P.V., J.O.J., S.F., T.K.L., I.M. and S.O.). Also funded by the Theodore and Vada Stanley Foundation, the Regional Health Research Foundation for Eastern Region, Denmark; Roskilde County, Denmark, Helsefonden Lundbeck Pharma, Eli Lilly and Janssen-Cilag Pharmaceuticals (E.S.). Also supported by a National Alliance for Research on Schizophrenia and Depression (NARSAD) Distinguished Investigator Award and National Institute of Mental Health grant MH-01654 (T.H.McG) and NARSAD Young Investigator Award (T.K.L.).

REFERENCES

Altamura, A.C., Bassetti, R., Sassella, F., *et al* (2001) Duration of untreated psychosis as a predictor of outcome in first-episode schizophrenia: a retrospective study. *Schizophrenia Research*, **52**, 29–36.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders* (4th edn). Washington, DC: American Psychiatric Association.

Cannon-Spoor, H. E., Potkin, S. K. & Wyatt, R. J. (1982) Measurement of premorbid adjustment in chronic schizophrenia. *Schizophrenia Bulletin*, **8**, 470–484.

deHaan, L., Kramer, L., van Raay, B., *et al* (2002) Priorities and satisfaction on the help needed and provided in a first episode of psychosis. A survey in five European Family Associations. *European Psychiatry*, **17**, 425–433.

Drake, R. E., Osher, F. C., Noordsy, D. L., *et al* (1990) Diagnosis of alcohol use disorders in schizophrenia. *Schizophrenia Bulletin*, **16**, 57–67.

Drake, R. J., Haley, C. J., Akhtar, S., *et al* (2000) Causes and consequences of duration of untreated psychosis in schizophrenia. *British Journal of Psychiatry*, **177**, 511–515.

First, M. B., Spitzer, R. L., Gibbon, M., *et al* (1995) *Structured Clinical Interview of DSM–IV Axis I Disorders (SCID–I): Patient Edition*. New York: New York State Psychiatric Institute.

Friis, S., Larsen, T. K., Melle, I., *et al* (2003) Methodological pitfalls in early detection studies – the NAPE Lecture 2002. *Acta Psychiatrica Scandinavica*, **107**, 3–9.

Fuchs, J. & Steinert, J. (2002) Pathways to psychiatric care and duration of untreated psychosis in first-episode psychosis patients. *Fortschritte der Neurologie – Psychiatrie*, **70**, 40–45.

Johannessen, J. O., Larsen, T. K. & McGlashan, T. H. (1999) Duration of untreated psychosis: An important target for intervention in schizophrenia? *Nordic Journal of Psychiatry*, **53**, 275–283.

Johannessen, J. O., McGlashan, T. H., Larsen, T. K., *et al* (2001) Early detection strategies for untreated first-episode psychosis. *Schizophrenia Research*, **51**, 39–46.

Kay, S. R., Fiszbein, A. & Opler, L. A. (1987) The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, **13**, 261–267.

Larsen, T. K., Johannessen, J. O. & Opjordsmoen, S. (1998) First-episode schizophrenia with long duration of untreated psychosis. *British Journal of Psychiatry*, **172** (suppl. 33), 45–52.

Larsen, T. K., McGlashan, T. H. & Johannessen, J. O. (2001) Shortened duration of untreated first episode of psychosis: Changes in patient characteristics at treatment. *American Journal of Psychiatry*, **158**, 1917–1919.

Lincoln, C., Harrigan, S. & McGorry, P. D. (1998) Understanding the topography of the early psychosis pathways. *British Journal of Psychiatry*, **172** (suppl. 33), 21–25.

McGlashan, T. H. (1999) Duration of untreated psychosis; marker or determinant of course? *Biological Psychiatry*, **46**, 899–907.

Norman, R. M. G. & Malla, A. K. (2001) Duration of untreated psychosis: A critical examination of the concept and its importance. *Psychological Medicine*, **31**, 381–400.

Strauss, J. S. & Carpenter, W. T. Jr (1974) The prediction of outcome in schizophrenia: II. Relationships between predictor and outcome variables: a report from the WHO international pilot study of schizophrenia. *Archives of General Psychiatry*, **31**, 37–42.

https://doi.org/10.1192/bjp.187.48.s24 Published online by Cambridge University Press