

USE OF NICE GUIDELINES IN SCHIZOPHRENIA IN A POPULATION WITH A LEARNING DISABILITY

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Introduction

Schizophrenia is a major psychiatric syndrome, characterised by acute schizophrenia and chronic schizophrenia. The dominant clinical features in acute schizophrenia are delusions, hallucinations and interference with thinking, which are often called 'positive symptoms'. The main features of chronic schizophrenia are apathy, lack of drive, slowness and social withdrawal, which are often called 'negative symptoms'. Once the chronic syndrome is established few patients recover completely.

The point prevalence of schizophrenia in people with learning disabilities is about 3% compared with 1% in the general population. However, it is difficult to diagnose Schizophrenia in this population with learning disabilities, as it is difficult to elicit psychopathology, due to communication problems, both comprehension as well as expression. Most of the psychopathology is manifested as changes in behaviour.

The National Institute for Clinical Excellence (NICE) guidelines on the treatment and management of schizophrenia was

published in December 2002 and is divided into 3 phases: (i) the initiation of treatment at the first episode (ii) acute phase and (iii) promoting recovery. The guidelines make good practice points and recommendations for psychological, pharmacological and service level interventions in the 3 phases of care in both primary care and secondary mental health services. The psychological treatments mentioned are for use in addition to antipsychotic medication.

Audit measures suggested by NICE include (i) family interventions (ii) Cognitive Behavioural Therapy (CBT) (iii) Outreach/ Assertive community treatment (vi) parenteral medication (v) rapid tranquillisation (vi) polypharmacy, (vii) advance directives 1 and 2 (viii) information (xi) occupational needs (x) case registers in primary care (xi) physical health in primary care and second opinions.

The aim of this study is to look at how NICE guidelines in schizophrenia are implemented in a sample population with learning disabilities. A second aim is to look at areas that need improvement and to establish a high standard of care in management of schizophrenia in this population.

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Method

The study included patients with a diagnosis of learning disability and schizophrenia, schizophreniform psychosis, schizoaffective disorder or psychosis in the mid-Essex and North Essex areas of the Trust.

The data collection form included information about (i) demographic variables such as sex, age, accommodation, inpatient or outpatient status

(ii) degree of learning disability, diagnosis, international classification of diseases, ICD 10 coding (iii) medication such as antipsychotics, regular and as prescription required as needed (PRN), number of antipsychotic medications, the type of antipsychotic medication and dose of antipsychotic medication. The use of anticholinergic medication, regular and prescription required as needed (PRN) for the side effects of antipsychotic medication. The use of PRN antipsychotic and anticholinergic medication, the indications, frequency, the maximum daily dose, and regular reviews of the medication. Also included is the decision making process for the prescription of antipsychotic medication.

Audit measures suggested by NICE mentioned above and exceptions to these audit measures are discussed. The data was collected by doctors between December 2005 and March 2006 from patients medical notes and from relatives, carers, staff during clinic appointments and ward rounds

Results

The demographic variables and diagnosis of the learning disability population studied is shown in TABLE I. The group consisted of a total number of 52 patients, of which 30 (58%) were males and 22 (42%)

are females. Thirty members of the group (58) were over the age of 50 years, of these 33% (N=17) are males and 25% (N=13) are females. The remaining 42% (N=22) were under the age of 50 years and of these 25% (N=13) are males and 17% (N=9) were females. The group consists of 87% (N=45) who were out patients and 13% (N=7) who are inpatients. While 7% (N=4) lived in their own or family home, 84% (N=43) lived in residential or group homes with staff support, 2% (N=1) is a long-term in-patient living in hospital 7% (N=4) accommodation not available in data collection forms. A total of 80% (N=41) have mild/moderate learning disability, while 20% (N=11) have severe/profound learning disability. A diagnosis of schizophrenia was made for 40% (N=21) of the group, with 12% (N=6) having schizophreniform illness, 13% (N=7) have schizoaffective disorder, and 35% (N=18) have a diagnosis of psychosis.

The use of antipsychotic medication, anticholinergic medication, as required PRN medication and decision to prescribe medication is given in TABLE II. 4% (N=2) were on no antipsychotic medication, 96% (N=50) were on antipsychotic medication both regular and as PRN. Of these, 74% (N=38) were on one antipsychotic and 22% (N=12) were taking two antipsychotics. Although one patient (2%) received regular intramuscular injections of antipsychotic medication, none of the group were on PRN intramuscular injections of antipsychotic medication. 46% (N=23) of the group were on regular oral Risperidone, 2% (N=1) on intramuscular injection of Risperidone, and 2% (N=1) on PRN Risperidone.

A total of 9 patients (18%) were being given Olanzapine, 10% (N=5) were on Clozapine, 6% (N=3) on Quetiapine, 6% (N=3) on Aripiprazole, 4% (N=2) on Amisulpiride, 4% (N=2) on Sulpiride, 8%

(N=4) on Chlorpromazine, 4% (N=2) on Zuclopenthixol, 4% (N=2) on regular Haloperidol and 8% (N=4) are on as required PRN Haloperidol.

14% of the group I (N=7) were on regular anticholinergic medication and 12% (N=6) were receiving PRN anticholinergic medication for side effects of antipsychotic medication. None of the members of the group were on both regular and as required anticholinergic medication.

As required antipsychotic and anticholinergic medications were prescribed in 28% (N=14) patients. Of these patients, the indications to use the medication, the frequency, maximum daily dose are clearly recorded in the notes and medication reviewed regularly in 92%.

In 68%, the patients were involved themselves in the decision to prescribe antipsychotic medication and in 96% relatives, carers, and/or multidisciplinary team

TABLE I
Demographic variables and diagnosis

Total	(N) 52	% 100
Sex		
Males	7	13
Females	45	87
Age		
Total >50 years	30	58
Males >50 years	17	33
Females >50 years	13	25
Total <50 years	22	42
Males <50 years	13	25
Females <50 years	9	17
Accommodation		
Own/Family home	4	7
Residential/Group home	43	84
NHS	1	2
Not Available	4	7
Status		
In Patient	7	13
Out Patient	45	87
Learning Disability		
Mild/Moderate	41	80
Severe/Profound	11	20
Diagnosis		
Schizophrenia	21	40
Schizophreniform illness	6	12
Schizoaffective Disorder	7	13
Psychosis	18	35
ICD 10 coding available		
Yes	48	93
No	4	7

were involved in the decision to prescribe medication where appropriate. In all, the medication is within the British National Formulary (BNF) recommended doses.

The NICE audit measures from this study are given in TABLE III. Family interventions were offered in 4% of cases but in 27% either the patient is not able to participate or the family refuses to participate. Ongoing support is offered to the family/carers in 70% with 4% unable to participate.

Cognitive Behavioural Therapy was offered to 10% of patients but 14% of patients were not able to participate. Outreach/Assertive community treatment was offered to 28% of patients.

Parenteral medication and rapid tranquillisation was not used at all for any of the patients. A total of 74% received only one antipsychotic at a time.

Advance directives (1) were present in 34% and consist of care plans that contain

**TABLE II
Medication**

Medication	(N)	%	Antipsychotics	(N)	%
Total Regular & PRN Antipsychotics	50	96	Risperidone Regular IMI PRN	23 1 1	46 2 2
Antipsychotic One	38	74	Olanzapine	9	18
Antipsychotic Two	12	22	Clozapine	5	10
Antipsychotic None	2	4	Quetiapine	3	6
IM Antipsychotic Regular	1	2	Aripiprazole	3	6
IM Antipsychotic PRN	0	0	Amisulpiride	2	4
Anticholinergic Regular	7	14	Sulpiride	2	4
Anticholinergic PRN	6	12	Chlorpromazine	4	8
Anticholinergic Regular + PRN	0	0	Zuclopenthixol	2	4
			Haloperidol Regular PRN	2 4	4 8
				Yes %	Not App %
If PRN antipsychotic/anticholinergic medication is prescribed are the following clearly recorded: Indications, Frequency, maximum daily dose. Medication reviewed regularly (N=14) 28%				92	0
Have the following people been involved in the decision to prescribe antipsychotic medications - Patient/Resident him/herself				68	4
Relative/Carer/Multidisciplinary team where applicable				96	4
Medication within BNF recommended doses singly/combination				96	4
If no, has it been recorded that the consultant has been involved					100

Not App - Not Applicable

TABLE III
NICE audit measures

NICE Audit Measures	Yes %	Exce %	Not App %	Std 100
Family interventions offered In recent relapse, Risk of relapse, Persistent symptoms	4	27	2	31
a) Family interaction offered (6/12 >10 planned sessions)	70	4	0	74
a) Ongoing support to family/carers offered				
Cognitive Behavioural Therapy offered C.B.T./Psychology input Specially Persisting Psychotic Symptoms	10	14	0	24
Outreach/Assertive Community Treatment Risk of relapse, High use of inpatient services Poor H/O engagement with services, Homelessness	28	0	0	28
Parenteral medication Given during rapid tranquillisation has base line recording and monitoring BP, Pulse, Temp, Resp	0	0	100	100
Rapid Tranquillisation Patients are debriefed	0	0	100	100
Medication One antipsychotic at a time	74	0	4	78
Advance Directive (1) CPA documentation treatment choice in acute episode	34	12	0	46
Advance Directive (2) CPA coordinator in acute episode notifies the Clinician	56	0	0	56
Information a) Information given to relatives about illness and treatment	70	4	0	74
b) Including copy of NICE guidelines produced for patients, advocates/carers	0	2	0	2
Occupational needs Comprehensive assessment of skills and needs	74	0	0	74
Case Registers in primary care Individuals recorded on a case register in primary care	76	0	0	76
Physical health in primary care or secondary care a) Physical health screening BP, diabetes, blood tests. Blood lipids in raised BP Screening for smoking, alcohol and drug/use ECG	86	2	0	88
b) Health Promotion advice offered on smoking, alcohol, drug use, exercise	82		0	82
c) Screening for side effects of treatment EPSE, weight gain, lethargy, sexual dysfunction	88		0	88
Second Opinion If requested, supported	2	0	98	100

Exce - Exceptions; Not App - Not Applicable

advance directives detailing the patient's treatment choices in an acute episode. 12% of patients did not receive this advance directive since they were not able to participate in an informed discussion.

Advance directive (2) present in 56% of cases where the care programme approach co-ordinator in an acute episode notifies the patients advance directive to the clinician. Information about illness and treatment given to relatives occurred in 70% of cases. No one received a copy of NICE guidelines.

Occupational needs, in the form of a comprehensive assessment of skills and needs occurred in 74%. A total of 76% patients were recorded in a case register in primary care. The physical health of patients in primary or secondary care was assessed by screening for blood pressure (BP), diabetes, blood tests, blood lipids, screening for smoking, alcohol, and drug use, and electrocardiograms (ECG) were determined in 86% of patients. One patient (2%) was uncooperative and so a physical assessment could not be made.

Health promotion advice was offered on smoking, drug use and exercise in 82% of the group. Screening for side effects of treatment such as extrapyramidal side effects (EPSE), weight gain, lethargy, sexual dysfunction was made available for 88%.

A second opinion was requested and supported in 1 patient (2%) but was not applicable for the other patients (i.e 98%).

Discussion

In this study, we looked at 52 patients from North & Mid Essex, who had a diagnosis of learning disability and schizophrenia, schizophreniform psychosis, schizo-affective disorder and psychosis due to diagnostic difficulties of schizophrenia

in some people with learning disabilities. There are slightly more males (58%) than females (42%) in the group of patients and slightly more of the members of the group are >50 years of age.

With the philosophy of community care and resettlement from large learning disability hospitals, increasing numbers of patients with mental illness are now managed in the community. In this sample, a large majority (87%) are outpatients, A large majority of this sample have a mild/moderate degree of learning disability and only 20% have severe/profound learning disability. This may be under represented by diagnostic difficulties of schizophrenia and related psychosis in people with severe/profound learning disability.

Schizophrenia is a major mental illness characterised by psychosis, apathy, social withdrawal and cognitive impairment which results in impaired functioning in work, self-care, and independent living. It is among the world top ten causes of long term disability (Muesur and McGurk, 2004). Co-existence of schizophrenia and learning disability compounds the disability and increases the demand on the carers. In this sample a large majority (84%) are in residential or group homes with staff support and this could be due to the burden of care in the family homes.

The International Classification of Diseases (ICD 10) coding is available for the large majority (93%) suffering from schizophrenia. The management of schizophrenia can be divided into pharmacological and psychosocial treatment. Pharmacotherapy is the mainstay of treatment, without which most psychological treatment would not be possible. (Muesur and McGurk, 2004).

NICE guidelines states that antipsychotic drugs are necessary to control symptoms in the acute phase and to prevent relapse in the recovery phase. Oral atypical antipsychotics should be considered as treatment

of choice, using doses within BNF limits. Clinical response and side effects should be monitored routinely and regularly, and the aim should be for a monotherapy.

In this sample, the majority (74%) are on monotherapy and 4% are not on antipsychotic medication. A large majority are on oral atypical antipsychotics, with only 2% on intramuscular atypical antipsychotic medication and a minority of 16% being on regular, typical, antipsychotics. Side effects are monitored well and in all doses are within BNF limits. Anticholinergic medication usage is minimal. The use of PRN medication is well documented.

Psychosocial interventions improve management of schizophrenia e.g. coping with symptoms, preventing relapse and enhance functioning in independent living relationships and work. Family interventions reduce relapses and re-admissions, as well as decreasing family stress and the burden of care. Cognitive behaviour therapy reduces the severity of psychotic and negative symptoms. (Muesur and McGurk, 2004).

The use of psychological interventions in relapse prevention and symptom reduction such as family interventions (31%) and cognitive behavioural therapy (24%) are minimal in this sample although ongoing support is given to the family/carers in a majority (i.e 74%).

Outreach/Assertive community treatment was provided to 28% of patients and none of the patients had rapid tranquillisation. A sizeable minority (34%) had treatment of choice documented, which could be related to their learning disability and inability to participate in informed discussions to provide input.

More than half (56%), had Care Programme Approach (CPA) co-ordinator involvement. In a majority of the patients (70%), information was given to relatives and carers about the illness and treatment,

but none of the parents received a copy of NICE guidelines. The occupational needs of the patient were met in the majority of cases (74%).

Case registers for patients in primary care were available for 86% and 82% had physical health screening done, with 88% having screening for side effects of treatment. A second opinion was not needed in all but one case (i.e 98%).

The priorities identified for effective local implementation were: appropriate use of atypical antipsychotics, access to CBT and family interventions, patient involvement in decision making, physical health checks in primary care and appropriate use of rapid tranquillisation (Pilling and Price, 2006).

In this sample, except for access to CBT and family intervention, all other identified priorities are met for the majority of patients.

Recommendations

Based on the outcome of the audit reported in this manuscript, I propose making the following recommendations:

- ICD10 coding should be available for all patients.
- Psychological interventions, family interventions, Cognitive behavioural therapy, Outreach/Assertive community treatment should be offered to patients where needed.
- Medication, aim towards one antipsychotic at a time wherever possible.
- Where PRN medication is prescribed, indications, frequency and maximum daily dose, should be clearly recorded and reviewed regularly in all patients.
- All patients should be incorporated

into the CPA process.

- All should have information given to the relatives about treatment.
- All patients should receive occupational needs, comprehensive assessment, case registers in primary care, physical health in primary care and secondary care.
- A second opinion, if requested, should be supported.

Summary

In developing and implementing clinical guidelines (Pilling and Price, 2006), pharmacological recommendations have focused on the promotion of atypical antipsychotics and the use of low to moderate doses and the avoidance of combined antipsychotics. In the group of patients reported here, the majority are on atypical antipsychotics, low to moderate doses, all medication doses are within BNF limits and the majority are on monotherapy. None had rapid tranquillisation. The psychological treatment recommendations, both cognitive behavioural and family interventions are minimal in this group. The majority had support given by the family and carers.

Recommendations were also made for specialist services, including Assertive Outreach teams, which is very limited in this sample. The guidelines focus on joint patient-clinician decision-making, use of advance directives and provision of information to patient and carers. Only a minority had advance directives which could be related to the learning disability and inability to participate in informed discussions. The majority had information given to patients and carers. The guidelines also make recommendations on the role of primary care

in monitoring the physical health of people with schizophrenia. In this sample, most of them have case registers in primary care and in a large majority had physical health screening done.

Co-existence of schizophrenia and learning disability compounds the disability and increases the demand on both health and social care services. Learning disabilities had not been included in NICE guidelines as of December 2002. The revision of the guideline should enable this to be considered. (Pilling and Price, 2006).

Implementation of NICE guidelines for the management of schizophrenia in people with learning disabilities will improve the standard of care provided and will facilitate better formulated care for this population.

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