NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

SCOPE

1 Guideline title

Psychosis and schizophrenia in children and young people: recognition and management

1.1 Short title

Psychosis and schizophrenia in children and young people

2 The remit

The Department of Health has asked NICE: 'to produce a clinical guideline on the recognition and management of schizophrenia presenting before the age of 18 years'.

3 Clinical need for the guideline

3.1 Epidemiology

a) Schizophrenia is a term used to describe a major psychiatric disorder (or cluster of disorders) that alters a person's perception, thoughts, affect and behaviour. The symptoms of schizophrenia are usually divided into positive symptoms (such as hallucinations and delusions) and negative symptoms (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect). Children and young people who develop schizophrenia will have their own unique combination of symptoms and experiences, the precise pattern of which will be influenced by their circumstances and stage of development.

b) Psychotic disorders, including schizophrenia, are major mental illnesses. The estimated prevalence across all ages and

populations in the UK is 0.7%. Schizophrenia usually starts in late adolescence and early adulthood but can begin in early adolescence, although rarely before the age of 10. In the UK the lifetime prevalence of schizophrenia and schizophrenia-related disorders is approximately 14.5 per 1000 people, although there is considerable variation between estimates.

c) According to the Office for National Statistics (ONS), the prevalence of all mental health disorders in children aged between 5 and 16 years is 9.6%. In 2002, the ONS reported that the prevalence of psychotic disorders in children aged between 5 and 18 years was 0.4%. A survey of hospital bed use in England and Wales between 1998 and 2004 suggests that schizophrenia accounts for 24.5% of all adolescent (10–18 years) psychiatric admissions (the overall admission rate is 0.46 per 1000 for this age range) with an exponential rise across the adolescent years. The rise in incidence increases most from 15 years onwards.

d) The prognosis of schizophrenia in adults has generally been seen to be much worse than in fact it is. Long-term follow-up studies in adults suggested that after 5 years of illness one quarter of people recover completely. For most people the condition gradually improves over their lifetime and it deteriorates in only 10% throughout life. Schizophrenia has a worse prognosis with onset in childhood or adolescence than with onset in adult life.

e) About one fifth of children and young people with schizophrenia have a good outcome with only mild impairment. However, one third have severe impairment that requires intensive social and psychiatric support. A recent Israeli whole-population study found that people younger than 17 years with schizophrenia had a poorer outcome overall with longer length of initial hospital stay, higher incidence of readmission, more days per year in hospital and more admissions to hospital than people aged 18 and older. Schizophrenia is also very frequently associated with significant

impairments in many aspects of life – social, educational, vocational and family – and it is associated with increased morbidity and mortality through both suicide and natural deaths.

f) Recognising schizophrenia in children and young people may be difficult for healthcare professionals who may be unaware of its occurrence in this age group and unfamiliar with the clinical picture of schizophrenia in younger people.

g) The symptoms and experience of schizophrenia are often distressing and the effects of the illness are pervasive, with a significant number of children and young people continuing to experience long-term disability. Schizophrenia can have a major detrimental effect on children and young people's personal, social, educational, and occupational functioning, placing a heavy burden on individuals and their carers, as well as making potentially large demands on the social and healthcare system.

h) The cumulative cost of the care of people with schizophrenia is high. In 1992/93 the direct cost of health and social care for people with schizophrenia was estimated to be 2.8% of total NHS expenditure, and 5.4% of NHS inpatient costs. Health and social services costs alone amounted to £810 million, of which inpatient care cost more than £652 million. It is likely that the younger onset of schizophrenia will prove to be most costly for the person, their family and society.

3.2 Current practice

a) With psychosis, and schizophrenia in particular, onset in childhood and early adolescence represents a major health challenge. There have been some significant improvements in pharmacotherapy, family interventions, psychosocial and psychological treatments, and most recently in the use of arts therapies. Through the National Service Framework for mental health, several service innovations originally developed and evaluated in other countries have been

implemented in adult services across England and Wales. These have been reviewed in the NICE guideline for adults with schizophrenia (NICE clinical guideline 82). However, there is considerable variation in both services and treatments for adults with schizophrenia, and probably more so for children and young people with schizophrenia.

b) The mainstay of treatment for all people with schizophrenia since the 1950s has been antipsychotic drugs, including chlorpromazine, haloperidol, trifluoperazine, sulpiride, olanzapine, risperidone and aripiprazole. Initial speculation that the newer and more expensive ‘atypical antipsychotics’ were superior to so-called ‘typicals’ evaporated. Nevertheless, the most commonly used drugs now are the newer ones (olanzapine and risperidone). There is limited evidence of the efficacy of antipsychotic drugs in children and young people with schizophrenia. There are also concerns that children and young people are more sensitive than adults to the potential adverse effects of antipsychotics, including weight gain, metabolic effects and movement disorders.

c) Psychological treatments that have been used for children, young people and adults with schizophrenia include family interventions, cognitive behavioural therapy (CBT), cognitive remediation therapy, social skills training, psychoeducation, arts therapies and many others. For adults, the evidence for effectiveness is limited to family interventions, CBT and arts therapies. Provision of these therapies for adults and young people, especially for family interventions, is variable and largely poor despite the growing evidence base.

d) Services for children and young people with schizophrenia include child and adolescent mental health services (CAMHS), especially tiers 2 and 3 (community services) and tier 4 (inpatient services), and early intervention services (EIS).

e) EIS were introduced for people aged 15 to 35 as part of the National Service Framework for mental health. They provide a more intensive therapeutic service than traditional community services for young people and adults. They are designed to intervene early, providing evidence-based treatments (pharmacotherapy, family interventions and CBT), family, social and occupational support, in a ‘normalising’ environment for the first 3 years after onset of psychosis. For adults, these services reduce relapse rates and symptoms of schizophrenia, improve quality of life and are preferred to community mental health teams. Precisely which aspects of EIS underpin these better outcomes is subject to debate. We do not know if EIS are better than generic CAMHS for children and young people with schizophrenia. The provision of all these services, how they are configured locally (for example, the degree of integration of the two services for people under 18) and how people are transferred from one to another or to adult services is highly variable geographically.

f) Children, young people and adults with schizophrenia from black and minority ethnic backgrounds tend to present late to services, are more frequently subject to compulsion and have less access to psychological therapies than their white counterparts. Much of the difference in receiving appropriate services at the right time seems to be determined by difficulty in gaining access to services and difficulty in engaging with healthcare professionals in primary and secondary mental healthcare. However, some studies that show ethnic variations in the take up of acute services and the need for compulsory admissions also show a broader picture of more similarities than differences.

g) Services for children and young people with schizophrenia need to be comprehensive and well integrated because schizophrenia affects all aspects of their life and experience. Educational outcomes can be seriously affected by schizophrenia. There is

considerable geographical variation in the configuration and integration of CAMHS and EIS mental health services, and in the provision and integration of other services for children and young people with schizophrenia, including education services, social services, employment and rehabilitation support. Provision for the specific needs of 16 and 17 year olds with schizophrenia, in particular, can be fragmented and inadequate. They may not have family support or be in education and yet they do not qualify as an adult. They can experience difficulties in gaining access to appropriate types of accommodation or vocational/occupational support and rehabilitation.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

a) Children and young people (younger than 18) who have a clinical diagnosis of schizophrenia (including schizoaffective disorder and delusional disorder).

b) Children and young people who are at-risk of developing psychosis and those who have early psychosis but do not have a formal diagnosis of schizophrenia.

c) Children and young people with schizophrenia and a mild learning disability.

d) Specific consideration will be given to the needs of children and young people from black and minority ethnic groups.

4.1.2 Groups that will not be covered

a) Adults (aged 18 and older).

b) Children and young people with psychotic disorders other than schizophrenia [but please see 4.1.1 b)].

4.2 Healthcare setting

a) Care that is received in primary care, secondary and tertiary CAMHS (tiers 1–4) and EIS from healthcare professionals who have direct contact with, and make decisions concerning the care of, children and young people with schizophrenia.

b) The transition from CAMHS to adult services, and the treatment and care received during transition.

c) The guideline will also be relevant to the work of, but will not cover the practice of, healthcare professionals and others working in accident and emergency (A&E) departments, paramedic services, services for the homeless, prison medical services, the police and those who work in forensic services and criminal justice. It will also be relevant to professionals who work in schools, colleges and other educational settings; and to those who work with looked after children.

4.3 Clinical management

4.3.1 Key clinical issues that will be covered

a) Recognition of schizophrenia and criteria for diagnosis, including the recognition and management of at-risk mental states and early

psychosis before a formal diagnosis of schizophrenia has been made.

b) Psychological or psychosocial interventions:

- CBT
- cognitive remediation
- counselling and supportive psychotherapy
- family interventions (including family therapy)
- psychodynamic psychotherapy and psychoanalysis
- psychoeducation
- social skills training
- arts therapies.

c) All antipsychotics licensed for the treatment of schizophrenia in the UK, including considerations related to the age of the child or young person, such as modifications to the dose. Note that guideline recommendations will not normally fall outside licensed indications. Exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended (for this guideline a number of drugs will be reviewed that are licensed for adults with schizophrenia but not for children or young people). The guideline will assume that prescribers will use a drug's summary of product characteristics to inform decisions made with individual service users.

d) Starting treatment with antipsychotic medication and/ or a psychological or psychosocial intervention.

e) Treatment of an acute psychotic episode with antipsychotic medication and/ or a psychological or psychosocial intervention.

f) Promoting recovery after an acute psychotic episode, using antipsychotic medication and/ or a psychological or psychosocial intervention.

g) Assessment and management (for example, routine blood tests and physical monitoring) of known side effects of antipsychotic medication, and of the child or young person's physical health.

h) Treatment options if antipsychotic medication and/ or a psychological intervention is ineffective and/ or not tolerated.

i) The organisation and integration of services, outlining a care pathway including primary care, CAMHS, EIS, and tertiary CAMHS (inpatient services).

j) Ways to improve access to, and engagement with, mental health services for children and young people and particularly those from black and minority ethnic groups.

k) Recommendations categorised as good practice points in NICE clinical guideline 82 will be reviewed for their relevance to children and young people with schizophrenia (including issues around consent and advance directives).

4.3.2 Clinical issues that will not be covered

a) Validity of diagnosis.

b) Primary prevention (although management of at-risk mental states and early psychotic symptoms prior to a diagnosis of schizophrenia will be covered; see 4.1.1 b).

c) Management of violence in children and young people with schizophrenia.

4.4 Main outcomes

a) Better recognition and earlier treatment.

b) Better treatment and care based on the best evidence available for effectiveness, safety and cost effectiveness.

c) Reduced adverse events resulting from pharmacological treatment, including side effects and discontinuation-related effects.

d) Better mental health and related outcomes.

e) Improvements in the experience of care for children, young people and their families.

f) Better equity in access to and engagement with services for children and young people from black and minority ethnic groups.

g) Better integration of services, treatment and care, with clearer care pathways.

h) Better support and guidance for the child or young person's family.

i) Better physical health outcomes.

j) Increased access to education and to better address the educational expectations of the child or young person.

k) Social and educational wellbeing.

l) Improved cognitive functioning (including better access to education).

4.5 Economic aspects

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY), and the costs considered will usually be only from an NHS and personal social services (PSS) perspective. Further detail on the methods can be found in 'The guidelines manual' (see 'Further information').

4.6 Status

4.6.1 Scope

This is the final scope.

4.6.2 Timing

The development of the guideline recommendations will begin in March 2011.

5 Related NICE guidance

5.1 Published guidance

5.1.1 NICE guidance to be incorporated

This guideline will incorporate the following NICE guidance:

- Aripiprazole for schizophrenia in people aged 15 to 17 years. NICE technology appraisal guidance 213 (2011). Available from www.nice.org.uk/guidance/TA213

5.1.2 Other related NICE guidance

- Schizophrenia (update). NICE clinical guideline 82 (2009). Available from www.nice.org.uk/guidance/CG82

6 Further information

Information on the guideline development process is provided in:

- 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS'
- 'The guidelines manual'

These are available from the NICE website (www.nice.org.uk/GuidelinesManual). Information on the progress of the guideline will also be available from the NICE website (www.nice.org.uk).