

The primary care of patients with schizophrenia: a search for good practice

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SUMMARY

The proportion of patients with schizophrenia who lose contact with the secondary services is between 25% and 40%. The general practitioner remains the health care professional most likely to be in contact with such patients. A consensus group of 14 members met on four occasions, reviewed the relevant literature, and developed good-practice guidelines in five areas: establishing a register and organizing regular reviews; comprehensive assessments; information and advice for patients and carers; indications for involving specialist services; and crisis management. The guidelines are presented and their supporting evidence summarized.

Keywords: schizophrenia; primary care; good practice.

The importance of primary care in maintaining contact with patients

SINCE the early days of community care in the 1960s, general practitioners (GPs) have been frequently involved in the care of many patients with schizophrenia.^{1,2} Despite developments in community services, the proportion who rapidly lose contact with the secondary mental health services has remained between 25% and 40%.³⁻⁶ The GP is still the health professional most likely to retain contact. Some patients probably do not need specialist psychiatric care. Needs for care will vary greatly between individual patients and over time. Many people with schizophrenia live restricted but stable lives after the initial stormy years.⁷ The flexibility, availability and non-stigmatizing nature of GP consultations is particularly suited to maintaining long-term contact with such patients.

The need for physical care

Schizophrenia sufferers have greater needs for comprehensive primary health care than the general population. Standardized mortality ratios in this group are more than doubled, partly from suicide and accidents, but also from doubled cardiovascular and respiratory disorders mortality rates.⁸⁻¹⁰ These patients often have undetected general health problems¹¹ despite a higher than average consultation rate.^{6,12} Some of these problems are secondary to long-term maintenance neuroleptics. Higher rates of smoking, hypertension and obesity contribute to the increased cardiovascular and respiratory mortality. GPs are usually aware of these risk factors, but do not appear to intervene very often, judged by patients' accounts and medical records.^{13,14}

Maladaptive help-seeking behaviour

Low detection of physical health problems may relate to the apa-

thy and lack of self-confidence characteristic of 'negative' or type II schizophrenia.^{15,16} Patients may attend regularly for repeat prescriptions, but be reticent to complain of physical problems or even to talk openly and spontaneously about their mental health problems. Few practices have specific policies for targeting their needs.¹⁷ Introducing a disease register and a modest comprehensive structured assessment at intervals affects the overall process of care,¹⁸ increasing changes of psychotropic drug treatment and referrals to community psychiatric nurses (CPNs) and psychiatrists. The 35 GPs in a study by Kendrick *et al*¹⁸ cited lack of confidence in managing mental health issues as leading to reluctance to enquire after problems.

Current state of research knowledge and existing guidelines

There is no confirmed efficacy for primary care assessment and intervention in schizophrenia. Kendrick *et al*'s study¹⁸ mentioned above demonstrated changes in the process of care (probably beneficial for patients), but did not have the power to measure health gain directly. A computerized MEDLINE search using the keywords 'mental illness', 'schizophrenia' or 'psychosis' against 'general practice' or 'family medicine' yielded only 55 articles. Only eight papers employed any form of scientific methodology and only three included health gain outcome measures.

At present, entirely evidence-based guidelines, as described by the Royal College of General Practitioners,^{19,20} cannot be derived for the management of schizophrenia in primary care. Hardly any 'grade A' recommendations (where at least one well-designed, randomized controlled trial exists linked to validated outcome measures²¹) can be made. This does not mean that conclusions cannot be reasonably drawn or action taken to improve care. There are well-conducted studies linking specific interventions to process variables such as compliance with medication or reviews of management;¹⁸ these, in turn, have been demonstrated to be advantageous for schizophrenia in other settings.²²

Schizophrenia research in general practice requires large numbers of practices given the average of eight patients per GP list.^{5,17} The production of guidelines, using both informal and formal consensus,¹⁹ has been most vigorous in the USA, although these are now well established in the United Kingdom.²³ Schizophrenia guidelines are not numerous and have been general in their content.²⁴ Work at St George's Hospital Medical School, London,¹⁷ has indicated the need for more practical and detailed advice about specific aspects of management.

Purchasing mental health services

Fundholding and commissioning by GPs²⁵ has fuelled the need for guidelines. What individual practices will wish to purchase from the secondary mental health services will depend on their own skills and competence. Only 40% of new trainees²⁶ and 25% of GPs overall^{17,27} have worked in a postgraduate psychiatric post, and there is considerable variation in attitude towards their role in mental health.^{17,28,29} This will be reflected when contracting for mental health services, and schizophrenia guidelines should help focus that process. Some GPs will feel competent

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and prepared to carry out all the interventions recommended, others will contract some to the secondary services (and negotiate accordingly), and yet others will seek training to equip them for these tasks.

The Primary Care Schizophrenia Consensus Group

In 1994, a consensus group was formed with the aim of furthering the search for good practice and producing brief guidelines for primary care teams. The group comprised 17 members: four part-time academic GPs, four full-time GPs, four academic psychiatrists, two full-time clinical psychiatrists, one CPN, one professor of health economics, and one primary care nurse facilitator. All the members were chosen for their interest in mental health or as local opinion leaders in general practice. The initiative for the group came from the pharmaceutical company Janssen-Cilag, but it has been both financially and intellectually independent of the company since its inception. Expenses were jointly funded by Janssen-Cilag and the Sainsbury Centre for Mental Health. The consensus group considered a clear policy for dissemination and support with adequate educational material essential. An undertaking was obtained from Janssen-Cilag and the Sainsbury Centre to coordinate and fund the dissemination, independent of its content. The intellectual ownership of the guidelines rests explicitly with the group.

The group met on four occasions and copies of the relevant literature were circulated to all members between the meetings. (A list of the literature available at the meetings is available from the authors at the correspondence address.) No formal literature evaluation was undertaken prior to the meetings and each submission was assessed in its own right.

The first meeting clarified the group's remit and objectives. The primary aim agreed was to produce guidelines on four, or at most five, aspects of schizophrenia management in general practice. The guidelines were to be brief, focused and practical — sufficiently concise to be contained on two sides of a single A4 laminated sheet. Separate supporting literature would be provided for those interested.

Extensive discussion ensued on whether the guidelines should be 'exemplary' (best practice), 'standard' (within the competence of most well-functioning health centres), or 'minimal' (essential for the care of these patients, to be purchased or commissioned from secondary services if the practice could not provide it). 'Standard' guidelines were chosen, recognizing that some practices might need to negotiate input from secondary services for both local and internal reasons. Referral and shared-care policies were excluded for being too locally specific. This meeting identified the areas to be covered by the guidelines:

- establishing a register and organizing regular reviews
- comprehensive assessment
- crisis management
- information and advice for patients and carers.

The first meeting divided into three sub-groups (each substantially representative of the overall group) to work on one draft guideline each. These were then presented to the full group for discussion. In the second and third meetings, the sub-groups were reconstituted to accommodate absences and to ensure that no individual worked on the same area twice. The same procedure was followed, although original drafts were available for consideration. At the fourth meeting, a final draft for wider consultation was agreed by the group. The drafts of the three guidelines were then widely circulated outside the group (Box 1, overleaf) for opinions on feasibility, omissions and clarity, and for

suggestions on dissemination and implementation.

Research evidence for the guideline recommendations

Establishing a register and organizing regular reviews

The feasibility of rapidly identifying patients suffering from major mental illness in relatively well-organized and computerized general practices has been demonstrated. The sensitivity and specificity of computer diagnostic entries for schizophrenia were greater than 90% in practices using the VAMP computer system. Over 95% of psychotropic prescriptions to schizophrenia patients were recorded on computer when examined in four practices.³⁰ Tapping the primary care team's knowledge ('Who do we know who has been suffering a long time from a major psychiatric illness?'), plus a search of the repeat prescription system (whether computerized or paper-based) and of the diagnostic register, if one exists, quickly yields around 90% of identifiable patients with long-term mental illnesses.⁶ Once the schizophrenia register exists, new patients can be added when they consult. However, a few people with schizophrenia do not consult from one year to the next and may be unknown to their GPs.^{6,31,32,33}

It is unclear how aware GPs are of mental health services' involvement in their patients' care (or what impact this has), so there is a risk of duplication of effort. Virtually all patients with psychotic illnesses of any duration will have had some specialist contact, usually early on.⁶ General practice records should indicate whether they are in current contact, although this is not always recorded.³⁴ The Care Programme Approach³⁵ and the Supervision Register³⁶ require GPs to be informed of their patients' involvement with psychiatric and social services, and to receive copies of care plans.

For patients with long-term mental illness (57% suffering from a chronic psychosis, 46% with schizophrenia), a programme of six-monthly, structured assessments in ordinary surgery appointments increased GPs involvement in their psychiatric care.¹⁸ Increased rates of referral back to CPNs and psychiatrists, and more frequent changes of medication, were demonstrated, although the study did not assess patient health gain outcomes. The study did not demonstrate a convincing relationship between frequency of assessment and outcome. The consensus on optimal frequency obtained from the participating GPs is used in these guidelines (i.e. once a year). Several studies of structured assessments of long-term mentally ill patients are in progress using assessment intervals of between 3 and 12 months (A Cohen and T Burns, personal communication), which should resolve some of this uncertainty. Nazareth and colleagues³⁷ demonstrated that a separate clinic session model had a small, but measurable, effect on clinical outcome. Limitations in the clinic's success were as much related to GP needs as to patients' willingness to attend. An opportunistic approach worked better in one practice. The routine involvement of practice nurses in these assessments is also being tested (T Burns, personal communication).

Comprehensive assessment

A comprehensive assessment, including mental state, social functioning, general health, and medication, is a core feature of needs assessment³⁸ and is essential for effective care.³⁹ Identifying needs in severe mental illness does not guarantee a consistent clinical response,³⁸ but appropriate interventions cannot be undertaken without it. Understanding the present state of affairs is needed by both patient and doctor to plan appropriately.

Life events, particularly stressful ones, have been shown repeatedly to influence the course of psychotic illnesses, including schizophrenia.^{40,41} Adverse social conditions (in particular, financial hardship and inadequate or insecure accommodation) also have a direct impact on outcome.⁴² The importance of struc-

<p>1. Identifying your patients and organizing a regular review</p> <p>a. Create a disease register, identifying patients with schizophrenia using the practice team's knowledge, repeat prescriptions, and computer diagnostic data if available. Check patients' medical records for the date of their last contact with specialist services and current status (i.e. inclusion in the Care Programme Approach or the Supervision Register, or being in receipt of social services Care Management).</p> <p>b. Use the disease register to check that patients have been seen in the practice at least once every 6 months (nominate a member of staff to check every other quarter).</p> <p>c. Invite patients for annual comprehensive assessments by their GP, together with the practice nurse or community psychiatric nurse where appropriate.</p> <p>2. Comprehensive assessment</p> <p>Social and environmental factors</p> <ul style="list-style-type: none"> ● Events since last review (achievements as well as problems), crises, and admissions ● Accommodation, carers, supports in the home, dependants (child care), and contact with social services ● Daily activities, employment and training, income, and benefits ● Substance abuse. <p>Mental state</p> <ul style="list-style-type: none"> ● Look for: rapport, behaviour, self-neglect, and abnormal movements. ● Ask specifically about all of the following: anxiety, depression, hallucinations, delusions, suicidal thoughts, and insights. <p>Physical problems</p> <ul style="list-style-type: none"> ● Health promotion: smoking, obesity, hypertension, and exercise ● Hearing, vision, dental, and chiropody needs ● Family planning ● Nutrition. <p>Medication</p> <ul style="list-style-type: none"> ● Review all current medication. ● Assess appropriateness (polypharmacy?), adherence, side-effects, and interactions. <p>3. Information and advice for patients and carers</p> <ul style="list-style-type: none"> ● Symptoms, management course, (including drug effects and side-effects), prognosis, and genetics ● Who to contact for which problems and when ● Money matters, benefits, housing, and employment training ● Arrangements for respite care: admission, night sitting, and holidays? ● Voluntary organizations (e.g. local MIND, NSF, and SANE) ● Advice about over-involvement and high 'expressed emotion'. <p>4. Indications for considering involvement of specialist services</p> <p>Review of medication</p>	<ul style="list-style-type: none"> ● Persistent symptoms ● Persistent side-effects ● Polypharmacy (three or more psychotropic drugs) ● Five-yearly consultant review. <p>Relapse</p> <ul style="list-style-type: none"> ● Sudden or gradual changes in behaviour <p>Increased risk of relapse</p> <ul style="list-style-type: none"> ● Poor adherence to treatment ● Major life events ● Substance abuse ● Family conflict. <p>Newly registered patients</p> <p>Any problem the GP cannot deal with</p> <p>5. Crisis management</p> <p>Planning for a crisis</p> <ul style="list-style-type: none"> ● Ensure clear mechanisms are in place for obtaining specialist help in an emergency (agreed with secondary care services and written down): <ul style="list-style-type: none"> – Identify day and night contact numbers for psychiatrist, social services, ambulance, and police. – Consider status and experience of the secondary care professional who will review the patient. – Consider whether the review takes place in the home, casualty department, or hospital ward. ● Ensure the carers know who to contact. ● Carry oral and parenteral tranquillizers and anticholinergics, and Mental Health Act forms in the night bag. <p>Acute situation</p> <ul style="list-style-type: none"> ● Assess risk of self-harm or violence before seeing the patient: <ul style="list-style-type: none"> – Check medical records for previous episodes. – Discuss the situation with carers and other professionals. ● Ensure physical help is available if needed. ● Avoid being left alone with the patient with no quick exit route. ● Assess whether the patient's mental state has changed or not. ● Consider drug treatment if the patient is willing. ● Consider informal admission. If compulsory admission indicated: <ul style="list-style-type: none"> – Contact the duty approved social worker. – Contact the duty consultant psychiatrist or other Section 12-approved doctor. <p>Review crisis and identify any lessons to be learnt for future crises</p>
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Box 1. Guidelines for the care of schizophrenia in general practice. This box is designed for use as an aide-mémoire for day-to-day practice. The guidelines are explained more fully in the body of this article, which includes references to the relevant research.

tured daily activity in containing anxiety and protecting patients with schizophrenia from both deterioration and relapses has been established in several studies. The impact of alcohol and drug abuse is receiving increased attention.^{43,44} Younger patients may use alcohol and drugs both to gain peer group acceptance, and to counteract dysphoria from maintenance medication.⁴¹ There is little agreement on how to reduce substance abuse in these patients. However, simple counselling approaches help non-psychotic patients and are possible in primary care.⁴⁵

Changes in mental state are probably the most important indi-

cators of impending relapse. Detailed mental state assessment is complex, but GPs who have a long acquaintance with patients may be sensitive to changes in demeanour and presentation: in particular, in the quality of rapport. Up to 70% of patients and 90% of carers report prodromal symptoms within the week prior to a relapse.⁴⁶ These prodromal signs are often idiosyncratic and include a wide range of non-psychotic features.⁴⁷ Monitoring prodromal signs to abort relapses by early intervention has received some support,⁴⁷ but overall it is not an alternative to adequate maintenance treatment.⁴⁸

The importance of 'focused questioning' about individual symptoms has been clearly demonstrated.^{39,49,51} A 'conversational' interview relying on open-ended questions yields inaccurate assessments of mental state. Structured diagnostic interviews reveal anxiety and depressive symptoms as indicators of severity of illness in schizophrenia, both during and between relapses.⁵²

Very little has been published on interventions to monitor or improve the physical health of the severely mentally ill. The doubled standardized mortality for schizophrenia patients is partly caused by an increased suicide rate,⁵³ but cardiovascular and respiratory deaths are also increased^{9,10,54} owing to high rates of smoking,⁵⁵ and to obesity resulting from the maintenance medication and a lack of physical exercise.^{11,14} Needs for care studies^{11,38} demonstrate a high level of physical care needs. Dental problems may be particularly important as a consequence of tardive dyskinesia.

The value of maintenance medication in schizophrenia has been convincingly demonstrated.^{57,58} Most patients will have been advised to remain on some form of maintenance indefinitely. The skill is to aim for the lowest dose that affords protection while minimizing side-effects. Minimizing side-effects improves quality of life and maximizes compliance.^{59,60} Polypharmacy is a particular problem with this group, and the accumulation of several antipsychotics can easily occur,⁶¹ thus increasing non-compliance.⁶² Prescribing anticholinergic agents unnecessarily (i.e. in the absence of identified side-effects of antipsychotic medication) is common.⁶¹ Regular reviews in primary care settings lead to more frequent dosage changes.¹⁸

Information and advice for patients and carers

Keeping patients and carers fully informed helps them to be active partners in management rather than passive recipients of care. The anxiety that an honest discussion of diagnosis and prognosis is too stressful for schizophrenia patients is confounded by the acceptability of open access to clinical notes.^{63,64} Hopes that educating patients and carers to identify stressors would lead to lower doses of maintenance medication (or none at all) have not been supported by the evidence.^{48,65,66}

Clinical deterioration and relapse are associated with social stressors, in particular insecure housing and financial problems.⁶⁷ A controlled trial of minimally sheltered accommodation for homeless men with schizophrenia in New York significantly improved clinical functioning.⁴² A whole new clinical service, 'clinical case management', has developed since several randomized controlled trials demonstrated that stabilizing the social environment of psychotic patients improved their clinical condition and reduced relapse.⁶⁸⁻⁷¹ The advantage of this approach over current practice is now subject to debate.^{72,73}

A series of carefully conducted trials has linked high expressed emotion (EE) by family and other carers with an increased risk of relapse in schizophrenia.⁷⁴⁻⁷⁷ Expressed emotion includes critical comments and hostility towards the sufferer, but also over-involvement and smothering. An extensive series of studies demonstrates reduced relapse rates by family interventions which reduce EE.^{65,78,85} Psychoeducation alone (educating patient and family about the illness and techniques for conflict avoidance) is not supported by the balance of evidence from controlled trials.⁸⁵⁻⁸⁷

Indications for considering involvement of specialist services

There is no comprehensive consensus on indications for specialist referral or intervention in established schizophrenia. A review of medication is indicated if there is poor response to treatment

or persisting side-effects.⁶¹ Clozapine benefits some patients who are resistant to traditional antipsychotics.⁸⁸ At present, Clozapine treatment can be initiated only by psychiatrists, and referral is therefore essential. A whole range of atypical antipsychotics has been launched whose cost and novel side-effect profiles suggest initial monitoring by secondary services is optimal although, unlike Clozapine, GP prescribing is permitted.

There is little pharmacological justification for using more than one phenothiazine. Over long periods, different drugs may be added, often for their sedative side-effects or in a temporary negotiation. Many GPs are reluctant to reduce these without supervision, especially when the patient appears well. The rationalization of medication is a recognized role of the secondary services.

There is no clear agreement on the optimum frequency for reviewing maintenance treatment, nor is there consensus on what symptom-free period warrants consideration of discontinuation. Given the natural history of schizophrenia⁷ and the inherent risks of irreversible movement disorders caused by maintenance treatment,⁸⁹ it is prudent to reconsider medication at regular, if infrequent, intervals.

Relapse is often preceded by alterations in the patient's reported experiences and behaviour specific for that individual.^{46,90} It is generally advisable to involve the secondary services, who can target greater resources to arrest decline and contain the relapse.

A number of factors that increase the risk of relapse have been identified and GPs could devote extra attention to patients exposed to these. Poor treatment compliance (often signalled by erratic collection of repeat prescriptions or failed depot neuroleptic appointments), stressful life events, and substance abuse (most commonly alcohol but increasingly cannabis and other street drugs)⁹¹ all increase the likelihood of relapse.

Crisis management

There are no carefully controlled studies of crisis planning and management for this patient group. Clinical experience suggests that there are benefits in forward planning. Work on prodromal syndromes⁴⁶ and impending crises has suggested that practices should develop their own highly detailed and specific crisis arrangements. These must accommodate the characteristics of local secondary and social services. Few practices have such arrangements.¹⁷ As in any branch of medicine, in dealing with crises there are benefits in staying with a small range of familiar drugs and procedures.⁹²

Conclusions

The past 40 years have witnessed a steady improvement in the accuracy and consistency of psychiatric diagnosis. Within mental health services, there has been a welcome convergence in the management of most disorders and a gradual retreat of idiosyncratic practice. Nowhere is this more dramatic than in the care of schizophrenia, where medical, social, and psychological interventions are no longer seen as rivals but as necessary components of best practice. Most research establishing this consensus has occurred either in hospital or secondary care. Attention to the role of the primary care team in schizophrenia has lagged considerably behind that in disorders such as depression.

The role of primary care in these patients is now being recognized. Fairly confident advice can be given for many aspects of this care. There are some areas (e.g. the role of maintenance medication, the protective power of stable accommodation, and specific psychological interventions in families) with convincing evidence of efficacy. However, much practice has not been sub-

ject to careful evaluation or research. The absence of research evidence for an intervention does not imply that it is wrong. However, it is in the interests of all (patients, carers and professionals) to continue adding to the evidence base for individual interventions. Mental health research in primary care encounters major logistical and methodological problems, and this review demonstrates the need for a real commitment to such research if our patients are to be properly served.

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