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**Table 1. Examples of potential problems identified with peers**

Individual	Speciality v. speciality	Peer group v. trust organisation
Not competent	Competition for courses	No authority to get resources
Uncooperative	Disparate	Coloured by local politics
No commitment to process	Difficulty in reaching consensus	Ineffective
Lack of trust	Lack of knowledge of other specialities	Different goals

The last part of the survey asked about the sharing of information from the peer group process, and the possible penalties for not complying with CPD requirements. Interestingly, only 40% of respondents thought the College should receive the information, while the medical director was cited in half of the replies. Yet CPD will be an integral part of the annual appraisal process in which medical directors will have a key role (British Association of Medical Managers, 1999) and the College will need to be involved in the process of certification.

Regarding possible penalties, over half of respondents cited "loss of accreditation as educational supervisor", either alone or with another penalty, as the most 'desirable' penalty. However, currently this only relates to consultants. Loss of individual accreditation was considered an option in only 10% of respondents. This is at odds with the intention of the General Medical Council to introduce revalidation for all doctors (Buckley, 1999). CPD will play a crucial role in this process, with failure to comply almost certainly resulting in loss of accreditation.

This survey demonstrates that participants in CPD show clear preferences for the way in which CPD is designed and implemented. These preferences may not necessarily reflect national or local CPD policy, either in method or in potential implications if CPD fails in individual cases. These findings suggest that, along with the

provision of appropriate resources, the participation of those undertaking CPD should be actively sought at every stage if the implementation of CPD is to be successful.

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### References

BRITISH ASSOCIATION OF MEDICAL MANAGERS (1999) *Appraisal in Action*. Stockport: BAMM.

BUCKLEY, G. (1999) Revalidation is the answer. *BMJ*, **319**, 1145–1146.

GRANT J. & CHAMBERS, E. (1999) *The Good CPD Guide: A practical Guide to Managed CPD*. London: Joint Centre for Education in Medicine.

GLEINER, J. A. (1998) Clinician acceptance of information technology. *Journal of Integrated Care*, **2**, 86–89.

KATONA, C. & MORGAN, G. (1999) The future of CPD. *Advances in Psychiatric Treatment*, **5**, 161–162.

NEWBY, D. (1999) What direction for Continuing Professional Development? An attitude survey in a teaching mental health trust. *Psychiatric Bulletin*, **23**, 490–493.

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## Conspiracy of silence? Telling patients with schizophrenia their diagnosis

### AIMS AND METHOD

We undertook a postal questionnaire survey of all consultant psychiatrists working in Scotland to examine whether psychiatrists themselves may contribute to the misunderstandings surrounding schizophrenia by avoiding discussion of the diagnosis with their patients.

### RESULTS

Two-hundred and forty-six (76%) responded. Ninety-five per cent

thought the consultant psychiatrist was the most appropriate person to tell a patient their diagnosis of schizophrenia, although only 59% reported doing so in the first established episode of schizophrenia, rising to 89% for recurrent schizophrenia. Fifteen per cent would not use the term 'schizophrenia' and a variety of confusing terminology was reported. Over 95% reported telling patients they had mood disorders or anxiety, under 50% that

they had dementia or personality disorders.

### CLINICAL IMPLICATION

Greater openness by psychiatrists about the diagnosis of schizophrenia may be an essential first step in reducing stigma.



Fuelled by recent inquiries into the apparent failure of psychiatric care (Department of Health and Social Security, 1988; Ritchie, 1994) and sensational media reports, society's view of schizophrenia is largely negative. Although the Royal College of Psychiatrists ('Every Family in the Land: Recommendations for the Implementation of a Five-year Strategy: 1998–2003'; available upon request from the External Affairs and Information Services Department, The Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG) and World Health Organization (Sartorius, 1997) have launched campaigns to reduce the stigma of mental illness, psychiatrists themselves have been implicated in contributing to misunderstandings about schizophrenia by withholding information from their patients (Svensson & Hanson, 1994; Leavey *et al*, 1997), giving them confusing information (Main *et al*, 1993; Barker *et al*, 1996) and of being reluctant to tell them their diagnosis (McDonald-Scott *et al*, 1992; Luderer & Bocker, 1993).

## The study

All consultant psychiatrists working in Scotland in May 1997 ( $n=323$ ; from a database supplied by the informa-

tion and statistics division of the NHS in Scotland) were sent a questionnaire asking their opinion and practice on telling psychiatric patients their diagnosis (copies available from authors upon request). Ninety-five per cent confidence intervals (95% CIs) for proportions and their differences were calculated.

## Findings

### Response rate

Two hundred and forty-six questionnaires were returned (76% response rate). Thirty-five were excluded from analysis: 25 respondents stated the topic was not relevant to their speciality, five were not practicing in clinical psychiatry, four questionnaires were spoiled and one respondent no longer worked in Scotland.

### Characteristics of the respondents

We achieved a 76% response rate. Seventy-seven (36%; 95% CI 30–43%) were women. One hundred and four (49%; 95% CI 42–56%) had been consultants for over 10 years. Women were a smaller proportion of the latter

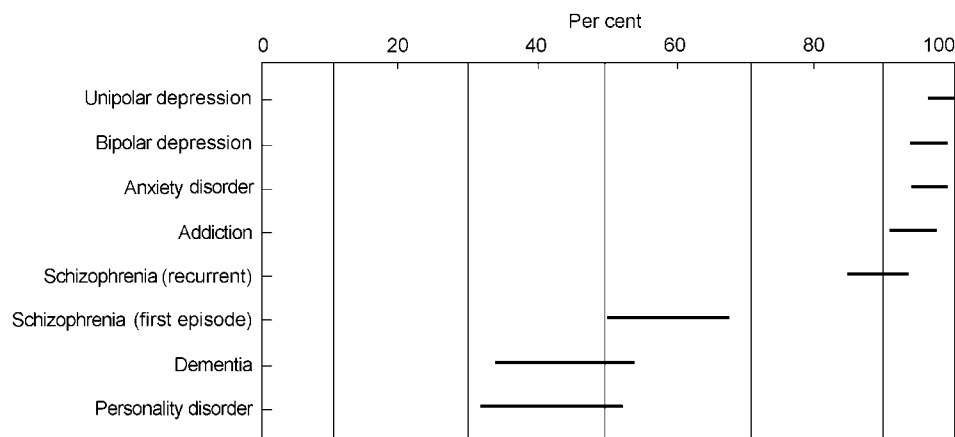


Figure 1. Percentage of consultants who would tell patients their exact diagnosis (Confidence Intervals).

Table 1. Terms used when telling a patient their diagnosis of schizophrenia

Terms	Number	Percentage	95% CI
Schizophrenia	180	85.0	80 to 91
Psychosis/psychotic illness	148	70.0	63 to 78
Major mental illness/mental illness	108	51.0	42 to 61
Mental breakdown	40	19.0	7 to 31
Paranoid psychosis	3	1.0	-12 to 15
Serious nervous illness	3	1.0	-12 to 15
Serious mental illness	2	1.0	-13 to 14
Major psychiatric illness	1	0.5	-13 to 14
Schizoaffective illness	1	0.5	-13 to 14
Sickness of the mind	1	0.5	-13 to 14
Insanity	1	0.5	-13 to 14
Loss of touch with reality	1	0.5	-13 to 14
Serious disorder	1	0.5	-13 to 14
Chemical imbalance in the brain	1	0.5	-13 to 14



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group – 24% compared with 49% of those with 10 years' experience or less (a difference of 25%; 95% CI 12–37%).

## Telling the diagnosis to different diagnostic groups

Consultants were asked if it was their normal clinical practice to inform patients who met standard diagnostic criteria of their exact diagnosis (Fig. 1).

The highest positive response was for unipolar depression (207; 98%; 95% CI 96–100%), followed closely by bipolar disorder, anxiety disorder and alcohol or drug misuse. In cases where the diagnosis of schizophrenia was not in doubt, 187 (89%; 95% CI 84–93%) would tell the diagnosis in a recurrent episode; 124 (59%; 95% CI 52–65%) would tell the diagnosis in a first episode. A minority would tell a diagnosis of dementia or personality disorder – 92 (44%; 95% CI 37–50%) and 88 (42%; 95% CI 35–48%), respectively.

## Telling patients they have schizophrenia

A variety of terms were used (Table 1). Two hundred (95%; 95% CI 9–98%) thought a consultant psychiatrist, perhaps with other staff, would be the best person to give the diagnosis. Various approaches were reported: 157 (74%; 95% CI 69–80%) would give the diagnosis as part of a routine consultation and 63 (30%; 95% CI 24–36%) would arrange a separate appointment, with 189 (90%; 95% CI 85–94%) meeting relatives if the patient consented. Most would give information about voluntary organisations (171; 81%; 95% CI 76–86%); 103 (49%; 95% CI 42–56%) gave written information; 84 (40%; 95% CI 33–46%) recommended books and 76 (36%; 95% CI 30–43%) referred the patient to an education group run by local psychiatric services. Only 108 (51%; 95% CI 44–58%) would volunteer the diagnosis without being asked. A variety of comments and experiences were reported (Table 2).

## Differences between groups of respondents

A higher proportion of women consultants volunteered the diagnosis of schizophrenia without being asked (56% v. 46%; 95% CI for the difference: 5–23%), referred the

patient to self-help groups (88% v. 77%; 95% CI for the difference: 1–22%) and met with relatives to discuss the diagnosis (94% v. 87%; 95% CI for the difference: 2–4%).

Consultants in post for more than 10 years were more likely to feel uncomfortable telling the diagnosis of schizophrenia (47% v. 38%, a difference of 9%; 95% CI 5–22%) and were less likely to volunteer the diagnosis without being asked (42% v. 60%, a difference of 18%; 95% CI 14–31%).

## Open text comments

A number of enlightening comments were received and the following list records some common themes:

- (a) "I give patients my formulation and don't normally give a diagnosis."
- (b) "... Experience of people with schizophrenia who commit suicide would suggest that insight is a factor in a number of cases. This emphasises the potentially devastating effect of knowledge of diagnosis and the importance of handling the information with extreme care and support."
- (c) "... I am impressed by the number of people with schizophrenia who I meet who do not know their diagnosis and the largely positive effects telling the diagnosis has."
- (d) "The most important thing in giving the diagnosis is to try to ensure they are ready to receive it and that they want to know the details."
- (e) "Knowledge of the diagnosis allows information and education on the subject."
- (f) "My problem is that I don't believe schizophrenia exists – even though there's a lot of it about."
- (g) "I don't know what standard diagnostic criteria are, but I know a schizophrenic when I've interviewed the relatives and he walks through the door."
- (h) "The consequences of schizophrenia in terms of social adaptation and symptoms cannot be hidden."

## Discussion

Doctors have a duty to give patients information in a way that is understandable to them (General Medical Council, 1998). They must decide how much information to give and how and when to give it, but not avoid the issue or

**Table 2.** Experience of telling patients their diagnosis of schizophrenia

Statement	Number who agree with statement	Percentage	95% I
Most patients have guessed before I tell them	122	58	49 to 67
Most patients cannot understand the term schizophrenia	121	57	49 to 66
It makes me feel uncomfortable to tell patients their diagnosis	90	43	32 to 53
Most patients don't want to know their diagnosis	28	13	1 to 26
Telling often worsens the doctor–patient relationship	21	10	–3 to 23
I don't have adequate time to tell patients their diagnosis	188	9	–4 to 21
Telling may worsen the prognosis	11	5	–8 to 18
Telling often worsens the mental state	6	3	–11 to 16



presume patients do not want to know (Pendleton & Hasler, 1983). Avoiding discussion of diagnosis may only heighten patients' anxieties (Carstairs et al, 1985).

Giving patients with schizophrenia information about their illness is recommended in good practice statements (CRAG-SCOTMEG Working Group on Mental Illness, 1995) and clinical guidelines (American Psychiatric Association, 1997; Scottish Intercollegiate Guidelines Network, 1998). Informed patients may enjoy many potential benefits: better engagement with services (Foulks et al, 1986; Bebbington, 1995); improved knowledge (Smith et al, 1992); higher quality of life (Atkinson et al, 1996); and reduced negative symptoms (Goldman & Quinn, 1988). Uninformed patients may discover their diagnosis in a distressing way, such as on a form, at court or when accessing their records (Atkinson, 1984). They may not access voluntary sector services or may give incorrect information in benefit claims or housing applications. They may not know their responsibility to notify the Driver and Vehicle Licensing Agency about their fitness to drive (DVLA, 1995).

There can be risks and difficulties in informing patients they have schizophrenia. The risk of suicide, thought to be highest early in the illness and associated with insight (King, 1994; Amador et al, 1996), must be assessed in each patient. Some psychiatrists do not use the diagnosis of schizophrenia even after the introduction of operationally defined criteria (World Health Organization, 1992; American Psychiatric Association, 1994), preferring their own idiosyncratic diagnostic system (Saugstad & Odegard, 1983). There is some debate about the validity of making a diagnosis of schizophrenia (Clafferty et al, 2000; Fisher, 2000; King, 2000), which is outside the remit of our study – we asked psychiatrists only about established illness where the diagnosis was not in doubt. Psychiatrists have been accused of using stigmatising labels (Lally, 1989), but stigma arises from the symptoms and signs of the illness itself, not merely its name (Penn et al, 1994).

Society's prejudice towards people with schizophrenia may improve with current education campaigns, but a change in psychiatric practice may also be necessary. When psychiatrists are willing to break free from the conspiracy of silence surrounding schizophrenia, the public may follow their example.

## References

- AMADOR, X. F., FREIDMAN, J. H., KASAPIS, C., et al (1996) Suicidal behaviour in schizophrenia and its relationship to awareness of illness. *American Journal of Psychiatry*, **153**, 1185–1188.
- AMERICAN PSYCHIATRIC ASSOCIATION (1994) *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edn). Washington: APA.
- (1997) Practice guidelines for the treatment of patients with schizophrenia. *American Journal of Psychiatry*, **154** (suppl. 4).
- ATKINSON, J. M. (1984) To tell or not to tell the diagnosis of schizophrenia. *Journal of Medical Ethics*, **2**, 1–24.
- , COIA, D. A., GILMOUR, W. H., et al (1996) The impact of education groups for people with schizophrenia on social functioning and quality of life. *British Journal of Psychiatry*, **168**, 199–204.
- BARKER, D. A., SHERGILL, S. S., HIGGINSON, I., et al (1996) Patients' views towards care received from psychiatrists. *British Journal of Psychiatry*, **168**, 641–646.
- BEBBINGTON, P. E. (1995) The content and context of compliance. *International Clinical Psychopharmacology*, **9**, 41–50.
- CARSTAIRS, G. M., EARLY, D. F., ROLLIN, H. R., et al (1985) Informing relatives about schizophrenia. *Bulletin of the Royal College of Psychiatrists*, **9**, 59–60.
- CLAFFERTY, R. A., McCABE, E. & BROWN, K. W. (2000) Telling patients with schizophrenia their diagnosis – patients should be informed about their illness. *BMJ*, **321**, 384–385.
- CRAG-SCOTMEG WORKING GROUP ON MENTAL ILLNESS (1995) *Services for People Affected by Schizophrenia. A Good Practice Statement*. Edinburgh: The Scottish Office.
- DEPARTMENT OF HEALTH AND SOCIAL SECURITY (1988) *Report of the Committee of Inquiry into the Care and Aftercare of Miss Sharon Campbell*. London: HMSO.
- DRIVER AND VEHICLE LICENSING AGENCY (1995) *Medical Aspects of Fitness to Drive. A Guide for Medical Practitioners* (Fifth edn). London: HMSO.
- FISHER, M. (2000) Patients expect a diagnosis. *BMJ*, **321**, 385.
- FOULKES, E. F., PERSONS, J. B. & MERKEL, R. L. (1986) The effect of patients' belief about their illness on compliance in psychotherapy. *American Journal of Psychiatry*, **143**, 340–344.
- GENERAL MEDICAL COUNCIL (1998) *Good Medical Practice*. London: GMC.
- GOLDMAN, C. R. & QUINN, F. L. (1988) Effects of a patient education programme in the treatment of schizophrenia. *Hospital and Community Psychiatry*, **39**, 282–286.
- KING, E. (1994) Suicide in the mentally ill. An epidemiological sample and implications for clinicians. *British Journal of Psychiatry*, **165**, 658–663.
- KING, J. (2000) What in fact is schizophrenia? *BMJ*, **320**, 800.
- LALLY, S. J. (1989) "Does being in here mean there's something wrong with me?" *Schizophrenia Bulletin*, **15**, 253–265.
- LEAVEY, G., KING, M., COLE, E., et al (1997) First-onset psychotic illness: patients' and relatives' satisfaction with services. *British Journal of Psychiatry*, **170**, 53–57.
- LUDERER, H. J. & BOCKER, F. M. (1993) Clinicians' information habits, patients' knowledge of diagnoses and etiological concepts in four different clinical samples. *Acta Psychiatrica Scandinavica*, **88**, 266–272.
- MCDONALD-SCOTT, P., MACHIZAWA, S. & SATOH, H. (1992) Diagnostic disclosure: a tale in two cultures. *Psychological Medicine*, **22**, 147–157.
- MAIN, M. C., GERACE, L. M. & CAMILLERI, D. (1993) Information sharing concerning schizophrenia in a family member: adult siblings perspectives. *Archives of Psychiatric Nursing*, **7**, 147–153.
- PENDLETON, D. & HASLER, J. (eds) (1983) *Doctor Patient Communication*. England: Academic Press.
- PENN, D. L., GUYNAN, K., DAILY, T., et al (1994) Dispelling the stigma of schizophrenia: what sort of information is best? *Schizophrenia Bulletin*, **20**, 567–578.
- RITCHIE, J. (1994) *Report of the Inquiry into the Care and Treatment of Christopher Clunis*. London: HMSO.
- SARTORIUS, N. (1997) Fighting schizophrenia and its stigma. A new World Psychiatric Association educational programme. *British Journal of Psychiatry*, **170**, 297.
- SAUGSTAD, L. F. & ODEGARD, A. (1983) Persistent discrepancy in international diagnostic practice since 1970. *Acta Psychiatrica Scandinavica*, **68**, 501–510.
- SCOTTISH INTERCOLLEGIATE GUIDELINES NETWORK (1998) *Psychosocial Interventions in the Management of Schizophrenia*. Edinburgh: Royal College of Physicians.
- SMITH, J., BIRCHWOOD, M., HADDRELL, A. (1992) Informing people with schizophrenia about their illness: The effect of residual symptoms. *Journal of Mental Health*, **1**, 61–70.
- SVENSSON, B. & HANSSON, L. (1994) Patient satisfaction with inpatient psychiatric care. *Acta Psychiatrica Scandinavica*, **90**, 379–384.
- WORLD HEALTH ORGANIZATION (1992) *The ICD-10 Classification of Mental and Behavioural Disorders*. Geneva: WHO.

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