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RUDOLF UHER AND CLIVE TIMEHIN

Managing patients' information in a community mental health team

AIMS AND METHOD

To explore current practice in offering patients copies of correspondence, we audited the documentation of 422 patients of a community mental health team.

RESULTS

Discussion about copying letters was documented in 194 case notes (46%);

older patients and those with medically unexplained physical symptoms were less likely to be offered copies. There were 159 patients (82%) that wanted to receive copies of letters; male gender was associated with declining this option. In 167 (87%) instances the professional completing the form was a psychiatrist.

CLINICAL IMPLICATIONS

Older patients need to be offered the opportunity to receive correspondence. Clinicians should record and substantiate their decision not to offer copies of letters to some patients. Professionals other than psychiatrists should be encouraged to discuss copying letters with patients.

A number of studies have demonstrated the benefits of sharing medical information with patients: these include enhanced trust and a cooperative relationship between patients and health professionals, better informed patients, increased adherence, health promotion and improved accuracy and clarity of records (Ross & Lin, 2003).

Although the right to access one's own medical records is granted in the Data Protection Act 1998 and Health and Social Care Act 2001, only a small number of patients request to see their documentation. The NHS Plan for England (Department of Health, 2000) incorporated the requirement to actively offer patients copies of medical correspondence. The good practice guideline on copying letters to patients specifies that during a consultation, patients should be routinely asked whether they want a copy of any letter written as a result of that consultation, how they want to receive such letters and what is their preferred format for such communication; their wishes should be clearly recorded and respected (Department of Health, 2003). Exceptions to this rule are instances where sharing information would cause serious harm to the patient or would reveal information provided by a third person who has not consented to disclosure. This directive has been implemented in the NHS from 1 April 2004 but it is not accepted universally (Boaden & Harris, 2005) and, to date, there are no data available on how it is applied in practice.

Although patients attending mental health services welcome the opportunity of receiving copies of correspondence (Ash *et al*, 1991; Marzanski *et al*, 2005), there have been specific concerns regarding sharing information in psychiatry (Stein *et al*, 1979; Ross & Lin, 2003). These include stigmatisation and distress associated with a psychiatric diagnosis, and illness-related litigation. Some subgroups of patients, especially those with psychotic illness, personality disorders and medically unexplained physical symptoms may present particular difficulties and many mental health professionals have reservations about sharing information with them (Stein *et al*, 1979; Goddard *et al*, 1997; Page & Wessely, 2003; Nandhra *et al*, 2004).

To gauge the practice in the first year of the implementation of the NHS Plan, we have performed an audit of the documentation of patients' wishes regarding copies of correspondence in a multidisciplinary community mental health team. We have addressed these principal questions.

- How many patients have been asked whether they want a copy of their letters?
- Are patients in specific age, gender, ethnic or diagnostic groups less likely to be offered copies of letters?
- How many patients want a copy of their letters?

- Are specific groups of patients less likely to want copies of correspondence?
- Which professionals ask their patients whether they want copies of correspondence?

Method

Files of all current patients in the care of a community mental health team in a suburb south of London were audited in January and February 2005. Details from the 'Consent and permission' or 'Managing patient information' forms were recorded. These two forms were successive versions of the same document used as part of the 'Patient Journey' note-keeping system in the South London Mental Health Trust. Both forms contained checkboxes on providing patients with information, asking them whether they wish to receive copies of medical correspondence and how they want to receive them. Forty patients were excluded because they had not attended any appointment since the implementation of the NHS directive in April 2004. Of the remaining 422 patients, 240 (57%) were women and the mean age was 42 years (s.d.=13). Data on ethnicity were only available for 191 patients, of which 123 (64%) were White British. The primary diagnosis was depression and/or anxiety in 194 (46%), psychosis in 111 (26%), personality disorder in 43 (10%), drug or alcohol misuse in 21 (5%), obsessive-compulsive disorder in 17 (4%), eating disorder in 8 (2%), adjustment disorder or bereavement in 12 (2.8%), medically unexplained physical symptoms or chronic fatigue syndrome in 7 (2%), learning disability in 4 (1%); no diagnosis was documented for the remaining 5 patients. Owing to common comorbidity, the diagnoses of unipolar depression and anxiety disorders were grouped together. Where multiple diagnoses were recorded without stating which was primary, the diagnosis considered to be more serious was given preference in the hierarchy: psychosis > personality disorder > addiction > depression / anxiety. The project was approved by and carried out in cooperation with the Clinical Governance Department of the South London and Maudsley NHS Trust.

Results

Who does not get asked?

The 'Permission and consent' or 'Managing patient information' forms were filled in and filed in 194 (46%) instances. Although there is an item on the form asking whether the discussion on copying letters is appropriate, it was not stated in any case that it is not. The participants who did not have a completed form in their notes were more likely to be older: higher age significantly predicted not having a completed form in a logistic regression analysis (-2LL=573.2; model $\chi^2_1=7.9$, $P<0.005$); when age was dichotomised, those under 40 had a 54% (107 out of 199) likelihood of having been asked compared with 39% (87 out of 222) for those over 40 (OR=1.8; $\chi^2_1=8.9$, $P<0.002$). We further explored whether patients referred

Table 1. Patients with documented information on their wish to receive copies of correspondence according to primary diagnosis

Primary diagnosis	Total <i>n</i>	Form completed <i>n</i> (%)	Want copies <i>n</i> (%)
Psychosis	111	48 (43)	37 (79)
Personality disorder	43	26 (60)	24 (92)
Alcohol or drug abuse/ addiction	21	12 (57)	8 (73)
Obsessive-compulsive disorder	17	7 (41)	4 (57)
Eating disorder	8	4 (50)	3 (75)
Medically unexplained physical symptoms/chronic fatigue syndrome	7	1 (14)	0
Anxiety and/or depression	194	83 (43)	72 (88)
Adjustment reaction/ bereavement	12	8 (67)	7 (88)
Learning disability	4	1 (25)	0
No diagnosis	5	4 (80)	4 (100)
Total	422	194 (46)	159 (82)

after the implementation of the NHS directive were more likely to have the forms completed: 52 out of 87 (60%) new referrals (after 1 April 2004) had completed forms compared with 142 out of 335 (42%) of those referred before April 2004 (OR=2.0; $\chi^2_1=8.4$, $P<0.005$). In forward stepwise logistic regression (removal criterion: likelihood ratio 0.1), both age and date of referral independently predicted the completion of 'Managing patient information' forms (-2LL=567; model $\chi^2_1=14.0$, $P<0.001$). Gender or ethnicity did not have a significant influence ($\chi^2_1<2.0$, $P<0.1$).

The relationship between the diagnostic group and the likelihood of being offered copies of correspondence is summarised in Table 1. Patients with a diagnosis of psychotic disorder were no less likely to be offered copies of correspondence than those with depression or anxiety. Patients with a primary diagnosis of personality disorder were more likely to be offered copies of correspondence than those without such a diagnosis (OR=2.0; $\chi^2_1=3.9$, $P<0.05$). Patients with medically unexplained symptoms or chronic fatigue syndrome were the least likely to be offered copies of correspondence: only 1 out of 7 (14%) had a completed form but because of the small numbers, the difference between those with and without this diagnosis showed only a trend for statistical significance (OR=5.2; $\chi^2_1=2.9$, $P<0.1$).

Who does not want to hear?

A total of 159 patients (82% of those with completed forms) wanted to receive copies of letters, 32 (17%) declined this option and in 3 instances this item was left blank. Furthermore, patients were asked whether they wanted to be sent only certain parts of correspondence: only 14 (7%) patients answered this question affirmatively and in 46 instances (23%) this item was left blank.



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There was a trend for men to be more likely than women to opt out of receiving copies of correspondence (OR=2.0; $\chi^2_1=3.1$, $P<0.1$). The decision not to receive correspondence was not significantly associated with age, time of referral, ethnicity or particular diagnosis. However, because of the small number of patients declining, these analyses lack sufficient power to detect moderate group differences.

Who asks the patients?

In 167 instances (87%) the professional completing the form was a psychiatrist, in 17 (9%) a nurse, and in 1 a psychologist; on the remaining 9 forms the profession was not given.

Discussion

Ten months after the implementation of the NHS directive, more than half of patients under the care of a community mental health team have not been given the opportunity to receive copies of letters written about them. Often it was the older patients who had not been asked. This age difference is not explained by the time of referral. It may reflect covert age discrimination as well as the fact that new procedures are more readily implemented with younger patients.

As there have been concerns about sharing information with patients with some psychiatric diagnoses (Stein *et al*, 1979; Ross & Lin, 2003), it was expected that patients with a diagnosis of psychotic or personality disorder would be less likely to be offered copies of letters. This was not confirmed: patients with psychotic disorder were no less likely to have been offered copies and no more likely to decline this opportunity than those without such a diagnosis. Those with personality disorder were offered copies of correspondence even more frequently than other patients. It is possible that this reflects more contact with the psychiatric services or is an effect of active requests from these patients. The one diagnostic group that appeared to be less likely to be offered copies of correspondence were those with medically unexplained physical symptoms (including conversion disorders) or chronic fatigue syndrome. As the number of these patients was very small, these data must be interpreted with caution. However, patients with medically unexplained symptoms have been reported to have difficult relationships with medical professionals and many are involved in litigation related to their condition (Goddard *et al*, 1997; Page & Wessely, 2003; Raine *et al*, 2004).

One reason why many patients have not been offered copies of correspondence is the restricted range of professionals who ask them about their wishes. In most cases the professional completing the form was the psychiatrist. Engaging other team members in the implementation of the policy may be crucial to attain satisfactory adherence.

Strikingly, the reasons for not offering copies of correspondence to the patient were not recorded for

any patient. Patients were either offered copies of correspondence or the form was left blank. Hence it is impossible to establish in how many instances the discussion was omitted intentionally and what were the reasons for this. There are legitimate reasons to withhold this opportunity from some patients. Indeed, in the Department of Health good practice guidelines it is specified that 'in some cases involving particularly sensitive areas, such as child protection or mental health problems, it may not be appropriate to copy a letter to the patient' (Department of Health, 2003). It is important to raise the awareness of clinicians and engage them in making their decision to offer patients copies of letters, or not, an explicit one. This would make the practice more transparent and would facilitate the collaboration between team members.

Declaration of interest

None.

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