Sharing letters with patients and their carers: problems and outcomes in elderly and dementia care

AIMS AND METHOD
In a cross-sectional survey, we assessed the attitudes of older patients and their carers towards receiving copies of letters about them and the effects upon outcomes of sharing letters. We also studied the opinions of consultants on letter-sharing.

RESULTS
Few old age psychiatrists shared letters with patients or carers, and many had concerns about this practice. In contrast, letters were considered ‘very welcome’ by 87% of patients and carers who received them, and 81% of those who did not would be ‘very pleased’ to receive them. Patients and carers who had received letters had significantly better knowledge of their care plan, whom to contact and ways of making contact with services.

CLINICAL IMPLICATIONS
Despite concerns expressed by psychiatrists, our findings support the sharing of letters with patients and carers of patients with dementia in old age psychiatry services.

For some time now there has been a shift towards greater public accountability within the health service and more involvement of patients in discussions about their health (Farrell et al, 1998). Under the Health Records Act 1990 and the Data Protection Act 1998 patients have the right to access their medical records and to see what is written about them. The National Health Service (NHS) Plan (Department of Health, 2000) and the Government’s response to the Kennedy report (Kennedy, 2001) (recommendation 17) set out the Government’s intention that patients should receive, as of right, letters about them written from one health professional to another. The objective of this policy is to improve communication with patients and enable them to participate in their care.

In response, a working group on copying letters to patients was set up by the Department of Health (Meredith, 2002). During 2002 the Government established pilot schemes and directed that from April 2004 all patients should receive by right copies of letters written about them from one health professional to another (Chantler & Johnson, 2002). Although successful models for copying letters in general medicine, general practices and genetic and special clinics have been reported, fears about patients who lack insight, might not accept a diagnosis of mental illness or might not cooperate with treatment and care plans have made mental health services an area of particular concern for the implementation of this idea.

A study by Asch et al (1991) in a psychiatric out-patient clinic found that patients who received a summary of their consultation were significantly more satisfied with their consultation than those who did not receive one. Similarly, Humfress & Schmidt (1997) found a greater satisfaction of patients when a personalised summary was sent to them. However, Parrott et al (1988) reported considerable problems in a forensic setting as a result of a patient accessing letters. Nandhra et al (2004) reported that general adult psychiatric patients found it helpful to receive copies of their assessment letters. Similarly, Lloyd (2004) showed that patients approved of receiving copies of their letters, but suggested that a ‘narrow path’ would have to be followed to maintain trust while avoiding paternalism, complaints and litigation.

In old age psychiatry matters may be even more complicated. Patients may lack capacity for decisions, they may have dementia and information often comes from third parties (e.g. relatives, carers and others involved with the patient). With severe cognitive impairment, sharing of information with carers may be both helpful and good practice, but confidentiality is an inevitable concern (General Medical Council, 2000).

We began sharing letters with patients from 2000 onwards, routinely (for A.T.) from 2001. In this study we wanted to assess the impact of this service on patients and carers and also solicit the views of psychiatrists in our area. Null hypotheses tested were:

(a) that patients and carers do not wish to receive and do not like receiving copies of letters about them;
(b) that there is no evidence of improved outcomes as a result of this practice;
(c) that there is no anxiety about doing this among consultants in old age psychiatry.

Method
The study period was April to July 2003. All patients and carers attending four out-patient clinics (two memory, two functional) in the Oxleas NHS Trust Memorial Hospital during this period were approached once. At that time about half of all patients were receiving copies of letters to their general practitioners. All those attending the clinics were asked to complete semi-structured questionnaires while waiting for their appointment. By asking them to fill out the questionnaire while waiting for review appointments, we ensured that respondents could not refer back to letters they had received. To test hypothesis (a), those who had received a letter from their previous attendance were asked how
to find a contact number (adjusted residual=2.4, overall Fisher’s exact test shows only a trend, \(P=0.058\)). However, there was no difference between the groups regarding the outcome variable ‘whom they would contact if a problem arose’. Using free text responses, three respondents reported distress from the letter and seven respondents described reassurance from the letter in the same question (Box 1).

**Doctors**

Of 46 consultants identified, we contacted 38 (there were 8 wrong addresses) in the old South East Thames Regional Health Authority area, sent them questionnaires and received 25 answers (66% response rate) without reminders. Only two consultants sent copies of their letters to the patients (one to more than 80% and the other to about 50%); both avoided medical terminology in their letters or tried to explain medical terminology. One had a rate of complaints from patients of about 1% and the other had a rate of about 5%. Both consultants found this procedure helpful, as did their patients.

The other 23 consultants did not send copies of letters to their patients; their answers are shown in Table 2. We coded the doctors’ free text responses, and developed them into thematic categories. These are summarised in Box 2. Some consultants expressed anxieties more than once in the same category. The most frequent worries expressed by doctors (expressed in free text, 29 statements) were that sharing the letter would disrupt the therapeutic relationship or offend the patient. The next most frequent concern \((n=23)\) was about third parties not wanting to let patients know what was going on, or having the information they had given about the patient shared with the patient. Confidentiality \((n=9)\), misunderstanding caused by letters \((n=7)\), the need for separate letters specifically for the patient \((n=2)\) and problems of psychosis \((n=3)\) were also mentioned.

Content analysis of doctors’ answers highlights the level of worries through the frequency of words with ‘negative’ meaning. These ‘negative’ words were ‘problems’ \((n=7)\), ‘concerns’ \((n=6)\), ‘distress’ \((n=6)\), ‘upset’ \((n=5)\), ‘risk’ \((n=3)\), ‘conflicts’ \((n=3)\) and ‘censor’ \((n=2)\). Some of the most typical thoughts and anxieties expressed are presented in Box 2.

**Discussion**

This study showed substantial anxiety among consultants in old age psychiatry about the idea of sharing copies of their letters to general practitioners with their patients. This is in marked contrast to the views of patients and carers as well as to the finding of improved outcomes. The study’s limitations were that the patient and carer study was conducted in only one district, and that the consultants survey was conducted in one part of the UK. Although the findings are not therefore automatically generalisable, we are confident that they do reflect the perceptions and feelings of the older patients attending our out-patient and memory clinics.
Old age consultants’ anxieties resembled those of the general adult psychiatrists surveyed by Nandhra et al (2004) and suggest that introducing letter-sharing in old age psychiatry would have similar problems. Main areas of concern were disruption of therapeutic relationships, misunderstanding of letters by patients and disclosure of third party information. In complete contrast, our patients and carers welcomed letter-sharing. The responses of patients were similar to those in general adult psychiatry studies (Asch et al, 1991; Lloyd, 2004; Nandhra et al, 2004) and with similar questions our patient group appeared to be even more welcoming of the practice. We also demonstrated improved knowledge outcomes in patients and their carers about what is recommended for the patient medically, and better knowledge about whom to contact if problems arise. It is of particular interest that in this group of patients, where carers have such a central role, concerns about confidentiality did not arise. This suggests that in day-to-day work, confidentiality might be more of a theoretical concern than an actual problem. Stacked up against the benefits of information-sharing for the patient, this is welcome news. It is likely that sharing letters with patients will lead to some alteration of content.

### Table 1. Results of patient and carer questionnaires

| Was pleased to receive letter | Received copies of letters (n=48) | Did not receive letters (n=54) | Significance |
|--------------------------------|----------------------------------|------------------------------|--------------|
| Very                           | 42                               | NA                           |              |
| A bit                          | 4                                |                              |              |
| Unsure                         | 2                                |                              |              |
| Not pleased                    | 0                                |                              |              |
| Would be pleased to receive letter | NA                             | 44                           |              |
| Very                           | NA                               | 44                           |              |
| A bit                          | 6                                |                              |              |
| Not sure                       | 3                                |                              |              |
| Not pleased                    | 1                                |                              |              |
| Was the letter easy to understand? | Very                            | 43                           | NA           |
| Very easy                      | 43                               |                              |              |
| Fairly easy                    | 5                                |                              |              |
| Disagreement with some things stated | In letter                    | 2                            | NA           |
| In letter                      | 2                                |                              |              |
| In clinic                      | NA                               | 1                            |              |
| Accuracy of letter             | Very accurate                    | 33                           | NA           |
| Fairly accurate                | 13                               |                              |              |
| Not sure                       | 1                                |                              |              |
| Fairly inaccurate              | 1                                |                              |              |
| Very inaccurate                | 0                                |                              |              |
| Anything upsetting in the letter | Very upsetting                  | 0                            | NA           |
| Very upsetting                 | 0                                |                              |              |
| A bit                          | 3                                |                              |              |
| Not sure                       | 7                                |                              |              |
| Letter reassured               | 20                               |                              |              |
| Very reassured                 | 17                               |                              |              |
| No answer                      | 1                                |                              |              |
| Easy to find the telephone number of the clinic or doctor’s secretary (n=97) | Yes, very easy | 34 | 22 | Fisher’s exact test 9.607, $P=0.013$ |
| Fairly easy                    | 6                                | 17                           | test 9.607, $P=0.013$ |
| Not sure                       | 7                                | 9                            |              |
| Quite difficult                | 0                                | 0                            |              |
| Very difficult                 | 0                                | 2                            |              |
| No answer                      | 1                                | 4                            |              |
| Who patient/carer should contact in case of problems (n=87) | Wrong person | 4 | 15 | Fisher’s exact test 7.819, $P=0.014$ |
| Partially correct              | 0                                | 3                            | test 7.819, $P=0.014$ |
| Correct person                 | 34                               | 31                           |              |
| No answer                      | 10                               | 5                            |              |
| What was planned in clinic (n=76) | Disagreement with the plan   | 5                            | 17           | $\chi^2=6.636$, $P=0.036$ |
| Partial agreement              | 6                                | 12                           | $\chi^2=6.636$, $P=0.036$ |
| Agreement with the plan        | 20                               | 16                           |              |
| No answer                      | 17                               | 9                            |              |

NA, not applicable.
Although further practice development in this area is appropriate, we believe that there is no justification for delaying widespread implementation of this practice in our care group.

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References

ASH, R., PRICE, J. & HAWKS, G. (1991) 
Psychiatric out-patients’ reactions to summary letters of their consultations. 
British Journal of Medical Psychology, 64, 3–9.

CHANTLER, C. & JOHNSON, J. (2002) 
Patients should receive copies of letters and summaries. 
BMJ, 325, 388.

DEPARTMENT OF HEALTH (2000) The NHS Plan. London: Stationery Office.

FAIRBELL, C., LEVENSON, R. & SNAP, D. (1998) 
The Patient’s Charter: Past and Future. London: King’s Fund.

GENERAL MEDICAL COUNCIL (2000) 
Confidentiality: Protecting and Providing Information. London: GMC.

HUMFREY, H. & SCHMIDT, U. (1997) 
Dictating clinic letters in front of the patient. Effect of sending clients a personalised summary letter is being studied. 
BMJ, 314, 1416–1417.

KENNEDY, J. (2001) 
Learning From Bristol: The Report of the Public Inquiry into Children’s Heart Surgery at the Bristol Royal Infirmary 1984–1995. 
London: Stationery Office.

LLOYD, G. (2004) Medical records: copying letters to patients. 
Psychiatric Bulletin, 28, 57–59.

MEROEIE, B. (2002) 
Copying letters to patients: policy should be implemented as soon as possible. 
BMJ, 325, 1359.

NANDHRA, H. S., MURRAY, G. K., HYMAS, N., et al (2004) 
Medical records: Doctors’ and patients’ experiences of copying letters to patients. 
Psychiatric Bulletin, 28, 60–62.

PARROTT, J., STRATHDEE, G. & BROWN, P. (1988) 
Patient access to psychiatric records: the patients’ view. 
Journal of the Royal Society of Medicine, 81, 520–522.

*Adrian Treloar Consultant in Old Age Psychiatry, Oxleas NHS Trust, Memorial Hospital, Shooters Hill, London SE18 3RZ. e-mail: adrian.treloar@oxleas.nhs.uk.

Dimitrios Adamis Consultant in Old Age Psychiatry, Oxleas NHS Trust, Memorial Hospital, London SE18 3RZ.