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Do patients really want copies of their GP letters? A questionnaire survey of older adults and their carers

AIMS AND METHOD

The National Health Service Plan stated that all correspondence between clinicians would be copied to patients by April 2004. We wanted to find out whether this practice reflected the true desires of their patients. A questionnaire survey was therefore performed in older adults

In accordance with the National Health Service (NHS) Plan, since April patients have been receiving copies of all correspondence between clinicians working in the NHS as a matter of course (Department of Health, 2000). The rationale behind this is that patients have a right to know what is being written about them and that to refuse to provide such information, if this is the patient's wish, is to deny them their autonomy (Chantler & Johnson, 2002). Evidence suggests that patients appreciate this practice, and many organisations and individuals in the NHS are either already copying letters to patients or are keen to do so (Meredith, 2002). In addition, research indicates that carers would like to be incorporated into the planning and delivery of care (Noble *et al*, 1999) – a sentiment that has been reflected in the National Service Framework for Mental Health.

However, concerns have been raised about the implementation of this plan without further thought and research. It has been highlighted that particular patient groups, such as those with mental health problems and those who lack the mental capacity to give consent, need closer attention and consideration before the plan is implemented nationwide (Jelley *et al*, 2002). Information sharing is a vital part of good clinical practice, but it is clear that some psychiatrists have anxieties about copying medical correspondence to patients (Murray *et al*, 2003). At present, there is a lack of any clear guidance on how to implement this practice in the mental health service setting and it is not certain whether this proposal reflects the true desires of mental health service users. This study aimed to ascertain how older adult psychiatric patients and

and their carers attending a psychiatric out-patient clinic.

RESULTS

A total of 88 participants were recruited; 50 patients and 38 carers. The majority of patients and carers wanted a letter about their care but most preferred a separate, simple letter rather than a copy of the letter sent to their general practitioner.

CLINICAL IMPLICATIONS

Although this study supports the existing evidence that patients would like written information about their care, it indicates that certain patient groups might not want this in the form of copies of their medical correspondence. Further research into patient and carer preference is needed before the implementation of this policy.

their carers would prefer to receive information about their treatment and care and, in particular, whether they wish to receive copies of their medical correspondence.

Method

A questionnaire survey was performed in the out-patient department at the Queen Elizabeth Psychiatric Hospital, Birmingham over a 10-week period, between September and November 2002. All older adult patients and their carers attending the clinic during the study period were approached by reception staff to take part in the study and given an information leaflet. All those who were able to give their informed consent participated by completing the questionnaire. The research tool comprised separate questionnaires for patients and carers. A multiple-choice, tick-box format was employed. The participants completed the questionnaire while they were in the waiting area before their appointments. Reception staff and doctors were on hand for further help if it was necessary. The results were analysed using the Statistical Package for the Social Sciences version 11.

Results

A total of 88 participants were recruited. Fifty participants were recruited in the patient group. Most patients said they had a carer ($n=43$, 86%) and the majority of carers were relatives ($n=37$, 88.1%). Most patients wanted a letter of some sort about their treatment and care ($n=42$, 84.0%; Table 1). The majority of patients

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papers**Table 1. Need for letter**

	Patients n=50 (%)	Carers n=38 (%)
Yes	42 (20)	36 (24)
No	3 (28)	0 (29)

Table 2. Letter preference of patients and carers

Letter preference	Patients n=50 (%)	Carers n=38 (%)	χ^2	P
GP letter	10 (20)	9 (24)	0.069	NS
Letter to patient with copy to GP	14 (28)	11 (29)		
Separate/simple letter	18 (36)	16 (42)		

GP, general practitioner; NS, not significant.

preferred to have a simple, separate letter ($n=18$, 36%) or their own letter containing their medical information, with a copy of this later going to their general practitioner (GP) ($n=14$, 28.0%). However, only 10 patients (20%) wanted a copy of the usual letter sent to their GP. A small number ($n=3$, 6%) did not want a letter at all. Most patients said they would like their carer to receive a copy of their letter ($n=27$, 54%); only nine patients (18%) did not. A total of 14 patients (28%) gave no response.

A total of 38 participants were recruited to the carer group. The majority of carers ($n=29$, 21.4%) were relatives. Two carers identified themselves as friends and seven as professional carers. All the carers who gave a response wanted a letter about the patients' treatment ($n=36$, 94.7%; Table 1). For letter preference, the results of the carer group closely resemble those of the patient group. The majority wanted a separate, simple letter ($n=16$, 42.1%), whereas 11 participants (28.9%) preferred to receive their own letter with a copy of this later going to the GP. Only nine subjects (23.7%) wanted a copy of the usual letter sent to the GP. There was no significant difference between the patient group and carer group for letter preference (Table 2). A total of 34 carers (89.5%) said they should receive information about a patient's treatment and care if the patient was unable to give their permission and only three (7.9%) said they should not. One participant gave no response.

Discussion

This study was limited by a small sample size and could have been influenced by responder and acceptability bias. Because of the design, it was not possible to calculate the response rate or to assess reasons why subjects did not participate. It does, however, provide an interesting snapshot into patient and carer preference regarding the copying of clinicians' correspondence to patients.

It is clear that patients want written information about their care and the survey reflects this current understanding. However, the results indicate that the majority of patients in our population would like a separate, simple letter rather than a copy of the

correspondence sent to the GP. Interestingly, the carer group shared this preference. Indeed, the survey has highlighted the fact that we must consider the needs and wants of carers when we decide how best to relate medical information, as both groups felt it was desirable to share information about a patient with their carer.

We would argue that extra caution should be taken before implementing this practice within the older adult population and psychiatric patients, where vital issues such as mental capacity and risk must be considered. This introduction has wide-ranging implications for our current practice and could lead to the omission of important, but sensitive, information in the correspondence between medical professionals for fear of jeopardising the therapeutic relationship. It also raises serious concerns about confidentiality, medico-legal issues and the need to invest in extra resources to explain complex medical terminology. Interestingly, it seems that the patients' and carers' preferred option of receiving a separate letter rather than a copy of the letter sent to the GP could be the safest and the best way of maintaining the professionalism of medical communication while keeping patients informed. In any case, the results from this study show that not all service users want the same method of communication. One could therefore reason that individual preferences should be sought routinely before giving everyone copies of their medical correspondence.

Conclusion

Further thought and research is needed to find a way to satisfy patients, carers and their doctors. It appears that we are faced with the task of implementing policies with little, or no, evidence base and which have no regard for potentially undesirable, even harmful, implications. Furthermore, with April 2004 now in the past, we feel it is still unclear whether the practice of copying medical correspondence to those using the NHS really represents the desires of patients and their carers.

Declaration of interest

None.

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