Access to records and client held records for people with mental illness

A literature review

Richard Laugharne and Anna Stafford

Increasing involvement of users in health service planning has led to a movement towards patients having more information about their care. Some have advocated patients having access to their medical records and this is now a statutory right. There has been concern as to whether this is suitable in mental health. An addition or alternative to access to medical notes is a client held record which might increase the patient's feeling of autonomy while also improving communication and compliance. In studies on access most patients and staff have found this beneficial. Client held records have also been positively received in the few studies reported but more evaluation in routine practice is needed.

A major development in health care during the present decade has been the increasing involvement of users of services. A greater emphasis has been placed on the empowerment of patients in a system which has been perceived to be over paternalistic. More information about their illness and its treatment might enable patients to increase their sense of autonomy.

Another development has been the increase in the care of long-term mentally ill people in the community, involving both primary and secondary care, often with several professionals involved. Communication between these professionals can be difficult, and it has been noted that "evidence is lacking that primary and secondary mental health services are integrating their functions well enough to provide effective and efficient care" (Wilkinson, 1991).

Patient autonomy may be aided by availability to patients of access to their medical records. As an alternative, or in addition, a client held record might be incorporated into mental health care. The development of client held records, which are an established part of maternity and diabetic care, would achieve some targets of the *Health of the Nation* report (Department of Health, 1993), in particular involving users in their own treatment and providing them with more information. Communication between professionals might also be improved. One model is for the client to hold their entire medical record, but an alternative is a record in addition to notes kept by professionals.

In this article we shall review previous work concerning both access to records and client held records.

Access to records in general health care

The 1990 Access to Health Records Act, applicable to all records after 1st November 1991, establishes the right of access to information relating to physical or mental health in connection with care and treatment, although the Department of Health already held the principle that patients should be allowed to see what was written about them. However, the information given to the patient can be limited if, in the holder's opinion, the disclosure might cause serious physical or mental harm to any person, or information disclosed is about or provided by an identifiable third party without their consent.

Shenkin & Warner (1973) were one of the first to suggest that giving patients access to all their medical records could be beneficial. This view was echoed by Gilhooly & McGhee (1991) who described the literature on access to medical records, and Metcalfe (1980) who took the idea further suggesting that patients should hold the record.

Studies in which patients were given access in both primary care (Tomson, 1985; Baldry *et al*, 1986; Bird & Walji, 1986; Melville, 1989) and secondary care (Bouchard *et al*, 1973; Golodetz, 1976) found the exercise beneficial. However, an assessment based on a consultant's opinion of how patients would react to reading their own records concluded that it would be problematic (Short, 1986).

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In studies where patients themselves were asked about access to their own records (Stein, 1979; Michael & Bordley, 1982; Parrott *et al*, 1988; Melville, 1989; Kosky & Burns, 1995) the majority were in favour.

Client held records in general health care

The use of client held records is widespread in the UK in maternity care where they have been used successfully (Elbourne *et al*, 1987; Lovell & Elbourne, 1987). In the United States Giglio & Papazian (1986) evaluated four different types of client held records in general medicine, all of which were acceptable and used by patients. It is important to distinguish between the client held record as the only medical record proposed by Metcalfe (1980) or as an addition to the hospital record. Generally the latter is the case.

Access to records for people with mental illness

A working party of a committee of the Royal College of Psychiatrists expressed concern about giving psychiatric patients access to their records in their response to the Department of Health and Social Security consultation paper on the Data Protection Act (Priest, 1986). It recommended that patients should not be given access to personal health data. An important concern was that information from relatives contained in medical records might not be given if patients had access. Other arguments against access included the problems of information which might be hurtful to patients and the difficulty of selecting information for access. Gilhooly & McGhee (1991) noted that many US states allowing access to records also included provision to exclude all or part of psychiatric records from direct patient review under certain circumstances. They argued, however, that this exclusion was difficult to justify ethically and agreed with Showalter (1985) that psychiatric patients should be given access.

Cohen (1985) and Healy (1990) suggested that giving psychiatric patients access to their records could be positively useful when used as a basis for discussion and therapy. Cohen gave the example of a study of children with severe behavioural problems who were given access to their records at an educational guidance centre as part of their treatment, and which appeared to help the children build relationships with staff. Cohen argued that if this could work with such a client group, it could work for adults in other contexts. Sergeant (1986) argued that giving patients access would not be beneficial as did Short (1986), on the basis of his own review of patients' notes.

Primary care

Three of the primary care studies previously discussed specifically mention access for people with mental health problems (Tomson, 1985; Baldry *et al*, 1989; Bird & Walji, 1989). It appears that generally this was not a problem and information in these cases was rarely withheld. There were instances where people with a psychiatric diagnosis were upset by seeing their notes but nevertheless found it informative and helpful.

Psychiatric hospital notes

In a study recording the views of patients and staff of giving in-patients access to their notes 90% of staff and 92% of patients were in favour of access (Stein *et al*, 1979). Recent studies in the UK (Kosky & Burns, 1995; Parrott *et al*, 1988) also found that giving patients access could be beneficial for both staff and patients. Parrot *et al* investigated the subjective views of patients on access to records on two psychiatric wards, one which had a policy of open access and one which did not. The study investigated whether patients wished to have access and their views on the effect of access. Eighty per cent on both wards were interested to read the notes. Although reading their notes could sometimes be upsetting, there was a general consensus among patients that it was not harmful.

In a recent study by Kosky & Burns (1995) in which 40 patients on a psychiatric in-patient unit were encouraged to look at and discuss their notes with the registrar, 28 (70%) accepted the opportunity. It was noted that the 12 who refused all had long psychiatric histories and had generally lower educational attainments. The registrars found that the exercise of making their comments in an honest but accessible and inoffensive way sometimes enabled them to gain a better understanding of their patients and was a useful training exercise.

In the studies described patients were not given blanket access, but were given access to the notes made in their current admission, where staff were aware that patients would be reading what they were writing. The studies indicated that where thought was given to the writing of medical records access to psychiatric hospital notes could be beneficial for the patient and could also be helpful for the clinician.

Where the process is not managed and thought not given to the way the notes are written, problems may occur. Rapp (1986) describes an instance in which allowing someone access to records may have contributed to their committing

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suicide. He concluded that there are problems in allowing very sick patients access to their records as they are presently kept.

Client held records for people with mental illness

In studies concerning client held records for people with mental illness the record has always been in addition to the normal hospital or primary care notes. Most professionals would view the client holding the only record as unrealistic in clinical management.

Reuler & Balazs (1991) carried out a small study of a client held record for the homeless mentally ill in East London. This was to aid communication between health providers, as this population often see many different providers who are unfamiliar with their background. Although limited because of its size (28 people completed the whole study) the study indicated that the record was used, and gave providers information for coordination of care. In addition to its value for health providers, patients themselves were pleased to read their medical records.

Essex *et al* (1990) developed a shared care card for people with mental illnesses, mostly schizophrenia or other forms of chronic psychotic illness, in an area of South East London. Eighty-four patients held these records over a period of 18 months, and both patients and staff completed a questionnaire to assess their views. Almost all patients said that they liked to see what had been written about them and liked holding their own records. Usage was poorest among people who experienced feelings of paranoia and those who did not accept they had a mental illness. It was noted that usage was also affected by the interest shown by health workers.

Essex and his colleagues found that professionals believed the shared care card improved communication with their patients and patients felt that having more information improved their relationship with health staff. Professionals using the record believed that the record made people more aware of the involvement of other health workers, enabling input to be adjusted accordingly. Overall, the study concluded that many people with chronic psychotic illnesses can hold, use and value a client held record, and that these records could lead to improved communication between health staff as well as between clinicians and their patients.

Comment

The studies suggest that allowing patients to see their notes can have benefits of improved communication between patient and clinician, giving patients greater understanding and a feeling of autonomy (Bouchard, 1973; Golodetz, 1976; Stein, 1979; Parrot *et al*, 1988). Compliance with treatment may be improved, although this has not been evaluated. Issues for consideration are the recording of sensitive information, the possible reluctance of relatives to disclose relevant information if the patient has access to it, and the importance of the use of appropriate language (Priest, 1986). There was one reported suicide which may have been associated with a patient having access to his records (Rapp, 1986).

While there has been much debate about giving patients access to records, particular concern is raised with regard to psychiatric patients. The studies cited would indicate however that the benefits and concerns of giving people access to their records are applicable in all areas of medicine. In the studies assessing access to records in mental health (Stein *et al*, 1979; Parrott *et al*, 1988; Kosky & Burns, 1995) most patients felt it to be beneficial, and serious problems were not created. However, in these studies the professionals making the records were aware that the patients would be reading them, therefore the records may not be typical routine notes.

Reservations concerning access to medical records might be overcome by advocating a client held record. This would enable clinicians to select information put into the record but would still enable them to give patients information on their care and at the same time improve communication. The two main research studies in client held records in mental health (Essex *et al*, 1990; Reuler & Balazs, 1991) have been short-term and so far have not led to sustained routine practice. Clearly there is a big jump between experimental work and establishing new routine measures which can be implemented in different centres. Therefore it is important to build on this work by introducing integrated, client held record schemes with full evaluation.

Most studies have focused on how access to records or client held records are perceived by patients and affect the clinician–patient relationship. Less has been shown on the effect on communication between professionals and on compliance. Further research in these areas in the future might prove valuable, especially as care in the community has resulted in a less centralised service and communication can be problematic.

We conclude that most of the reservations of professionals in giving psychiatric patients access to their medical records have not been borne out in studies on groups of patients. Client held records in addition to professional held records may be an alternative which gets over certain objections to full access and still gives patients important information and improves communication. Fuller evaluation of client held records is

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needed to assess the extent to which they can empower patients, improve communication between those involved in care and improve compliance with treatment.

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