



special articles

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Medical records:

Patient-held records in mental health

'But don't they get lost?' This is usually the first comment made when the authors mention the use of patient-held records (PHRs) to colleagues. Nevertheless, PHRs have been used in mental health care as well as several other settings, including services for diabetes, cancer, maternity and child health. In some of these services, including mental health, PHRs have been an addition to clinician held standard notes, whereas in others the patient holds the only record for their care. The main purposes of introducing PHRs have been to empower patients with a sense of ownership of their care and to improve communication, between both patients and clinicians, as well as between different clinicians involved in that person's care (Laugharne & Stafford, 1996).

An earlier review of literature on PHRs in mental health suggested that they are received positively by patients who use them, but few studies had evaluated their benefits (Laugharne & Stafford, 1996). Since then a Cochrane systematic review (Henderson & Laugharne, 1999) and two randomised controlled trials (Warner *et al*, 2000; Lester *et al*, 2003) have been published and other trials of these records have evaluated their use in cancer care (Drury *et al*, 2000; Williams *et al*, 2001; Cornbleet *et al*, 2002; Lecouturier *et al*, 2002).

The evidence

Early studies using PHRs in mental health were limited to patient and staff views in relatively small numbers of patients. Essex *et al* (1990) used the record in a patient group suffering mainly from a psychotic illness in south-east London. Eighty-four patients used the record over a period of up to 18 months. Patients were positive about using a PHR, with usage being poorest among patients with paranoid ideation and those who did not accept they had a mental illness. Reuler & Balazs (1991) encouraged 28 homeless people with a mental illness in east London to use a PHR. Again the record was used by most patients and was approved by a majority. Stafford & Laugharne (1997) introduced the PHR to patients in an east London community mental health team (CMHT). Fifty-six patients took up the offer, most (50) suffering from a psychotic illness. Of 45 patients interviewed after 2–14 months (mean 6 months) using the record, over

80% found the record and the information it contained useful. Compared with CMHT notes, 74% of face-to-face contacts were recorded in the PHR. These patients were approached for interview again 5 years later (Stafford *et al*, 2002). Although only 19 patients were seen, 12 were still using the record and of these 12 records, 72% of CMHT contacts were recorded in the PHR. Although this study involves small numbers, it demonstrates that PHRs can be sustained over 5 years in a naturalistic, rather than a research, setting.

Two randomised controlled trials of a PHR have been conducted over the last 5 years. Warner *et al* (2000) conducted a cluster-RCT involving 90 patients with a 12-month trial period. Patients had long-term mental illnesses, with more than 50% having a functional psychosis. The PHR did not improve outcomes in admissions to hospital, clinical symptoms or patient satisfaction. Only 44% of the PHR group said they had used the record. Patients with a psychotic illness were less likely to use the PHR and both patients and staff were reluctant to use the record.

Lester *et al* (2003) also used a cluster randomised controlled trial method for their study. However, their patient population specifically had schizophrenia, and the perspective was from primary care. The patient sample was large, at 201, and follow-up was again 12 months. Again no difference between users of the PHR and non-users was found in outcomes in terms of symptoms, service use and patient satisfaction. However, 69% of patients in the PHR group used the record and of those, 61% had been regularly used by their keyworker. Patients were less likely to use the record if they had a higher symptom score.

Several controlled trials of a PHR in cancer care have been reported recently (Drury *et al*, 2000; Williams *et al*, 2001; Cornbleet *et al*, 2002; Lecouturier *et al*, 2002). It is interesting to note that in common with trials in mental health, the PHR did not result in benefit in terms of patient satisfaction or clinical outcomes when compared with the control group. However, patients felt that they did benefit from using the PHR.

Arguments for and against PHRs

The RCTs have not shown any overall benefit in clinical outcome when patients are allocated a PHR, and thus the

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extra documentation might not be justified in terms of benefit. However, the findings of the early, non-randomised studies of PHRs suggested that those patients using them appreciated having their own record in that it gave them a sense of ownership in their care. The use of the PHR is also sustainable over time among such patients. In the randomised trials many patients allocated the PHR did not actually use it, for reasons that have not been studied in any detail. It could be that there are benefits detectable by the outcome measures used but that intention-to-treat analyses result in these benefits not being apparent, because of high rates of non-use. It is also possible that some benefits to patients who use the records are undetected by the outcome measures used in the trials. If the goals include empowerment and improved communication (Laugharne & Stafford, 1996) then it could be argued that these should be measured more directly, rather than the use of possibly distantly related measures of patient satisfaction and use of services. For example, an empowerment scale has been developed for use among users of psychiatric services (Rogers *et al*, 1997; Wowra & McCarter, 1999). It must be noted that most of the patients in these studies have had a psychotic illness, so the results apply only to that population and not to those without psychosis.

Conclusions

There is no evidence that PHRs improve clinical outcomes in patients with a mental illness. This finding is also evident in patients with cancer. However, in randomised controlled trials, many patients allocated the PHR did not actually use it, and the reasons for this require elucidation for better interpretation of the trial results. In non-randomised studies, patients chose to use the PHR, and the majority of them approved their use and found them beneficial. From these findings, there would seem no justification to support their use for all patients. However, it could be argued that if patients choose to keep a PHR and feel it would help them to be empowered in their care, the PHR can be beneficial in terms of user involvement. Anecdotally, these patients are generally easier to engage and more likely to already comply with treatment offered to them. Thus there are a number of challenges. The first is to understand why many patients do not use

PHRs when offered them. This understanding could then facilitate the creation and evaluation of other attempts to empower patients with respect to their mental health problem. Similarly, the aims of improving communication between patients and professionals and among professionals might also require other methods and measures.

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