

Shared care? Some effects of patient access to medical communications

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Abstract

This paper describes the introduction of a model of community mental health services in out-patient settings within which a key feature is a letter-sharing scheme. Copies of letters from psychiatrists to GPs are routinely sent to both patients and CMHT keyworkers. It is hoped that such a practice may empower patients *and* potentially improve clinical outcome. In a preliminary attempt to identify a range of benefits and problems relating to the practice a qualitative study was undertaken which involved interviews with all relevant stakeholders: psychiatrists, GPs, keyworkers and patients. The data raise a variety of problems which require further quantitative investigation but also point to a number of predicted benefits which may be of use to others considering the introduction of similar schemes.

Introduction

With the move to community mental health services, there has been a de-institutionalisation of mental health care. This 'geographic' move has coincided with deeper-rooted political changes in the doctor–patient relationship, partly characterised by the growth of the user movement (Rogers & Pilgrim, 1991) and by calls from both pressure groups and government for increased patient rights (DHSS, 1984; Welsh Office, 1991). This paper explores a 'letter-sharing' practice in community mental health as a way of simultaneously improving clinical outcome and acknowledging and increasing patients' rights.

While the structure of out-patient clinics within general practice is varied, the majority fall into two broad models: the displaced out-patient model and the liaison approach. The 'displaced out-patient' model represents the traditional out-patient clinic removed to the community setting – it maintains the same essential structure and operation. The GP refers the patient to the psychiatrist and will usually relinquish management and responsibility. At the same time those areas operating within the context of a Community Mental Health Team (CMHT) are likely to offer the services of a keyworker. A second model involves a liaison approach, in which a consultant psychiatrist or psychotherapist meets with members of a general practice on a

regular basis and deals with queries that they raise regarding problem patients. The desired outcome of this model is the skilling of general practitioners to handle their own mental health case work. However, in these days of fundholding, it is not clear that such sessions, which do not commit the psychiatrist to seeing any patients, will be attractive to general practitioners. These models will be briefly examined before describing a third model currently being operated in North Wales.

‘Displaced out-patient’ and the ‘liaison approach’: a critique

While the geographical move to general practice settings may represent an attempt to de-stigmatise mental illness it remains unclear whether the retention of an out-patient or liaison model acknowledges changes in the status and rights of patients. The most fundamental and important issue in user empowerment is the right to information and this is not addressed by traditional models. Furthermore, the Audit Commission (1994) has recently stressed the importance of information provision in the attainment of clinical outcome:

‘There is increasing evidence of a positive relationship between communication and clinical outcomes across a range of clinical conditions and types of treatment. This applies to communication both between doctors and patients and between clinical teams and patients.’ (Audit Commission, 1994, p. 3)

Both the displaced out-patient model and the liaison approach outlined above can be critiqued in terms of their communication and information provision between the four stakeholders. The relationship between the psychiatrist and the GP will usually involve a two-way correspondence. However, because it is written (rather than oral), the referral

letter is frequently brief, with little background information about the patient’s history and family circumstances. This is information that many GPs may have but which the GP frequently seems to expect the psychiatrist to find out him/herself from the patient. Similarly, the patient *might* be able to provide some of this information in the consultation; however, a notable feature of clinic attendance behaviour is the tendency on the part of patients to assume that the psychiatrist can ‘read their minds’ and thus there is little need to say much. Consequently, the psychiatrist may be at a disadvantage. While the keyworker assigned to the patient is likely to have access to both the referral letter and copies of correspondence from the psychiatrist to the GP, traditional correspondence gives a limited insight into the consultation(s) between the psychiatrist and the patient.

In terms of the communication and information provision involved in the displaced out-patient model four points may be highlighted:

1. The psychiatrist has very limited access or insight into the relationship between the GP and the patient other than through the referral letter.
2. The GP and keyworker have very limited access or insight into the relationship and communication between the psychiatrist and the patient other than through a brief letter from the psychiatrist.
3. The patient has no insight at all into the relationship and communication (about him/her) between the psychiatrist, the GP and the keyworker.
4. Information provided to the patient by the psychiatrist (including what his/her thoughts are and what treatments are recommended) is provided orally and not in written form.

While the limitations in communication highlighted in the first two points may poten-

tially reduce clinical efficacy, points 3 and 4 may be regarded as both jeopardising clinical outcome *and* failing to acknowledge the rights of patients to information about themselves. The oral provision of information may reduce clinical efficacy as research has indicated that less than half the information imparted in medical out-patient settings is retained by patients (Silverman, 1987). This is likely to be an even greater problem in mental health services where anxiety, over and above the usual anxiety consequent on attending a medical consultation, can be further expected to compromise retention.

In the liaison model the psychiatrist has no direct relationship with the patient and is not responsible for the management of care. The liaison approach therefore represents a trade-off between the more specialised skills of the psychiatrist not being directly available (only *through* the GP) and the individual medically responsible (the GP) having a fuller stock of detailed background information about the patient. Whether this trade-off is clinically efficacious or not is beyond the scope of this paper. However, it is important to note that this model does not effectively address points 1, 3 or 4 outlined above.

A third option – the ‘umpire’ model

A third option for the conduct of mental health out-patient clinics in general practice has been in operation in the Aberconwy area of North Wales for the past 5 years. We have termed this an ‘umpire’ model. This has arisen in an attempt to change the communication interface between psychiatrist, general practitioner, keyworker and patient. The central feature of this model is that after the consultation the psychiatrist writes his or her considered thoughts and recommendations for treatment in a letter to the GP which is then copied to the patient and his/her

keyworker (Healy, 1995). Responsibility for management of the patient is left with the general practitioner, with the keyworker providing a link with the local CMHT. The psychiatrist acts as a third party or ‘umpire’. The important aspect of this model to be considered here is not the retention of management by the GP but rather the letter sharing practice as an attempt to improve clinical outcome *and* acknowledge patients’ rights. It therefore attempts to address the problems highlighted in the above critique of the displaced out-patient and liaison models.

In attempting to examine the letter-sharing process it is useful to highlight four important characteristics of this model which influence its efficacy as a means of addressing patients’ rights and facilitating clinical outcome.

1. The provision of a *considered synthesis* of the psychiatrist’s thoughts and recommendations put together after the consultation.
2. The provision of the above in *written* form.
3. The copying of correspondence intended for the GP to both the patient and the keyworker (so that, the relationship between the psychiatrist and GP is revealed).
4. The keyworker exists within the CMHT and not the primary health care team.

The letters composed differ from traditional letters in that they are aimed as much, if not more, at the patient than at the general practitioner. While they need to contain an expert opinion, there is also a need to compose letters that emphasise that this particular referral is but one episode in the drama of a person’s life rather than to copy letters that simply give a medical formulation in medical jargon. There is also a need to lay out in a manner comprehensible to the patient a programme of care with a range of options that can be made use of by the general practitioner, keyworker and patient. Finally, there

may also be a need to spell out the details of therapeutic manoeuvres – such as for instance what paradoxical treatment involves or the mechanics of exposure therapy in the case of panic attacks. Because of this the letters involved, in general, are lengthier than the traditional letter; they can run to two or three pages.

This practice was aimed at simultaneously improving patients' access to information about themselves (i.e. user empowerment) *and* improving communication in a way that would potentially facilitate improved clinical outcomes. It was envisaged that this would address the four criticisms of the displaced out-patient model outlined above. While the psychiatrist still has little access to information held or known by the GP about the patient's history or background the limitations of the psychiatrist's knowledge (and inability to 'read' the patient's mind) become more apparent to the patient through a reading of the correspondence sent to the GP. This makes it possible for the patient to add to or correct any false information or assumptions. Since the letter represents a considered synthesis of the psychiatrist's thoughts (as opposed to on-the-spot comments in the consultation) and is lengthier than the traditional letter it was thought that both the GP and the keyworker would have an improved insight into both the psychiatrist's thoughts and his or her relationship with the patient. The fact that the psychiatrist's thoughts and recommendations are received by the patient in *written*, as opposed to *oral*, form enables the problem of retention to be addressed. This would seem to be particularly important where complex or counter-intuitive procedures have been recommended, such as the self-exposure strategies advocated in cognitive and behavioural treatments of panic disorder.

The remainder of this paper reports on a qualitative study which attempted to identify

the range of benefits and problems that were arising from the implementation of this model from the perspectives of psychiatrists, GPs, keyworkers and patients.

The study

In West Aberconwy, which has a catchment area of 22,000 patients, served by 13 general practitioners in four practices, the 'umpire' model of out-patient practice outlined above has been in use for 5 years. The policy is to send copies of letters on all patients irrespective of diagnosis. Subjects receive letters and discharge summaries (if they have been in-patients), whether they have paranoid disorders, schizophreniform disorders, manic-depressive disorders or neuroses and whether they present as acutely disturbed or in remission. The only exceptions are for dementia and in rare cases where the patient has explicitly asked for letters not to be sent to them. In addition, detailed handouts on anti-depressant and anti-psychotic medication, which were constructed as consensus statements by members of the CMHT, may be given (Healy, 1993, 1995). The community mental health team, which serves both East and West Aberconwy (total population 55,000) consists of eight full or part-time community mental health nurses, six psychiatric social workers, two part-time occupational therapists and a clinical psychologist. Out-patient clinics are held in two of the general practice surgeries.

This paper reports on the findings of an exploratory study designed to identify the range of ways in which the model was impacting on the relationships between the four parties involved. The aim of the investigation was not to establish statistically significant relationships or events but rather *to identify and explore the range of ways in which the integral elements of this model*

were operating and to locate those problems which patients, GPs, keyworkers or psychiatrists had experienced with it. The use of quantitative methods for an exploratory study such as this would have been inappropriate for three reasons. First, the use of questionnaires would have been highly inefficient as their design is dependent upon the issues to be investigated being known or assumed *a priori*. Secondly, the use of questionnaires would have failed to provide the opportunity to explore *why* particular issues had been deemed problematic by particular individuals. Thirdly, if other CMHTs elsewhere were to consider the umpire model outlined here the most useful information would not be a knowledge of a few particularly prevalent problems but an awareness of, and insight into, a *wide range* of problems and benefits that might be encountered elsewhere.

Interviews were conducted by two researchers and included keyworkers, junior hospital doctors, GPs and patients. Health professionals were interviewed by a senior registrar (KF) who had been placed with the consultant operating this model (DH) for 6 months 2 years previously and therefore had some hands-on experience of operating the system. Eight of a possible 12 trainee doctors who had used the system, 10 of 14 general practitioners who had received letters, and 12 of a potential 13 keyworkers were interviewed. Interviews lasted for approximately half an hour; notes were taken during the interviews.

Interviews were also undertaken with patients as part of a study to investigate the beliefs about mental health care of depressed and anxious persons being referred for a mental health consultation for the first time. These interviews were conducted once before the patient had any contact with any member of the mental health team and once after the consultation with, and letter from, DH. Interviews with patients were under-

taken by BW, a social scientist with experience of qualitative research methods and data analysis. This was a detailed study which aimed not only to identify users' views but also to explain them. Interviews were tape-recorded, transcribed and analysed using a constant comparison method (Strauss & Corbin, 1990; Lincoln & Guba, 1985) aided by the Ethnograph software for the management of text-based data. Seventeen service users were interviewed in depth, 15 of whom had had no previous contact with mental health services, and their views of the shared letter system were explored.

Results

Issues that were raised by the groups interviewed fell into four themes. These are examined in turn before the practice of letter-sharing is reassessed.

A. Inherent rights

Junior doctors, keyworkers and patients all approved of the principle of sending a copy of the letter sent to the GP to the patient. It was possible to differentiate the support for the *existence* of the letter from views about its content (see below). All those patients interviewed approved of the receipt of letters on the basis of 'right'. This is apparent in the following quote from a young woman 2 weeks after her first consultation with a psychiatrist.

He didn't think he needed to see me again but I knew he would do a report on it. I knew I would get a letter, you know. Which I must admit pleased me no end that did. A letter came to me as well as to the doctor (GP). I got a copy of that, I liked that...That's really good. You know what's going on then. Why should the doctor just know what happened.

One middle-aged woman likened her approval of receipt of the letters to approval of the right to have access to medical records.

I do like it {receipt of the letters}. No, I do like it, and I think you should have access to your medical records and everything; I think that's a good idea.

Junior doctors and keyworkers also reported that from their experience patients appreciated and approved of the receipt of the letters as it made them feel 'actively involved and important'.

GPs' views of the letters tended to be based on a pragmatic assessment of their effect on clinical outcome and their relationship with patients rather than from support of a 'rights' principle. As a result GPs' views were more varied and complex than those of junior doctors, keyworkers and patients.

An important qualification must be made to the widespread approval on a 'rights' basis reported above. Patients approved not of letters *per se* but rather of access to *information about themselves*. The former quote asked 'why should the doctor just know what happened?'; and the latter points to the access of information via medical records. Consequently, the letters are perceived as providing a right of access to information about themselves. This is apparent again in the following comment from a woman who was concerned that without the letter some information might be withheld from her.

I was really happy when he said that he would write up a letter and send it to the GP and send me a copy as well. I thought that's good. You know he wouldn't be talking about me behind my back – I like that.

This clearly begs the question as to whether the content of such letters accurately embody the psychiatrist's views of a situation or whether the content is modified because the client will see it. In other words, do the letters actually provide access to the information or is it simply a cosmetic exercise? Surprisingly, no patients raised this as a possibility and all assumed that the content of letters was

an accurate portrayal of the psychiatrist's views. While the reason for this is unclear, faith in the accuracy of contents may have stemmed from it being a copy of that sent to the GP and keyworker. It is impossible to determine from this study whether or not the psychiatrists involved changed or 'vetted' the content of letters in such a way as to undermine true access. The interviews do suggest, however, that some psychiatrists may be tempted to adapt the content of some letters as a few openly admitted that they felt 'uncomfortable about telling the truth'. This is explored in more detail below.

B. Content and/or language?

While many of the interviewees approved of patients' access to information about themselves as a matter of right a variety of problems were recognised relating either to the substantive content or the language of the letters. Since the letters are received by GPs, patients and keyworkers they must be written in a language which is accessible to all parties while retaining the substantive content. This caused some problems. GPs reported that letters were 'vague, too chatty and too long' and represented a 'de-medicalised' view of the patient's problems. The majority of GPs preferred the style of traditional letters in which problems were described briefly and succinctly in medical terms with a clear recommendation of treatment. This was perhaps of increased importance as the letter-sharing practice was being used in a context in which GPs retained management of the patient. A number of junior doctors also reported that they felt that the need to use a 'conversational style rather than medical jargon which forced the letter-writer to neutralise the problem'. Similarly, keyworkers felt that some letters might 'normalise' too much. These views appear to present a similar concern. The ability to make letters accessible to

patients by using a medical terminology-free and more conversational style while retaining substantive content may have failed. The very use of 'normal' language and terms may inevitably lead to a change in content.

Two issues arise from this which require further attention. First, it is unclear whether it is possible to convey information in demedicalised terms without changing its substantive content and meaning. Secondly, since the letter-sharing practice is based on a belief that patients should have access to information about themselves it could be argued that letters should not be demedicalised if they change the meaning and content of the letter. Despite these problems of language and content keyworkers stressed that by framing the problem in words the patient could understand the letters provided the opportunity to open up discussion and allow the patient to correct wrongly construed information. Keyworkers reported that they routinely found the letters useful as a basis for meetings with patients. They were able to work through the letters, discuss their content and possibly interpret the content for the benefit of the patient. Some keyworkers did, however, stress that such discussions, if not handled carefully, could reveal differences in opinion between themselves and the keyworker; it is difficult to know whether such revelation would be beneficial to the patient.

C. Reinforcement

GPs, keyworkers and patients confirmed that the letters acted to reinforce the efficacy of the consultation. This was seen to be done in two ways: either by conveying new information to the patient that had not been given to them at the time or by reminding the patient of what had been said, thus addressing the problem of retention. If the information had already been conveyed to the client and they

had either failed to grasp or remember it then the letter can reinforce what has already been said. Consequently, the benefit stems from the fact that the letter is a *written record*. If the information had *not* been conveyed during the consultation then the fact that the letter is a considered synthesis of the psychiatrist's thoughts is of relevance. In this case the letter can be seen as an aid to the psychiatrist in that it provides a way of rectifying any deficiencies in the original consultation.

Since this study did not have access to what had *actually* been said in the consultation it is impossible to identify whether issues raised in the letters were performing a 'reminder' function or a 'new information' function. Despite this it is clear that the content of the letter did provide a way of reinforcing the consultation. The following woman in her early twenties had been suffering from depression with occasional panic attacks. She had been particularly afraid that she was 'going mad' and had burst into tears during the consultation. Consequently, she could remember little of what had been said. The letter, however, provided the reassurance that had not effectively been conveyed in the meeting.

Client: *It was a good letter, you can read the letter if you want to. Do you want to?*

BW: *Err, I wouldn't mind as long as you don't mind.*

Client: *No, I don't mind. {Interviewer reads the letter}... It's not bad is it.*

BW: *Well, it's very reassuring. I guess my impression from reading that is basically you're not 'cracking up' and you're entirely normal considering the circumstance. You are actually coping quite well. As well as anybody would do.*

Client: *Yes, exactly. That was reassuring.*

Another woman described the content of the letter she had received in terms of a coherent 'plan'. This was something that she

had not experienced before and had not been apparent at the time of the consultation.

It said I was depressed and mentioned some drugs I was on and gave a bit of a plan as well of what he was going to do because he had suggested two drugs and he had written that in the letter otherwise go on and get the prescription right away – went to the surgery and got that. He'd suggested two and then said that start on this dose and then maybe I'll see you again and maybe change it at a later date. It seemed like a bit of a plan and it wasn't like a one off thing

The important point to note from these two quotes is that while the issues mentioned by the clients could be incorporated into a consultation it was the letter and *not* the interaction in the consultation which ultimately helped. As already mentioned, this may be either due to the fact that the clients did not remember what had been said or to the fact that the psychiatrist had the opportunity to produce a well-thought-out synthesis of his or her thoughts. The letters, therefore, *did* appear to reinforce the consultation.

Despite these reported benefits keyworkers pointed out that their existence within the CMHT and corresponding reduction in contact with GPs and other members of the primary health care team meant that the opportunity to discuss the content of letters with GPs was reduced. They believed that if based in primary care their increased informal contact with GPs would provide a channel for GPs to have issues raised in the letters clarified and for other relevant information or mistakes in letter content to be passed on to the psychiatrist via the keyworker.

D. Empowerment?

For service users the attainment of the right and access to information can be seen as inherently empowering (Williams, 1995). In other words that right is a *power*. However,

it was apparent from the study that information acquired from the letters was used by patients in attempts to achieve particular goals. Consequently, in terms of empowerment the letters are both an end in themselves and a means to an end.

The most common situation mentioned by service users was their newly acquired ability to rectify any false information believed to be contained or assumed within the letter.

I suppose mental health patients are perhaps more vulnerable than those that have got physical complaints. If a wrong bit of information gets through, if it's been based on a mis-understanding you might never know; and in years to come you might be treated wrongly. Whereas if you were kept informed, at any stage, you or somebody who was in your family (even if you are not capable of taking in the contents of the letter) can actually say 'hey, wait a minute, this doesn't sound right', and you can get back to the person who has written it.

While this might be considered empowering there is the possibility that this may, in some situations, pose problems for the psychiatrist. One person interviewed pointed to a letter that had been received which suggested that his mental state had improved. The family disagreed with this verdict and felt that this pointed to the inabilities of the psychiatrist. Eventually, the daughter commented:

I can't see the point of you going there if he's like that.

Empowerment, through a written account of the psychiatrist's views, clearly raises the possibility that clients will be able to 'evaluate' those views against the yardstick of their own experience. This may or may not prove problematic. In the former quote an attribution is made to a simple 'misunderstanding' which could be corrected by the client. In the latter example, however, the psychiatrist's

'incorrect' views were attributed more to a lack of competence. The likely outcome of this situation is that psychiatrists using a shared letter model must be more prepared to *explain and justify* why they hold the views contained in those letters. There remains the possibility that those clients who disagree with the letter received may not seek clarification or attempt to put the psychiatrist 'right', but may cease to attend appointments or take medication if they are dissatisfied (Wilson & McNamara, 1982; Ludy, Gagnon & Caiola, 1977).

While the above highlights the potential empowerment such letters may provide, other factors within the latent structure of service provision may still exist which prevent their effective usage. In the course of this study it became apparent that one patient had been receiving medication from her GP other than that recommended in the psychiatrist's letter. While this discrepancy was evident to the patient she did not question the actions of her GP in prescribing something different. It is likely that the patient perceived the costs of challenging the GP (in terms of damage to the relationship) as outweighing any benefits. This is likely to be a common problem.

Discussion

Informal discussions suggest that a number of psychiatrists around the country have begun to adopt approaches to mental health consultations similar to that outlined here. Some, for instance, tape-record the exchanges between themselves and their patients and give the recording to the patient. Indeed, the adoption of such an approach is not restricted to mental health consultations; a number of genetic counselling clinics, for instance, have adopted the practice of corresponding with patients. A recent survey of patients' reactions to letters from psychiatric consultants

after out-patient consultations found similar results to those noted above (Price & Asch, 1990), although the sample of patients who received letters was restricted to those with neurotic diagnoses or milder disorders.

While the patients interviewed in this study gave a clear-cut approval of the letter-sharing practice, there remains a question over the ability of 'de-medicalised' letters to embody accurately '*what the psychiatrist thinks about me*'. Furthermore, there may be a temptation among some psychiatrists to 'manage' the content of letters, thus removing their importance as a tool for addressing patients' rights to information. The issue of information management therefore calls into question the link between good communication and clinical outcome identified by the recent Audit Commission report (1994). 'Good communication' may be defined from a consumer perspective as accurately conveying information to an individual for which they have a right of access.

From a clinical perspective, however, 'good communication' may be defined as 'managing' the content and style of information provision in order to facilitate compliance. In such circumstances, a link between good communication and clinical outcome would appear self-evident as the former is defined by the latter. The point here is that from the perspective of GPs and some psychiatrists the premise that users' rights and clinical outcome can be simultaneously improved may not be correct. In some instances the clinician may believe that the two may operate antagonistically and manage information so as to improve clinical outcome. Unfortunately, such management is highly problematic from a consumer perspective as the patient would not know whether they were routinely accessing accurate information about themselves or not. The search for a solution clearly requires further research.

Despite this problem the research has demonstrated that the uncensored provision of information *can* act to reinforce the consultation through addressing retention and allowing the psychiatrist more time to consider the case and possible solutions. An important question that remains is therefore whether the benefits accrued through this 'reinforcement' outweigh the possible costs outlined above.

A further issue concerns the structure of services. The majority of general practitioners did not discuss the contents of the letters with their patients, in part perhaps because any drive to discuss on the part of patients had been satisfied by discussions with their keyworker. In practice, the umpire function of the letters then only happened in situations where there was a good exchange between GPs and keyworkers. In some surgeries there were complaints that keyworkers were rarely seen and reciprocal complaints from keyworkers that they were not invited into the practices to discuss patients. The impact of the letters on services therefore would seem to differ between services which locate keyworkers in a mental health team as opposed to those which base them in primary care.

Conclusion

The study has identified a range of benefits and problems with the letter-sharing practice as embodied in the 'umpire' model. Furthermore, these have been examined from the perspective of various stake-holders. By outlining the *range* of issues involved in a practice of this kind it is hoped that this will inform decision making by other groups contemplating following a similar model. At this stage in a service development of this kind qualitative research is vital in identifying and

exploring a breadth of issues. The results and discussion, however, have pointed out that the next step in the evaluation of the practice must be a more targeted and quantitative investigation of the potential benefits and costs identified.

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