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Changes to leave of absence in Scotland: the views of patients

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ABSTRACT Sixty-four patients were interviewed about changes to leave of absence brought about by the Mental Health (Patients in the Community) Act 1995 in the context of their views about services and medication. Few patients were clear about the change in the law, which suggests that more has to be done to inform patients of their rights and legal status. A number of patients reported difficulty in negotiating preferred medication with their psychiatrists and felt compelled to take medication that resulted in debilitating side-effects. A third of patients eligible to be interviewed agreed to an interview and ethical and practical difficulties in accessing patients for this type of research are discussed.

The views held by patients about the services they are receiving have never been considered so important as they are today. Policy documents demand that patients and carers are consulted over service development and community care plans and that their views be listened to (Scottish Office, 1997; Department of Health, 1999). How much is rhetoric and how much actually happens in good practice is open to debate. In an area where research is sparse, the researching of patients' views on mental health legislation and their experience of living under its restrictions is notably lacking. Five service users who had experience

of the Mental Health Act in England were included in a qualitative study by Marriott *et al.* (2001) but their voices are not heard separately from those of professionals and carers. Autobiographies and biographies of people with psychiatric diagnoses give some indication but are unlikely to be wholly representative of the population (Laing and McQuarrie, 1989; Read, 1989; Hart, 1995).

Research that asks patients what they know about the law and their rights in hospital emphasizes patients' lack of knowledge (Goldbeck and Mackenzie, 1997; Bradley *et al.*, 1995). Mental health professionals must take some responsibility for this. Their knowledge of the law is also lacking (Humphreys and Ryman, 1996; Humphreys, 1997, 1998).

This study was part of a larger one evaluating the impact of the Mental Health (Patients in the Community) Act 1995 in Scotland. The research focused on the impact of the reduction of leave of absence (LOA) in Scotland to 12 months (previously it had been indefinitely renewable) and the introduction of community care orders (CCOs) (Atkinson, Garner *et al.*, in press a, in press b). CCOs were not believed to have the same power as LOA to ensure compliance with drug treatment and were seen as overly bureaucratic (Atkinson, Garner *et al.*, 2000). Concerns about patients not remaining on medication when discharged from LOA have been voiced by psychiatrists (Atkinson, Garner *et al.*, 2000). Exploring changes in the law also means exploring patients' attitudes to medication.

METHOD

Population

The population was all those patients who reached the new legal maximum of 12 months LOA between 1 April 1996 and 31 December 1998, or who were placed on a CCO during this time. This identified 266 patients. Details of the procedures used for identifying this group of patients from the Mental Welfare Commission for Scotland (MWC) records are given in detail elsewhere (Atkinson, Garner *et al.*, in press b).

No formal exclusion criteria were included in the research protocol. As part of the process of checking current contact details (see below) information was given on the patient's current mental state. Patients were not written to where staff members advised that the patient was currently unwell or where it was thought therapeutically undesirable for other reasons. In some cases patients were approached at a later date when staff advised this was now appropriate. Patients were not excluded where the only concerns were the patient's ability to concentrate. Where advised by staff, an independent chaperone accompanied the researcher. In a very few cases patients were interviewed in a psychiatric services setting.

Contacting patients

The responsible medical officer (RMO) was identified for each patient from the files and was contacted by letter explaining that his or her patient would be approached, by letter, for interview but that before this was done the researcher (H.C.G.) would contact the patient's key worker to discuss this, including confirming current address. Some RMOs responded with details of either patients or appropriate staff to contact. Staff were not given information about who agreed to be interviewed unless this was initiated by the patient or the patient was interviewed at a clinic. Patients were contacted by letter stating at the outset that their name had been obtained from the MWC. It invited them to contact the researcher if they agreed to be interviewed and assured them of anonymity and confidentiality.

Interview schedule

An interview schedule was drawn up which covered personal details, services the patient received, hospital admissions, CCOs (where relevant), knowledge of changes in the law, involvement with the police, medication and care plans. The schedule covered this wide range because it was believed that patients' views about the law needed to be in the context of their general circumstances, including the way they lived and their access to services. Patients were not prevented from talking about topics that were important to them, even if not on the schedule. The researcher followed the interviewee's lead, noting relevant points which did apply to parts of the schedule.

Interviews were not tape-recorded as concern had been expressed that recording might aggravate paranoia in some patients. The researcher made notes throughout the interview, sometimes verbatim and sometimes paraphrased. In each case, the note was read back to the patient for confirmation that it was accurate. Where patient quotes are used in the results they are anonymized. Direct quotes are given in italics in the results.

It was anticipated that not all patients would have a full understanding of their rights in relation to taking medication and to changes in the law. It was agreed with the ethics committee that it was inappropriate for the research assistant to give information on this and she directed the patient to his or her medical team and/or the MWC for further information.

Figure 1 gives a sample of questions from the interview schedule relating to the law and medication.

CHANGE IN THE LAW

Did you know that the law about LOA has changed? If yes. Can you tell me how you think that this affects you? How do you feel about these changes? Prompt. What do you like? What do you dislike? Are you currently on LOA?

Medication

Has your psychiatrist prescribed medication for you to take at the moment? Do you take that medication? *Take a note of the name(s) if mentioned. If no.* Why not? *If yes.* How do you feel about taking it?

Figure 1 Sample of questions from interview schedule relating to the law and medicine

RESULTS

Response rate

The response to attempts to contact patients and requests for interview are given in Table 1.

Two further patients agreed to be interviewed but 1 of them withdrew agreement before interview and 1 became ill before the interview could be arranged. One patient chose not to complete the interview after it had started. Thus, one-third of patients actually contacted were interviewed. Patients were interviewed from across Scotland. Not all interviewees answered all questions. Response rates are given throughout.

Description of patients

Of the 64 completed interviews 53 (83%) were with men and 11 (17%) were with women. Men were more likely to agree to be interviewed (30%) than women (13%) ($\chi^2 = 7.71$, p = 0.0005). All patients identified themselves as white. Seventeen (27%) had been formal inpatients during the follow-up period. At the time of interview 47 (73%) were voluntary patients, 12 were or had been on CCO (8 were on CCO, 1 was on LOA, 3 had been on CCO), 3 were inpatients (2 voluntary due to accommodation problems and 1 detained under s.18 in a hospital-run hostel) and 2 were again on LOA.

Table 1 Contact with patients, N = 266

| | n | % |
|---------------------------------------|-----|-----|
| Interviewed | 65 | 24 |
| Refused | 66 | 25 |
| No response to letters | 65 | 24 |
| Excluded or too ill to be interviewed | 44 | 17 |
| Died | 4 | 2 |
| No contact made (location known)* | 20 | 8 |
| Location unknown | 2 | 1 |
| Total | 266 | 100 |

Key * No contact could be made with the key worker although other staff members indicated the patient's whereabouts was known to the team.

There were 35 patients (55%) who lived alone (compared with 68% in the total study population) and 29 (45%) with other people. Three men lived with wives/partners and 7 men lived with both parents or just their mother. No women lived in these relationships. Three men and 1 woman lived with a combined total of 8 children. Of those who lived alone 46% (16/35) reported having at least 1 carer (11 parents, 11 siblings, 3 adult children, 1 other relative) compared with 68% (19/28) of those who do not live alone (16 parents, 3 partners, 1 adult child, 2 other relatives/friends). Not all interviewees wanted to describe a relative as carer and saw the relationship as mutually supportive.

All patients were in touch with at least one professional. There were 63 (98%) who reported being in touch with their GP, 62 (97%) with a consultant or other psychiatrist, 48 (75%) with a community psychiatric nurse and 34 (53%) with a social worker. Other staff were an occupational therapist, residential staff members, an advocacy worker, home helps, other nurses, counsellors and befrienders. There were 73% (44/60) who were in contact with some form of day service. Of the 27% who were not in contact with day services, 2 were in casual work and 2 in contact with residential accommodation staff. The majority (41/64, 64%) thought the amount of input they received from services was about right, 8 (13%) would have liked more and 9 (14%) thought it was too much. Only 1 person reported not wanting services at all.

Care plans

All 64 patients were asked if they had a key worker and a care plan or care programme. Responses from interviewees are difficult to interpret because terms used varied and there was not a common understanding of what

constituted a care plan. For example, for one patient a care plan was something he had drawn up with a volunteer befriender, for another it was something she had drawn up herself. For others it was something shared with staff but not necessarily part of the official Care Programme Approach (CPA). Likewise, the use of the term key worker was wide and included people who would not be so designated under CPA.

Within this self-defined category of care plans of the patients who did not go on to CCO, 28 (55%) said they did not have care plans, 14 (28%) did, 1 was uncertain and for 8 the information was missing. Of all the patients, 31 (48%) said they did have a key worker, 27 (42%) said they did not and the rest were uncertain.

Medication

Medication was prescribed for all. Only 1 person claimed not to be taking medication and 4 indicated they would stop when their current hospital admission/LOA expired. Of the 62 who discussed their feelings about medication, 39 (64%) reported they were happy to take it or, with qualifications, accepted it (accepting group); 10 were continuing medication but were not happy with all aspects (ambivalent group); and 13 were negative (including the 4 who were intending to stop) (negative group).

Problems with side-effects of medication, past negative experiences contributing to distrust of staff, problems in negotiating acceptable specific medication or level of dose were common to all groups. In the accepting group, however, the problems were generally in the past and had been resolved. Few patients gave an indication that they did not accept they had an illness.

Accepting group

Many comments indicated an awareness of the medication's keeping them well:

I've got to take it to keep me well. I got a leaflet and had a lengthy discussion with the doctor about it.

Got to take it as I get ill if I don't. It doesn't bother me, just a couple of seconds every day to take the pills.

Acceptance could be qualified to certain medication only:

I've got to take them to keep illness at bay. I won't take injection.

It used to be awful, used to spit it out, it reduced [my] level of consciousness.

The latter patient was happy with new medication.

Acceptance of certain medication was usually related to negative experiences with other drugs and was mentioned by 12 of the 39 patients in this group.

Diabetics have to take insulin and I have to take these tablets. The side-effects are not as bad as [previous medication, to which the patient attributed a weight gain of 3 stones]. I was walking bent over because of muscle contractions caused by side-effects of the medication. The injection used to make me look half drunk. I couldn't string a sentence together. [A relative] said, 'I would rather have you off your head than like this.' It felt like punishment not treatment because I had [assaulted someone when ill].

I have to take them [pills]. No hardship to take but the injection seriously disordered me. I had more than two years of suffering.

Successfully negotiated changes were also noted in this group. For 1 patient a change had resolved a sexual dysfunction and that patient now had a partner. Another attributed the change to a new psychiatrist who 'would sit and talk to you for half an hour and talk to you like a human being, not a type'. Another patient attributed change in medication to carer intervention.

Ambivalent group

Some patients were unhappy with aspects of their medication and generally were looking for a reduction, although in general accepting the need for some medication. Two were planning to stop medication under their psychiatrists' supervision.

I like it [medication]. I need it. I pleaded with them to change from [injection] but it doesn't work.

This patient believed that pills had not been given because of a past overdose.

I feel it is too much – it has been reduced twice and I would like to reduce it more. It shouldn't be the total answer on its own.

A couple of the patients in this group were generally averse to medication and the idea of having to take drugs long-term but most of the negative feelings reflected side-effects and an inability to negotiate a desired change.

Negative group

Almost all patients in this group reported major problems with side-effects. The two who did not commented:

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I don't feel as if I need it now

and

I would rather be without it if I could. I find it difficult to gauge what difference it is making to me really.

Side-effects complained of included stiffness, slurring when talking, generalized sense of pain, Parkinsonian symptoms and sexual dysfunction.

Unfortunately, it has side-effects – dryness in throat and mouth which is unpleasant, also cracked lips.

Two of the patients who reported intending stopping medication once LOA expired were doing so because of sexual dysfunction.

It prevents sexual relationships and I like sexual relationships with [opposite sex].

There was a general sense of lack of control in being compelled to take medication, particularly a non-preferred medication, against their will. In many cases patients were requesting a drug they had had in the past rather than a 'new' drug they had not tried. Their anger or bafflement at being ignored was clear.

One woman, who was otherwise happy with her medication, mentioned that she had been given depot provera against her wishes. She was politely furious at the control the doctors had over her life:

Who are they to say you can't have a baby?

Changes in the law to leave of absence

Patients were asked a number of questions about their knowledge of the legal changes. The responses have been aggregated into themes to give an overall picture rather than reporting responses to individual questions. Sometimes a later response indicated an awareness of issues that had received a nil response earlier. Thus, although only 12/51 (24%) patients not on a CCO said they knew of changes later comments from a few others indicated some knowledge, even if not linked to change.

Specific understanding of changes was limited. Only 2 patients were quite clear that they could not be compelled to take medication when LOA ended. Both had stopped taking medication when previous LOA finished. Currently back on LOA, both intended to stop medication when LOA again ended. A third patient knew the psychiatrist could not compel the taking of depot medication any more and attributed to this a change to an atypical antipsychotic. This patient commented:

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It's quite a nice feeling taking the medication because I want to rather than it being enforced.

Another patient, who did not know of legal changes, nevertheless knew that LOA was restricted to 12 months. Feeling unable to function in the community because of side-effects this patient had asked for readmission to hospital. This was not forthcoming. The patient was told that in 2 months' time when LOA ended there would be a choice about continuing medication. It was suggested that the patient 'keep going' until then. The patient reported stopping injections at the end of LOA:

I didn't feel myself on them.

A few patients had concerns about LOA ending. One patient regretted its loss and preferred to be on LOA.

They [staff] could automatically get you into hospital if you get ill and catch it in the bud.

This patient reported:

I didn't want to come off section 18... I was anxious about changing and about losing support. As time has gone by I've felt the same as when I was on LOA. The doctor made an offer to admit me to hospital for a couple of days so that he could renew the section.

The patient declined the offer and was experiencing the impact of the change as less than anticipated.

Another patient, who did not know the details of the legal changes, had, however, been on improperly long LOA and had received a letter apologizing for this. The patient's reported reaction was: 'Didn't mind' as, in retrospect, all the detentions had been necessary.

Many patients were happy with their relationship with staff and the services they were receiving. Some patients were unhappy with the relationship because they felt staff did not care about them as persons. In a few cases there was a specific issue about control and lack of choice. This did not necessarily mean that the relationship with staff was seen negatively in its entirety:

I don't think they realized that they were undemocratic, they just seemed to assume that I wouldn't be going home at that particular time.

Supporting more freedom for patients this individual took the view:

If a patient wants to go it alone they should be encouraged to go it alone.

Taking the opportunity to describe an appeal against a s.18, 1 patient reported being 'appalled' at how psychiatrists listen to and agree with each

other but did not listen to him or her. The patient recalled that 'the judge' (sic) had told him or her that the appeal 'was wasting court time' but also that their solicitor 'was shocked' by his attitude.

Patients were asked if they were currently on LOA. When checked against MWC records it was found that of 63 interviewees, 49 (77%) answered correctly, information was missing for 5 (9%), 4 people were uncertain but were not on LOA, 3 (5%) said they were but were not, 1 (2%) said yes but was on a CCO and 1 (2%) said no but was on LOA.

DISCUSSION

Response rate

The response rate was low and even with hindsight it is difficult to know how this problem could have been easily resolved. It raises a number of issues about involving patients to obtain their views. The requirement by MREC for patients to opt-in by letter may have reduced the response rate. Although asking patients to opt-out of interviews might have increased the response rate it would probably have also resulted in a number of wasted journeys for the interviewer, with patients either then declining or not being available. The commitment of the patients who did respond, however, is indicated by every patient being there for the pre-arranged interview.

The letter which was sent to patients inviting them to take part was fairly lengthy and complex but met the requirements of MREC. We had some concerns, echoed by other professionals and one of the LRECs, that the letter itself might prove an obstacle to patients with negative symptoms such as poor concentration, low motivation and apathy.

The low response rate from patients means they are unlikely to be a fully representative sample but it is not clear in what way the sample was biased, apart from the obvious one that those who wanted nothing to do with services and to be left alone were unlikely to respond. If patients' views are to be taken seriously ways must be found to make it easy for patients to be involved in this sort of research.

More men than women agreed to be interviewed and there is no clear explanation for this. It may be that men felt more confident in meeting the (female) researcher or that unemployed women having more community/social commitments/involvements than men had, thus, less time to meet the interviewer.

All patients reported currently taking their medication. It is unfortunate that less compliant patients were not interviewed. Nevertheless, interviewees do take in the range of people with a severe and enduring mental illness in terms of their symptoms at the time of the interview. Although no attempt

was made at formal identification, major negative and ongoing positive symptoms are difficult to overlook. Despite this, the majority of interviewees were articulate, capable of giving their opinion and, in all instances, willing, and in some very keen, so to do.

Whatever else comes from the interviews they are an important reminder that this is not a homogenous group. The patients were people of varied perspectives and the perspectives they held were not necessarily those of either professionals or researchers. This is reflected in the focus of the research being the change in legislation but for many patients the more natural and appropriate comparison was between being on some form of restrictive order and not being under any form of compulsion.

The impact of changes to the legislation

Of the patients discharged from LOA and not transferred to another order, only a minority appeared to know there had been a change in the law and, of these, most could not clearly articulate what the change was. This may not be surprising but it is worrying. There appears to have been no consideration given by any national or local agency to routinely informing patients who might be affected by the change. Patients' lack of knowledge of their rights is not necessarily a straightforward result of never having been given information, although this may be a factor (Goldbeck and Mackenzie, 1997). Information may have been given in a way or at a time that could not be recalled or understood. While some patients have a keen interest in their rights others do not appear to organize their experience of treatment within these terms. Patients in general hospitals for non-psychiatric treatment do not necessarily have a clear understanding of their rights in relation to treatment (Sugarman and Moss, 1994).

The confusion surrounding the powers of CCOs, particularly in relation to medication, is discussed elsewhere (Atkinson, Garner *et al.*, in press a) but would appear to be reflected here in how little patients had been told. That several believed themselves still to be under a section when this was not the case suggests that they are not being fully informed of their legal status and rights either at all or in a way that makes sense to them and is remembered. That in some cases this might be deliberate in order to encourage continued compliance with medication, must be a possibility (Atkinson, Garner *et al.*, in press a).

This lack of information and the agreed inability of the interviewer to give patients any information meant that for many patients this part of the interview was shorter and less exploratory than we would have wished. A number of patients commented on their feelings about being under some form of restrictive order. Even when the patient understood that he or she was, or had been, ill and welcomed services there was often an underlying resentment at

being given no choice. These feelings were expressed clearly by many in relation to medication.

Support for patients

The majority of patients reported they had carers or support from family in contrast to the psychiatrists' estimate of informal carer support for the population as a whole which was put at only 45% (Atkinson, Garner *et al.*, in press b). This may reflect an underestimation by psychiatrists of support received from relatives or a bias in those interviewed. Generally, the support from family was warmly welcomed and recognized as 'caring' while for a minority it was seen as a more mutual relationship.

The majority of patients were content with the level of services they received with only a minority wanting less contact and only one person not wanting contact with services at all. This may be a reflection that contact with services was not necessarily high, with a quarter of patients having no contact with day services. Elsewhere, psychiatrists report that in some cases contact with services is less than they would wish but limited by a patient's willingness to accept more (Atkinson, Garner *et al.*, in press b). The disruption to people's lives of multiple visits, while only being an issue for a small number, may, nevertheless, suggest that multidisciplinary teams and multi-agencies may need to co-ordinate their support more to the benefit of the patient.

Medication

It should not be assumed that those patients who are kept on LOA for 12 months are necessarily the least compliant with medication. Some patients discharged to LOA will fail to comply with medication or to co-operate with treatment teams and be readmitted to hospital either as a consequence of lack of compliance or for other reasons. Being on LOA is not sufficient for all who are thus discharged to maintain compliance. There is another group of patients who are discharged from LOA before the maximum is reached because they are compliant with treatment. The research did not look at these last two groups.

One theme of the comments about medication was acceptance that it was a necessity, even though the side-effects caused variable degrees of problems. In some cases this tied in with the theme that (unwanted) medication was more acceptable when taken out of choice rather than being compelled. Despite assurances of confidentiality, some patients might have felt it necessary to offer reassurances about their attitudes to medication. Not all did, however, and a few indicated that they would stop medication at the first opportunity they had to exercise choice.

The relationship between choice of particular medication and side-effects

was an important issue for some when patients indicated they would prefer a different medication because of current side-effects. That patients report being given non-preferred medication sometimes against their will when they say they would take another might raise questions about their relationship with their psychiatrist. In some cases it may be that they are objecting to a depot medication but have previously been non-compliant with oral medication, even if preferred. In a few cases a change of psychiatrist (for example, through retiral) had led to a review of medication and subsequent change. The social impact of side-effects (including appearance and weight gain, comments from family and sexual dysfunction) were severe for some patients but they believed this was discounted or unrecognized by staff.

Even allowing for only one side of the relationship to be presented, some patients appeared unable to communicate with psychiatrists and other staff even where the individual staff member was liked.

CONCLUSION

Most patients who were affected by the change to indefinitely renewable LOA did not understand the change and its implications for compulsory medication. A number of patients reported problems in negotiating preferred medication with psychiatrists and did not believe that their problems with side-effects were taken account of appropriately.

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