



THE MEANING AND MANAGEMENT OF NEUROLEPTIC MEDICATION: A STUDY OF PATIENTS WITH A DIAGNOSIS OF SCHIZOPHRENIA

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Abstract—The meaning of medication and the way in which people use medicines has been the focus of a number of studies in recent years. However, there has been little attention directed to the meaning and management of neuroleptic medication by people who have received a diagnosis of schizophrenia. This topic is highly relevant to policy because of the central role given to neuroleptics in contemporary mental health and community care services. Using data from in-depth interviews with people with a diagnosis of schizophrenia we explore patients reasons for taking neuroleptics and the ways in which patients self-regulate their medication. The data suggest that the main utility of taking neuroleptic medication is to control specific symptoms and to gain personal control over managing symptoms. The costs of taking medication were side-effects which at times equalised or outweighed the positive gains of the neuroleptic medication. Patient accounts suggest that everyday medication practices are to a significant degree related to a policy context which stresses the need to survey and control the behaviour of people living in the community and the wider meaning and symbolic significance that schizophrenia has for patients in their everyday lives. For this reason, self regulatory action in this group of patients tends to be less evident and the threat of external social control greater than patients taking medication for other chronic conditions. The findings suggest the need to develop a collaborative patient-centred model of medication management for patients diagnosed with schizophrenia. © 1998 Elsevier Science Ltd. All rights reserved

Key words—mental health policy, schizophrenia, adherence, medication, self-regulation

INTRODUCTION

The medical literature has portrayed non-adherence with prescribed medication as problematic because it is perceived to be a common cause of the failure of medical treatment, leading to an increase in the use of medical resources (Ley, 1992). Non-compliance is seen to create particular medical and social problems when the drugs concerned are neuroleptics (anti-psychotics) such as chlorpromazine or haloperidol. These drugs are commonly prescribed to patients diagnosed as suffering from schizophrenia in order to control or diminish positive psychotic symptoms such as hallucinations, delusions and

ideas of persecution. These drugs are also used to tranquillise patients who are seen to be a danger to themselves or others and have little or no impact on the negative symptoms of psychosis, such as apathy or social withdrawal (Hirsch, 1986). Continuing and changing the dosage of this medication is the primary method of medically managing psychosis, even though the outcome literature indicates that the response to neuroleptics is highly variable†. Other means of management such as family and individual psychotherapy based on cognitive behavioural principles, though of proven efficacy, remain marginal to mainstream practice (Haddock and Slade, 1996). The failure of patients who are prescribed these medications to submit to medical authority by adhering to prescribed regimens is usually regarded as evidence of a lack of “insight” which is viewed as integral to the illness (Bartko *et al.*, 1988). Moreover, failure to take neuroleptic drugs has been linked with frequent readmissions to hospital (Green, 1988). In social policy terms, non-compliance with neuroleptic

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†There is no one to one correspondence between taking or missing medication and a reduction in symptoms. The medical outcome literature indicates that responses to neuroleptics is so variable that a proportion of patients will continue to experience symptoms whilst taking medication whereas some others who discontinue medication may not experience a re-occurrence of their symptoms.

medication has come to be seen as a threat to the legitimisation of de-institutionalisation and functioning of community mental health policies (Scheff, 1976; Scull, 1977; Rogers and Pilgrim, 1995). Despite the importance attributed to this form of medication taking, little attention has been paid to the patient meaning and management of these drugs or the way in which the specific context of mental health policy impinges on peoples medication practices. This paper is concerned with applying a patient-focused approach to understanding this issue using qualitative data derived from the personal accounts of people diagnosed as suffering from schizophrenia.

MENTAL HEALTH POLICY AND NEUROLEPTIC MEDICATION TAKING

Within wider society, psychiatric patients "non-compliance" with neuroleptic medication has emerged as a significant social problem. Images of de-institutionalisation, often promoted via the media, have become synonymous with the creation of a new social problem, the occurrence of socially unacceptable behaviour by ex-psychiatric patients living in the community (Monahan, 1992). As neuroleptic medication has been accepted as a valid means of managing and controlling people who are viewed as a potential threat to the social order, compliance with these drugs has come to be seen as an indicator of the success or failure of a "care in the community" mental health policy. In policy terms, the need for patient compliance rests not only with public pressures to be seen to be managing psychiatric patients appropriately but is a central tenet in the management of mental health problems more generally. Both the closure of mental hospitals and caring for patients in the community has been predicated on the assumed effectiveness of neuroleptics. Traditional explanations for de-institutionalisation suggest that advances in medical treatment of mental illness permitted patients to be discharged from institutions en masse. For example Iversen and Iversen (1981) have stated, "Since the introduction and widespread use of neuroleptic drugs, the in-patient population of such (*mental*) hospitals has declined dramatically". Even though this view of events has been contested by pointing to the decline in the numbers of mental hospital inpatients prior to the widespread use of neuroleptics (Scull, 1977; Busfield, 1986) the importance attached to the prescribing and management of neuroleptics continues to dominate community mental health policy for people with a diagnosis of schizophrenia.

The introduction during the late 1960's of depot medication can be seen as an early attempt to devise a strategy for the more efficient control of patients behaviour in the community. Depot medication was uniquely marketed as a means of ensur-

ing the receipt of medication was not contingent on patients' consent to treatment on a daily basis (Daniel, 1968; Rasmussen, 1970). More recently, neuroleptic medication has been viewed as the principle means of preventing "the revolving door patient" phenomena and is central to "out reach" care such as the care management (programme) approach, supervised discharge and the management of those with "a severe and enduring mental illness". However, the centrality of medication to mental health policy has not been unproblematic. The iatrogenic effects of medication has also become a focus of critical scrutiny (Brown and Funk, 1986; Bentall *et al.*, 1996). Neuroleptics have a wide range of side effects including neurological effects (especially Parkinsonian symptoms and akathisia or extreme restlessness), anticholinergic effects (dry mouth, constipation and blurred vision), cardio-vascular effects, hormonal effects, sexual dysfunction, weight gain, haematological disorders and adverse psychological reactions (in particular, a severe dysphoric reaction). The negative effects of neuroleptics have been the focus of criticism from campaigning and mental health user organisations. Policy makers are now faced with balancing the need to maintain adherence with the risks of the damaging effects of medication (Rogers and Pilgrim, 1995). This dilemma has become increasingly difficult for policy makers to manage in a cultural context of high sensitivity to risk (Giddens, 1991), the emergence of a consumerist philosophy within the health service and the growing acceptance of the legitimacy of lay perceptions and assessment of modern medicine as part of modern health care systems (Allsop, 1995; Calnan and Williams, 1996). Added to these dilemmas have been obstacles to implementing effective and legitimate ways of ensuring compliance. Legally enforceable methods of ensuring adherence, such as Community Treatment Orders, have proved difficult to devise and operationalize. Most have foundered because of opposition from campaigning and pressure groups and because professional groups such as community mental health nurses have viewed such methods as uncondusive to the development of patient-centred approaches to mental health care (Bynoe, 1993; Harrison, 1994). Within this context the development of collaborative and voluntaristic medication management strategies are highly desirable.

ADHERENCE TO NEUROLEPTIC MEDICATION

Contrary to the assumption amongst some professional groups that non-compliance is worse amongst people with a diagnosis of schizophrenia, the literature suggests that adherence to neuroleptic medication is similar to groups of patients taking medication for other conditions. At least one third of medical patients do not adhere to medically pre-

scribed drug regimens (Stockwell Morris and Schulz, 1992) and adherence rates with medications over a long period tend to converge at approximately 50% (Sackett and Snow, 1979). Amongst those diagnosed as suffering from schizophrenia, estimates of non-compliance range between 50 and 70% (Kane, 1985). This rate of non-consumption of prescribed medication suggests that, for many individuals, non compliance holds more benefits than compliance. Consistent with this, Rogers *et al.* (1993) found that 27.7% of patients described neuroleptics as "harmful" or "very harmful". Another study (Finn *et al.*, 1990) found that, on average, patients diagnosed as schizophrenic rated the side effects of neuroleptics as just as bothersome as their psychotic symptoms. Hoge *et al.* (1990) found that common reasons given by patients for refusing neuroleptics included side effects (35%), a "denial of mental illness" (21%) and the avowed ineffectiveness of medication (12%). A further 30% were judged to explain their refusal in terms that reflected overtly psychotic thought processes. Psychiatrists, in contrast, attributed non-compliance to psychotic illness in 49% of cases of refusal. This latter view, points to a difference between the way in which non-adherence is viewed compared to other groups taking medication for other conditions. Whilst in the latter not taking prescribed medication may be viewed as problematic in therapeutic terms, "non compliance" for those with a diagnosis is viewed as a symptom of illness. Negative attitudes to medication are seen as irrational and a direct consequence of the underlying psychoses.

In recent years, alongside more traditional approaches to compliance, a patient-focused approach has emerged which has been concerned to examine the meaning that medication has for different groups in the population (Blaxter and Britten, 1996). This "client centred" approach enhances the control and status of the client by viewing the patient as a resource for improved health care and the rational management of medication (Chewning and Sleath, 1996). A number of studies have made links between the meaning and use of medication in relation to long term conditions such as epilepsy (Conrad, 1985), diabetes (Kelleher, 1988) asthma (Osman *et al.*, 1993) and musculoskeletal problems (Arluke, 1980). Findings from these studies suggest the presence of complex self-monitoring strategies, regulation and control mechanisms used by lay people. In the mental health field the relationship between the meaning and use of medication has been a feature of the analysis of benzodiazepine taking. Helman's study revealed a number of dimensions to the symbolic meanings of these drugs which embodied different types of use (Helman, 1981). Gabe and Thorogood (1986) highlighted the way in which the assignment of meaning to benzodiazepines is embedded in interaction within a

specific social context. Women respondents in their study were most likely to find benzodiazepines to be a prop in the absence of access to resources within which to manage their every day lives or other means of support such as paid work, adequate housing and leisure activities.

Despite the greater importance attached to compliance with neuroleptic drugs in policy and social terms, there has been little in-depth examination of patients beliefs about this type of medication. The "housewife" hooked on minor tranquilizers seems to have evoked more empathy amongst both the public and social scientific researchers than patients who have been diagnosed as schizophrenic. This gap may also reflect a perception that patients with a label of schizophrenia are irrational and therefore incapable of giving a valid viewpoint, although research has shown that patients who have been diagnosed as schizophrenic are able to make accurate assessments about the effects of their medication (Van Putten *et al.*, 1984; Day *et al.*, 1995). Recent studies which have addressed the issue of patients views about neuroleptic medication have either been simple surveys or mainly concerned with patient satisfaction rather than lay action and meaning surrounding the use of medication (Hogan *et al.*, 1983; Rogers and Pilgrim, 1993). A notable exception is an ethnographic study undertaken by Estroff (1981) who examined the significance that side-effects had for psychiatric clients in an American community. This study found that the side effects of taking neuroleptic medication contributed to the social withdrawal of patients and the lack of support provided by significant others. This background provides a context for exploring the meaning and medication practices of patients with a diagnosis of schizophrenia taking neuroleptic medication.

METHOD AND SAMPLE

The larger research project from which these data are drawn endeavours to assess the effectiveness of two psychological interventions designed to enhance compliance with neuroleptic medication. One intervention is the current "gold standard" in which information is provided as suggested by "good" psychiatric practice. The other is a cognitive-behavioural model designed to work with patients' own definitions of their condition and which requires patients to self-monitor their most distressing symptoms so that they may make an informed decision about the effectiveness of the drugs in relation to their own particular circumstances. At the outset it was decided to embark on a qualitative study of compliance from the patients' perspective, the results of which are presented here. It was clear from the literature that adherence was not a simple "yes" or "no" category and that an understanding of the meaning and use of medication would be im-

portant in constructing an intervention which reflected the reality of patients' everyday lives and constructs about compliance. Thus, our intention in this study was to gain a conceptual understanding of compliance with neuroleptic medication which would inform the design of the main study.

Thirty four people were interviewed, all of whom were currently prescribed a regimen of long term neuroleptic medication and had been given a diagnosis of schizophrenia or schizo affective disorder according to American Psychiatric Association criteria (American Psychiatric Association (1994). All were prescribed oral neuroleptic medication and 14 also received regular intramuscular injections of depot maintenance neuroleptic medication. The sample included 22 men and 12 women, aged between 18 and 56 years, from different social class backgrounds and living arrangements.

At the time of the interviews 13 of the participants reported taking oral medication regularly. Seven of these were being given depot (intramuscularly injected) medications and 3 were inpatients. A further 16 stated that they sometimes took their oral medications at times and in amounts which were inconsistent with medical instruction; 7 of these were in receipt of depot medication and 3 were inpatients. A final group of 5 participants stated either that they had refused to take their medication or, in the case of the 1 inpatient in this group, that he would refuse to take his medication on discharge from hospital; none of these participants were receiving depot medications.

People were purposefully recruited from different points in the mental health system. As different values have been associated with different types of service use the purposeful sampling strategy was designed to include the broad range of views and practices that were likely to reflect the range of meanings and medication practices undertaken by patients. It was for example, considered that those recruited from voluntary/alternative organisations such as the Hearing Voices Network (a self-help group for people experiencing auditory hallucinations) and MIND day centres may reflect differences in beliefs attitudes and response compared to those who mainly used traditional out-patient and day centre facilities or were inpatients. This latter group tended to give more elaborate accounts of the reasons for staying on or coming off medication and of their everyday medication practices and had well formulated conceptions of the negotiations between patients and their treating psychiatrist or other mental health professionals.

We used a topic guide in which the following topics were explored: conceptions of the cause and nature of "schizophrenia", experience and knowledge about medications, the nature of medication practices used on a day to day basis, lay management strategies, the involvement of others in managing the medication and attitudes towards

professionals. Interviews lasted for 1–2.5 h. Interviews were recorded and fully transcribed. The data presented below focuses on: the reasons and meaning given to the taking of medication and the influence of social context and the diagnosis of schizophrenia on everyday medication practices.

THE COSTS AND BENEFITS OF TAKING MEDICATION

Symptom reduction vs side-effects

Respondents were asked what they viewed as the benefits and costs of taking neuroleptic medication. Three of the respondents reported no beneficial effects of taking medication. However, for most of the participants, continuation with prescribed medication stemmed from a recognition of the benefits that were gained from the medication and/or the personal costs associated with not complying with the regimen. Four people considered that preventing relapse and thus preventing hospitalisation was the main benefit to be derived from medication. The benefits of taking medication were mostly portrayed in terms of the "calming" effects of the medication (identified by 10 people) and the potential to control or reduce specific symptoms. The most common symptoms mentioned in this regard were the control of voices or auditory hallucinations and untoward thoughts (mentioned by 11 and 10 people respectively). A 39 year old man attending a day centre described voices telling him "I wish you were dead". He reported a qualitative change in the thoughts and voices as a response to having taken neuroleptic medication (C3):

I'm not getting them so much now, they are not as severe and I'm not wishing people dead. The tablets they calm me down quite a lot.

Similarly a 50 year old man using a drop in centre compared what he was like when he took medication with when he did not take it (C10):

I'm more prone to hear voices er, the television will talk to me if it's speaking about something... I can't stand it. That's what I'm like when I don't take my medication.

In the main the utility of medication, in line with an official view, was seen in terms of its ability to act directly on symptoms by stopping or removing symptoms such as untoward voices and thoughts. However it was not the total removal of symptoms per se which was necessarily the most important aspect of taking medication for respondents, but rather, that the drugs improved their *personal ability to cope* with symptoms which they viewed as distressing (e.g. "I still hear the voices but they're nicer and I can control them"). These accounts from two men both in their thirties describes the success of medication in promoting their sense of personal coping (C28 and C12, respectively):

Some of them are really funny voices but er sometimes I get the shits up, you know the telly and er, you know you get frightened but if you take your drugs you cope and

dismiss it, do you know what I mean?... I know it sounds daft; like I hear voices like Brian Ferry you know the pop star you know saying "get out of town", and all this you know, "I'll kill you" and all this and I've just dismissed em and have a laugh, I laugh at half of them you know.

I used to go around saying stupid things but the Depixol now seems to suppress them. It stops me from thinking high and I never had no trouble since. I have got the thoughts but I just go to bed and sleep on it and next morning I'm OK.

Controlling symptoms or enhancing the ability to cope with them were not the only reasons given for taking neuroleptic medication. Whilst for some of the respondents symptoms were problematic, for others they were not in themselves negative experiences, but became problematic within particular situations. One respondent identified the presence of noisy children outside his flat as a reason to take medication (because they made him agitated) and another the pressure to appear normal in the face of neighbours who were felt to be monitoring him for indications of strange behaviour. At times the benefits of medication were far removed from the professional purpose envisaged. One man used chlorpromazine to counter the adverse effects of smoking cannabis, thereby preventing the "horrors" he would otherwise experience and for another compliance appeared to be a result of irrational thinking or delusions since he explained his full adherence ("I've never forgot to take it") to the fact that he was the doctor. A further patient stated that although he felt he could manage without tablets, he felt he had to take them because he became anxious about not taking them. That medication was used to deal with certain situations and other feelings that arise on everyday bases suggests that neuroleptic medication taking maybe somewhat different from taking medication for other conditions in so far as symptoms are not always seen as needing to be eliminated.

Whilst the neuroleptic medication dealt with some symptoms it introduced others. One of the costs of taking neuroleptic medication involved experiencing a wide range of side effects with varying levels of severity. This was despite the administration of medications specifically to counteract negative effects. Some descriptions of these side-effects were relatively unspecific. A number of respondents simply described the experience as unpleasant or combined a number of negative phenomena in a common word such as "zombie" (mentioned by 6 people). The most commonly reported side-effects by respondents included a combination of the following physical and psychological effects: "drowsiness, tiredness, sleepiness" (12), "restlessness" (11), "lack of motivation" (8), Dry mouth (7), Weight gain (6) dizziness/fainting (5), blurred vision (5), shakes (5), nervousness (3), slurred speech (3), loss of concentration (3), spasms (3).

Descriptions of the physical and psychological effects were prominent in patients accounts about side-effects (e.g. my throat tends to be very dry and my toungue tends to be like it's, like there's a film on it... lethargic... dizzy tired). However, it was the way in which physical and psychological side effects acted to inhibit everyday social interaction and opportunities which were particularly important to some people as explained by these respondents (C23, C3 and C5, respectively):

Well you just sort of, you're walking around like a zombie and you're like sort of you can't join in with things, I wouldn't be talking to you like what I'm talking now. I know I might seem a bit high, but when you're on Melleril you can't even be bothered holding a conversation you know, you're just sat there saying yes and no, so I won't take it I'm sorry but I'm not taking it.

I'm not getting as agitated as I was before and I can sleep a bit better at night...but sometimes they make me drowsy during the day as well... I don't want to stay unemployed, I really want to get a job. But like since I've been on a lot of tablets it's not quite recommended at the moment because they make me a bit drowsy as well.

It makes me dizzy, doped and it won't let me do things I like to do.

For some patients there was little to choose between taking the medication or not taking it in terms of the perceived undesirable consequences of both symptoms and medication. One man for example reported not experiencing side effects and that taking medication "made no difference". At times, the participants appeared to weigh up the impact of side effects against quality of life and the taking of neuroleptics was perceived to be associated both with high risks (severe side effects and shortened life expectancy) and high gains (staying out of hospital) which led to some uncertainty. Those belonging to the voluntary/alternative service group such as MIND or Hearing Voices network were more likely to question the continuation of taking medication more generally and specifically based on the impact of the side effects (C25 and C23, respectively):

I've heard I'm likely to die five or ten years sooner than if I didn't have them and the argument is that if I have a tolerable life of 60 years er its better than tearing my hair out and being mad as a hatter for 70 years.

To me its a vicious circle, you're either taking the tablets and feeling drugged up or you're just bloody hearing the voices and freaking out at people you know.

Not surprisingly, perhaps the incidence and management of side effects and symptoms were sometimes related to changes made to prescribed regimens by patients' psychiatrists as described by this man attending a depot clinic (C32):

He {the psychiatrist} put me on Artane twice a day and that bucked me up, then another problem would start you know, I'd have the shakes and they'd give me an injection for that, and then you've got a massive headache... and you'd get another tablet for that...

The degree of variance in everyday medication practices

Over and above identifying directly the perceived costs and benefits of medication the way and degree to which people manage their medication on an everyday basis is an important indicator of the degree of autonomy and control that people feel that they have in the management of a particular health problem and their lives more generally (Conrad, 1985). In common with the findings of other studies of medication use, there was evidence that respondents had acquired a knowledge of what levels of medication they needed to control the underlying condition and beyond that had gained some freedom to adjust the medication to manage the various side effects and other problems involved. There were a variety of ways in which patients changed their medication from the manner in which it had been prescribed. Whilst about two thirds of the sample reported taking medication as prescribed, 3 people regularly lowered the medication as prescribed, 4 people took extra medication. Over and above these changes, respondents reported making smaller situational adjustments. Some people increased or decreased the dose or changed the time of day it should have been given in order to cope with distress when it arose as illustrated by these two respondents. The first respondent reported taking three times the prescribed dosage to get through the day whilst the second reported dropping her medication because of the need to control her distress at night (C28 and C19, respectively):

Why do I take them in the day? Cos it helps me get through the day (laughs). It knocked me out at night which is what I think they were hoping for but I get restless sometimes during the day you know and I take them and they just help me get through the day.

I used to take 150 mg of chlorpromazine but I got it down to 100 because I was getting too many side effects on 150, so I dropped it myself to 100... I was screaming, you know with taking 150 so I dropped it down myself to 100 because by the time I was going to bed I was trying to doze off I was just like waking up and having fits you know like crying and screaming and you know like bouncing about.

Competing priorities that could not be accommodated within the prescribed regimen because it interfered with social interaction and enjoyment was also a reason for change which often related going to the pub or other leisure activities. Eight respondents altered medication situationally because of the poor interaction between alcohol and medication. Seven of the eight respondents reported stopping taking medication on the day the drank

alcohol whilst I person reported taking extra tablets before going to the pub. As one respondent explained, "Stelazine will probably ruin a good night if I know I'm off to the pub or something". In this regard respondents appeared to be aware that drinking alcohol should be avoided when taking neuroleptic medications. However, rather than the wholesale dismissal of the advice to avoid alcohol there was at times evidence of a process of risk assessment in decisions surrounding the consumption of alcohol and devising of strategies which balanced the accommodation of social activities with the need to take medication. One strategy mentioned was to regulate the frequency of risky activities (e.g. by drinking only at the weekend) or take measures to reduce the likelihood of adverse effects as indicated by this respondent (C28):

If I know I'm going out for a drink I have three good square meals... so it soaks absorbs all the alcohol and its stops it rushing in to my blood well into your system.... and I can feel like er if I've over done it 5 or 6 pints maybe and I've lost count. I go home and I get my drugs out and I say to myself, well if I don't take it I'll be ill in the morning right.

Alternative coping strategies

One further alteration to the medication regimen is the inclusion of other ways of coping with symptoms which are not ordinarily recognised as part of a more traditional psychiatric regimen. A range of management strategies were used as a supplement to the taking of prescribed neuroleptic medication*. The most common coping strategies included listening to music or the radio (7), talking to other people (6), exercise (6), praying or religion (5), alternative medication including herbal and homeopathic remedies (7), massage, yoga or relaxation classes (4), walking (3), alcohol and cigarettes (3) and reading (2). Self-medication with other drugs, particularly non-prescription medicines, was one reported method of coping with both psychotic symptoms and the iatrogenic effects of prescribed neuroleptic medication. The complexities of the coalescence between prescribed and self-medication practices is illustrated by one respondent's account, in which an attempt by a psychiatrist to reduce the mood-depressing effects of neuroleptics by prescribing anti-depressants was, in turn, met by the need for recipient to take his own steps to ameliorate the adverse effects of the anti-depressants (C23):

Recently, I was lucky because he put me on Prozac you know. The thing about that is that it keeps you up you know. I've been up since half past four you know and you're knackered for the rest of the day. So what I did was I went to the chemists and bought some herbal tablets called Valerian because I thought at least they don't have side effects.

Supplementation with previously prescribed drugs, drugs prescribed for others and over the counter purchases were not the only way in which

*Those respondents who adopted a variety of ways of dealing with their problems were also those who were more likely to question the value of neuroleptic medication.

people with diagnoses of schizophrenia attempted to cope with and take control of their lives and their condition. Philosophising existential exploration was a strategy used by one man who attempted to cope with and understand his mental state after being offered a copy of Bertrand Russell's "A History of Western Philosophy" by his psychiatrist. Using this book, he began to pursue answers for some fundamental questions which had been central to his experience of schizophrenia. Spirituality was also identified as a dimension in adapting and coping with the experience of illness, as indicated here by one woman of 56 attending a day centre (C19):

I've been saying my prayers over the weekend so that's why perhaps I'm feeling a bit better this morning. When you've got these feelings you don't want to get up in the morning that's what I've been basically praying for, you know being all right getting up in the morning.

Resources which promoted autonomy were also important, in this respect money, friends and independent living were cited as ameliorating factors. Alcohol, cigarettes and music were also important coping strategies for some respondents. These were found to be helpful in the easing of undesirable feelings and voices. As one respondent stated "alcohol and cigarettes gets me through". Alternative therapies were sometimes preferred because of a perceived lack of side effects compared to neuroleptics "the thing about herbal things is that they don't have side effects and you don't feel shitty". Finally a number of respondents identified sleep as a means of bringing about the absence of symptoms. Sleeping tablets, could be used to bring on sleep as an escape from hearing voices. "What I do sometimes is abuse my Mogadon, if I can't stop, if it gets so bad I sort of take about four and go to sleep".

Whilst a significant number of people mentioned taking medication which was at times inconsistent with medical instructions such changes in medication practices were usually temporary and transitory. Notwithstanding the use of other ways of managing symptoms as a supplement to taking medication, in the context of the reported severity and wide ranging impact of side effects on peoples' everyday lives, the relatively minor deviations from prescribed medication is perhaps surprising. The data suggested that this cautiousness might be related to respondents feeling unable to alter or give up their medication because of the internalisation of external controls and social sanctions which characterise the social and response to the management of people with a diagnoses of schizophrenia. There maybe a number of reasons that there was not greater evidence of variation in peoples' everyday medication practices. A traditional psychiatric view might be that apathy and passivity are indications of the "negative" symptoms of schizophrenia which might prevent patients from being more proactive. Additionally reports from the

respondents themselves described the impact of side effects such as lethargy and sleepiness which might possibly impinge on peoples sense and willingness to take active control of medication taking. However, over and above these possible reasons medication taking was seen to be in the control of others and influenced by a range of social sanctions.

Coercion and the threat of social sanctions

Occasionally neuroleptic medication was described in terms which suggested little if any difference between the taking of psychiatric medication and medication for other medical conditions as suggested by this 38 year old man using a "drop in centre" (C12):

Every person in the country is on medication at some time or other in their lives and they take the treatment as what the doctors prescribed. That's the whole point that's what the doctors are there for.

However, this tended to be a deviant view in so far as most people considered taking neuroleptic medication to be different to the consumption of other forms of medication. Significantly, respondents descriptions of taking medication were frequently accompanied by a strong sense of the social reaction and sanctions which would follow if patients did not take their medication. A number of people expressed a wish to discontinue medication but felt unable to stop medication because of the perceived power that other people had over their lives and medication taking. These related to actions which could be taken by significant others and mental health professionals, the obligations patients felt towards others and the stigma attached to the label of schizophrenia.

The influence of significant others

The involvement of significant others was perceived at times as a possible point where coercion might occur. Whilst for most people the taking of medication beyond the clinical encounter was an individual act significant or lay others could also control medication taking. (7 people spontaneously mentioned being encouraged/reminded/forced to take medication by a spouse, parent or hostel worker to take their medication). Instances were described which suggested that such involvement was undertaken in a way which did not appear to impinge on the patients autonomy. One woman of 33 described how her mother wrote down the dosage and times when the medication should be taken so she wouldn't forget to take her medication. However in other instances, peoples' autonomy in controlling their medication was clearly limited. One person reported how his medication was administered by hostel staff to prevent him taking too much vis: "it can be a bit of a pain but it stops me committing suicide cos I've no tablets on

me at the time". Others reported more coercive experiences. Two women reported the influence of their husbands in ensuring the taking of medication. One woman of 51 who lived alone with her husband reported that her husband ensured she took her medication on time. Another woman who lived with her husband and children reported always taking medication in the context of "my husband tried to force my tablets down my mouth". Another woman who said of her medication "If I don't want to take it, I won't take it", protested about her husbands' ascribed role which she did not perceive to be totally within his control (C23):

My husband is supposed to sort of see that I take it, I don't see that its up to your husband to see that you take your medication, its up to you... but my husband gets blamed if I don't take my medication.

Fear of coercion from mental health professionals

In addition to the traditional deference to medical authority common amongst most patient groups (e.g. "I always take my medication because the doctor prescribed it for me" or "they're supposed to know what they are doing"), accounts from patients about the taking of medication tended to take place against a backdrop of how mental health professionals might view their practice and the perceived need to hide certain practices. Under British mental health law the legal and social consequences of not taking medication can result in coercive measures which involve the loss of liberty for patients who have been diagnosed as schizophrenic. The Mental Health Act (1983) also allows for the administration of drugs such as major tranquilizers without the patients consent and for compulsory admission to hospital. The existence of legal measures and awareness of mental health professionals role in implementing these was a salient factor in patients formulations and attitudes towards taking medication. At times this was context specific. For example, a young man of Vietnamese origin said of his medication "only when I'm in hospital I take, but when I go home I don't take". However, the power and control that others did have or were perceived to have extended beyond the hospital walls. One man described medication vis (C5):

They give me poison, that's what I get, "poison", I've always taken them, when they've given me them, but I've never wished to take them. I don't think they do me any good.

This young Afro-Caribbean woman found that much of her medication was unpleasant but continued to take it because of the possibility of being compulsorily detained in hospital (C23):

You're supposed to do as they (doctors) tell you, you know, otherwise you get sectioned and I have been sectioned so er its not very nice, police bringing you down to {local psychiatric hospital}, so, you take them to stop yourself from being sectioned.

A further reason given by the same woman concerned her fear that any obvious non compliance might put at risk the availability of future care when needed (C23):

I mean to be honest, you know chemicals, I don't like the sort of stuff running through your blood, you know, and like feeling doped up and that. I've had it since I was thirteen and I'm thirty two now so I'm sick of it you know, and I know I could just tell them to sod off you know but if I really needed help, if I really got ill, they wouldn't be there.

In the context of legal sanctions and medical authority some patients did not perceive themselves as having the autonomy to stop taking medication as indicated by this 38 year old man (C12):

I've never really tried myself to come off medication I don't know that the doctors would allow it or not I mean they could put you in a section for refusing your medication, couldn't they?

The relationship between medication taking and the power in certain circumstances to physically control patients, is a point clearly described in the following quotes (C24):

He's (psychiatrist) bawling and shouting at me in my own house, and quite a few other people have had this experience, he's got a very poor personal style. I feel intimidated by him and he's over-bearing and he's got the power to section me, he's got the power to do just whatever he wants to me so I'm very careful what I say to him.

Some peoples decision not to take medication had been met with direct experience of the exercise of professional power which extended beyond the threat of physical restraint and sectioning associated with hospitalisation to surveillance and persuasion in a community context. Four people who had made a purposeful decision not to turned up to the out patient clinic for a depot injection has been subsequently "visited" by the Community Psychiatric Nurse at home and had been "persuaded" to have the medication.

The background of coercion and a perception of the consequences of having been diagnosed with schizophrenia led some respondents to manage the information they provided to their psychiatrists in a particular way. For example, in physician/patient encounters alternative remedies were sometimes seen as an unacceptable topic of discussion because of a belief that the label of schizophrenia undermined the validity of patients' views in the eyes of the psychiatrist, as indicated by the following quotes from this Afro-Caribbean woman (C23):

If I mentioned it, if my psychiatrist knew you know that I take herbal remedies, he'd just put my medication up, he'd think it was a sign of illness. Its not you know, its common sense... It's a waste of time a waste of time you know talking to, you know, I can't really talk to my doctor about it because he sees me as a schizophrenic you know, and you haven't really got a mind of your own.

One participant's awareness that his personal medication practice would be unacceptable to his

treating professionals is indicated in the rehearsing of professionals reactions to what patients actually did, "I just like to compromise and like take half the dose, but I'm not supposed to do that, don't tell them (laughter)".

The stigma of living in the community with a diagnosis of schizophrenia

This silence about alternative management strategies represented attempts to retain a sense of self in the face of being in receipt of a stigmatising illness label, a method by which patients attempted to manage their encounters with professionals and a means of controlling medication, free from medical interference. The taking of medication was also seen as part of a social contract that patients were required to adhere to in order to be tolerated by the community. The need to avoid placing unnecessary burdens on significant others or "letting them down" was mentioned. One man took his medication in order to avoid hospitalisation and a worsening in his general condition as this would have consequences for both him and his family (C20):

I know very well the dire consequences if I don't take my tablets on time. I don't want to end up in hospital for six months. It doesn't do me any good, it doesn't do my kids any good, it doesn't do my friends any good, doesn't do my family any good. That's the motivation for me to take my tablets on time and the right tablets.

The perceived social and medical pressure to be seen to be "behaving appropriately" and stigma associated with schizophrenia was a reason for rejecting medication. Fourteen respondents made overt reference to the stigma associated with a diagnosis of schizophrenia. This respondent attempted coming off his medication in order to try and rid himself of the consequences of the diagnosis he had been given (C25):

I think it's very normal when you get a heavy label, like when they call you a schizophrenic psychopath or something... I think then it's perfectly natural to want to kick against it for a few years at least, it's not an easy thing to accept so er so initially I, like many other people, was trying to prove that I wasn't mad by getting off my injection you know and that would prove it I thought.

Echoing the findings of Estroffs' study (1981) some patients mentioned the fear that involuntary limb movements caused by the drugs would mark them out as psychiatric patients by non-psychiatric patients living in the community. Additionally, if it was discovered that someone was taking medication this could be regarded as an indication of having schizophrenia which might result in discrimination (C24):

It's completely ruined my capability of holding down a job. You see I can't get a job because nobody's going to employ me with me taking my medication and my injections.

CONCLUSION

In common with the findings of other studies of medication use for chronic illness, the self-regulation of neuroleptic drugs amongst those with a diagnosis of schizophrenia offers an example of how people attempt to retain or gain some personal control over a condition and its management. People were found to take medication and adopt other self care strategies in a way which helped them to manage a set of problems that they faced in their every day lives. For respondents in this study, taking neuroleptic medication appeared to be associated with high gains, such as the ability to stay out of hospital, the reduction of distressing symptoms and the personal ability to control symptoms better. There were also high costs in terms of the range and severity of side effects. The alleviation of one set of symptoms by one means, neuroleptic medication, introduced another set of psychological and physical problems that respondents had to deal with. There was evidence that respondents did at times deviate from the prescribed regimen and supplemented the taking of medication with alternative coping strategies. However, the development of autonomous medication practices appeared to be less than in relation to other chronic conditions and medication taking for other mental health problems (e.g. benzodiazepines). For these respondents who had a diagnosis of schizophrenia, the degree, nature and amount of the self-regulation of medication appears to be have been circumscribed or inhibited by the impact of the threat of social and professional sanctions operating in a wider mental health policy and practice context. The data presented here suggest that patients' views about compliance and medication decisions were influenced by their knowledge and personal experience of possible coercive professional action, including compulsory admission and enforced treatment. Other influential factors included: an awareness of the stigma associated with the diagnosis of schizophrenia; the conditional and precarious public acceptance of psychiatric patients living "in the community" and fear of disapproval or disappointment in significant others with treatment non-compliance. These findings suggest that the social control function of neuroleptic medication, evident in mainstream psychiatry and mental health policy, is not only an external threat which has to be managed by patients but is internalised by some patients and impinges on the autonomy respondents feel they have in modifying their prescribed medical regimen. The internalisation of social control by patients is likely to be problematic in a context where there is a need for patients to be more autonomous and self-reliant when living outside of hospital and where there is increasing recognition of the need to develop voluntaristic rather than coercive patient/professional relationships.

The development of a different approach and attitude to the prescribing and taking of neuroleptic medication by patients is required if the content and not just the form of mental health practices are to change with the closure of the large mental hospitals. As was noted in the introduction, coercive means of enforcing the uptake of medication is fraught with legal, practical and ethical problems. A voluntaristic approach which works with patients own definitions and self management strategies presents a potentially different way of working collaboratively with patients. The desire for such an approach is evident in the pressure to adopt patient-centred and alternative ways of managing mental health problems. This is the focus of some of the campaigning activities of mental health users' groups and the development of alternatives to traditional psychiatric practice (Rogers and Pilgrim, 1995). For example, Romme and Escher (1989) have noted that many people who hear voices do not seek psychiatric treatments and have described a clinical approach which encourages hallucinating patients to accept their voices as part of natural human variation. In this context, the incorporation of the lay monitoring of medication which has been advocated as a more positive approach to the rational use of medication for other patient groups seems appropriate to apply to the management of neuroleptic medication in the mental health field (Chewning and Sleath, 1996). Future practice and research might fruitfully examine the way in which placing value on patients' own definitions of their problems, experiences and management strategies presents an opportunity for rethinking the nature of professional/patient encounters about medication and mental health policy more generally.

Acknowledgements—This study was funded by a grant from the Medical Research Council the North West NHSE and the Welsh Office. We are grateful for the helpful comments of John Monahan and David Pilgrim and for the suggestions of two anonymous referees.

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