

THE MEANING OF MEDICATIONS: ANOTHER LOOK AT COMPLIANCE*

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Abstract—Most research on compliance with medical regimens takes a doctor-centered perspective and proceeds from certain assumptions. This paper presents an alternative, patient-centered approach to managing medications, using data from 80 in-depth interviews of people with epilepsy. This approach focuses on the meanings of medication in people's everyday lives and looks at why people take their medications as well as why they do not. I argue that from a patient's perspective the issue is more one of self-regulation than compliance. When we examine 'noncompliance' beyond difficulties with 'side effects' and drug efficacy, the meanings of self-regulation include testing, controlling dependence, destigmatization and creating a practical practice. What appears to be noncompliance from a medical perspective may actually be a form of asserting control over one's disorder.

Compliance with medical regimens, especially drug regimens, has become a topic of central interest for both medical and social scientific research. By compliance we mean "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" [1]. It is noncompliance that has engendered the most concern and attention. Most theories locate the sources of noncompliance in the doctor-patient interaction, patient knowledge or beliefs about treatment and, to a lesser extent, the nature of the regimen or illness.

This paper offers an alternative perspective on noncompliance with drug regimens, one situated in the patient's experience of illness. Most studies of noncompliance assume the centrality of patient-practitioner interaction for compliance. Using data from a study of the experience of epilepsy, I argue that from a patient-centered perspective the meanings of medication in people's everyday lives are more salient than doctor-patient interaction for understanding why people alter their prescribed medical regimens. The issue is more one of self-regulation than compliance. After reviewing briefly various perspectives on compliance and presenting a synopsis of our method and sample, I develop the concept of medication practice to aid in understanding patient's experiences with medication regimens. This perspective enables us to analyze 'noncompliance' among our sample of people with epilepsy in a different light than the usual medically-centered approach allows.

PERSPECTIVES ON COMPLIANCE

Most studies show that at least one-third of patients are noncompliant with drug regimens; i.e. they do not take medications as prescribed or take

them in correct doses or sequences [2-4]. A recent review of methodologically rigorous studies suggests that compliance rates with medications over a large period tend to converge at approx. 50% [5].

Literally hundreds of studies have been conducted on compliance. Extensive summaries and compilations of this burgeoning literature are available [1, 6, 7]. In this section I will note some of the more general findings and briefly summarize the major explanatory perspectives. Studies have found, for example, that noncompliance tends to be higher under certain conditions: when medical regimens are more complex [8]; with asymptomatic or psychiatric disorders [9]; when treatment period lasts for longer periods of time [5]; and when there are several troublesome drug side effects [4]. Interestingly, there seems to be little consistent relationship between noncompliance and such factors as social class, age, sex, education and marital status [8].

Two dominant social scientific perspectives have emerged that attempt to explain variations in compliance and noncompliance. One locates the source of the problem in doctor-patient interaction or communication while the other postulates that patients' health beliefs are central to understanding non-compliant behavior. These perspectives each are multicausal and in some ways are compatible.

There have been a series of diverse studies suggesting that noncompliance is a result of some problem in doctor-patient interaction (see [10]). Researchers have found higher compliance rates are associated with physicians giving explicit and appropriate instructions, more and clearer information, and more an better feedback [2, 10]. Other researchers note that noncompliance is higher when patients' expectations are not met or their physicians are not behaving in a friendly manner [12, 13]. Hulka *et al.* [3], Davis [2] and others suggest that the physician and his or her style of communicating may affect patient compliance. In short, these studies find the source of non-compliance in doctor-patient communication and suggest that compliance rates can be improved by making some changes in clinician-patient interaction.

The importance of patient beliefs for compliant

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behavior is highlighted by the 'health-belief model'. The health-belief model is a social psychological perspective first developed to explain preventative health behavior. It has been adapted by Becker [14–16] to explain compliance. This perspective is a "value-expecting model in which behavior is controlled by rational decisions taken in the light of a set of subjective probabilities" [17]. The health-belief model suggests that patients are more likely to comply with doctors orders when they feel susceptibility to illness, believe the illness to have potential serious consequences for health or daily functioning, and do not anticipate major obstacles, such as side effects or cost. Becker [15] found general support for a relationship between compliance and patients' beliefs about susceptibility, severity, benefits and costs.

Both perspectives have accumulated some supporting evidence, but make certain problematic assumptions about the nature and source of compliant behavior. The whole notion of 'compliance' suggests a medically-centered orientation; how and why people follow or deviate from doctors orders. It is a concept developed from the doctor's perspective and conceived to solve the provider defined problem of 'noncompliance'. The assumption is the doctor gives the orders; patients are expected to comply. It is based on a consensual model of doctor–patient relations, aligning with Parsons' [18] perspective, where noncompliance is deemed a form of deviance in need of explanation. Compliance/noncompliance studies generally assume a moral stance that not following medical regimens is deviant. While this perspective is reasonable from the physicians viewpoint, when social scientists adopt this perspective they implicitly reinforce the medically-centered perspective.

Some assumptions of each perspective are also problematic. The doctor–patient interaction perspective points to flaws in doctor–patient communication as the source of noncompliance. It is assumed that the doctor is very significant for compliance and the research proceeds from there. Although the health belief model takes the patient's perspective into account, it assumes that patients act from a rational calculus based on health-related beliefs. This perspective assumes that health-related beliefs are the most significant aspects of subjective experience and that compliance is a rational decision based on these beliefs. In an attempt to create a succinct and straight-forward model, it ignores other aspects of experience that may affect how illness and treatment are managed.

There is an alternative, less-developed perspective that is rarely mentioned in studies of compliance. This patient-centered perspective sees patients as active agents in their treatment rather than as "passive and obedient recipients of medical instructions" [19]. Stimson [19] argues that to understand non-compliance it is important to account for several factors that are often ignored in compliance studies. Patients have their own ideas about taking medication—which only in part come from doctors—that affect their use of medications. People evaluate both doctors's actions and the prescribed drugs in comparison to what they themselves know about illness and medication. In a study of arthritis patients Arluke [20] found that patients evaluate also the

therapeutic efficacy of drugs against the achievement of specific outcomes. Medicines are judged ineffective when a salient outcome is not achieved, usually in terms of the patient's expected time frames. The patient's decision to stop taking medications is a rational-empirical method of testing their views of drug efficacy. Another study found some patients augmented or diminished their treatment regimens as an attempt to assert control on the doctor–patient relationship [21]. Hayes-Bautista [21] notes, "The need to modify treatment arises when it appears the original treatment is somehow not totally appropriate" and contends noncompliance may be a form of patient bargaining with doctors. Others [22] have noted that noncompliance may be the result of particular medical regimens that are not compatible with contexts of people's lives.

These studies suggest that the issue of non-compliance appears very different from a patient-centered perspective than a medically-centered one. Most are critical of traditional compliance studies, although still connecting compliance with doctor–patient interactions [19, 21] or with direct evaluation of the drug itself [19, 20]. Most sufferers of illness, especially chronic illness, spend a small fraction of their lives in the 'patient role' so it is by no means certain that the doctor–patient relationship is the only or even most significant factor in their decisions about drug-taking. A broader perspective suggests that sufferers of illness need to manage their daily existence of which medical regimens are only a part (cf. [23]). Such a perspective proposes that we examine the meaning of medications as they are manifested in people's everyday lives.

This paper is an attempt to further develop a patient- or sufferer-centered perspective on adhering to medical regimens. We did not set out to study compliance *per se*; rather this paper reflects themes that emerged from our larger study of people's experiences of epilepsy [24]. We examine what prescribed medications mean to the people with epilepsy we interviewed; and how these meanings are reflected in their use.

METHOD AND SAMPLE

The larger research project from which these data are drawn endeavors to present and analyze an 'insider's' view of what it is like to have epilepsy in our society. To accomplish this we interviewed 80 people about their life experiences with epilepsy. Interviews were conducted over a 3-year period and respondents were selected on the basis of availability and willingness to participate. We used a snowball sampling technique, relying on advertisements in local newspapers, invitation letters passed anonymously by common acquaintances, and names obtained from local social agencies, self-help groups and health workers. No pretense to statistical representativeness is intended or sought. Our intention was to develop a sample from which theoretical insight would emerge and a conceptual understanding of epilepsy could be gained (see [25]).

We used an interview guide consisting of 50 open-ended questions and interviewed most of our respondents in their homes. The interviews lasted 1–3

hours and were tape-recorded. The recordings were transcribed and yielded over 2000 single-spaced typed pages of verbatim data.

Our sample ranged in age from 14 to 54 years (average age 28) and included 44 women and 36 men. Most respondents came from a metropolitan area in the midwest; a small number from a major city on the east coast. Our sample could be described as largely lower-middle class in terms of education and income. None of our respondents were or had been institutionalized for epilepsy; none were interviewed in hospitals, clinics of physicians' offices. In short, our sample and study were independent of medical and institutionalized settings. More detail about the method and sample is available elsewhere [24].

EPILEPSY, MEDICATION AND SELF-REGULATION

The common medical response to a diagnosis of epilepsy is to prescribe various medications to control seizures. Given the range of types of epilepsy and the variety of physiological reactions to these medications, patients often see doctors as having a difficult time getting their medication 'right'. There are starts and stops and changes, depending on the degree of seizure control and the drug's side effects. More often than not, patients are stabilized on a medication or combination at a given dosage or regimen. Continuing or altering medications is the primary if not sole medical management strategy for epilepsy.

Medications are important to people with epilepsy. They 'control' seizures. Most take this medication several times daily. It becomes a routine part of their everyday lives. Although all of our respondents were taking or had taken these drugs, their responses to them varied. The effectiveness of these drugs in controlling seizures is a matter of degree. For some,

seizures are stopped completely; they take pills regularly and have no seizures. For most, seizure frequency and duration are decreased significantly, although not reduced to zero. For a very few of our respondents, medications seem to have little impact; seizures continue unabated.

Nearly all our respondents said medications have helped them control seizures at one time or another. At the same time, however, many people changed their dose and regimen from those medically prescribed. Some stopped altogether. If medications were seen as so helpful, why were nearly half of our respondents 'noncompliant' with their doctors' orders?

Most people with illnesses, even chronic illnesses such as epilepsy, spend only a tiny fraction of their lives in the 'patient role'. Compliance assumes that the doctor-patient relationship is pivotal for subsequent action, which may not be the case. Consistent with our perspective, we conceptualize the issue as one of developing a *medication practice*. Medication practice offers a patient-centered perspective of how people manage their medications, focusing on the meaning and use of medications. In this light we can see the doctor's medication orders as the 'prescribed medication practice' (e.g. take a 20 mg pill four times a day). Patients interpret the doctor's prescribed regimen and create a medication practice that may vary decidedly from the prescribed practice. Rather than assume the patient will follow prescribed medical rules, this perspective allows us to explore the kinds of practices patients create*. Put another way, it sees patients as active agents rather than passive recipients of doctors' orders.

Although many people failed to conform to their prescribed medication regimen, they did not define this conduct primarily as noncompliance with doctors' orders. The more we examined the data, the clearer it was that from the patient's perspective, doctors had very little impact on people's decisions to alter their medications. It was, rather, much more a question of regulation of control. To examine this more closely we developed criteria for what we could call self-regulation. Many of our respondents occasionally missed taking their medicine, but otherwise were regular in their medication practice. One had to do more than 'miss' medications now and again (even a few times a week) to be deemed self-regulating. A person had to (1) reduce or raise the daily dose of prescribed drugs for several weeks or more or (2) skip or take extra doses regularly under specific circumstances (e.g. when drinking, staying up late or under 'stress') or (3) stop taking the drugs completely for three consecutive days or longer. These criteria are arbitrary, but they allow us to estimate the extent of self-regulation. Using this definition, 34 of our 80 respondents (42%) self-regulated their medication†.

To understand the meaning and management of medications we need to look at those who follow a prescribed medications practice as well as those who create their own variations. While we note that 42% of our respondents are at variance with medical expectations, this number is more suggestive than definitive. Self-regulators are not a discrete and separate group. About half the self-regulators could be defined as regular in their practice, whatever it might

*Two previous studies of epilepsy which examine the patients' perspective provide parallel evidence for the significance of developing such an approach in the study of 'noncompliance' (see [26] and [27]).

†Reports in the medical literature indicate that non-compliance with epilepsy regimens is considered a serious problem [28-32]. One study reports that 40% of patients missed the prescribed medication dose often enough to affect their blood-level medication concentrations [33]; an important review article estimates noncompliance with epilepsy drug regimens between 30 and 40%, with a range from 20 to 75% [34]. Another study suggests that noncompliant patients generally had longer duration of the disorder, more complicated regimens and more medication changes [35]. Attempts to increase epilepsy medication compliance include improving doctor-patient communication, incorporating patients more in treatment programs, increasing patient knowledge and simplifying drug regimens. Since noncompliance with anti-convulsant medication regimens is deemed the most frequent reason why patients suffer recurrent seizures [30], some researchers suggest, "If the patient understands the risks of stopping medication, he *will not stop*" [36]. Yet there also have been reports of active noncompliance with epilepsy medications [37]. In sum, epilepsy noncompliance studies are both typical of and reflect upon most other compliance research. In this sense, epilepsy is a good example for developing an alternative approach to understanding how people manage their medications.

be. They may have stopped for a week once or twice, or take extra medication only under 'stressful' circumstances; otherwise, they are regular in their practice. On the other hand, perhaps a quarter of those following the prescribed medical practice say they have seriously considered changing or stopping their medications. It is likely there is an overlap between self-regulating and medical-regulating groups. While one needs to appreciate and examine the whole range of medication practice, the self-regulators provide a unique resource for analysis. They articulate views that are probably shared in varying degree by all people with epilepsy and provide an unusual insight into the meaning of medication and medication practice. We first describe how people account for following a prescribed medication practice; we then examine explanations offered for altering prescribed regimens and establishing their own practices. A final section outlines how the meaning of medications constructs and reflects the experience of epilepsy.

A TICKET TO NORMALITY

The availability of effective seizure control medications early in this century is a milestone in the treatment of epilepsy (Phenobarbital was introduced in 1912; Dilantin in 1938). These drugs also literally changed the experience of having epilepsy. To the extent the medications controlled seizures, people with epilepsy suffered fewer convulsive disruptions in their lives and were more able to achieve conventional social roles. To the extent doctors believed medications effective, they developed greater optimism about their ability to treat epileptic patients. To the degree the public recognized epilepsy as a 'treatable' disorder, epileptics were no longer segregated in colonies and less subject to restrictive laws regarding marriage, procreation and work [24]. It is not surprising that people with epilepsy regard medications as a 'ticket' to normality. The drugs did not, speaking strictly, affect anything but seizures. It was the social response to medication that brought about these changes. As one woman said: "I'm glad we've got [the medications] . . . you know, in the past people didn't and they were looked upon as lepers".

For most people with epilepsy, taking medicine becomes one of those routines of everyday life we engage in to avoid unwanted circumstances or improve our health. Respondents compared it to taking vitamins, birth control pills or teeth brushing. It becomes almost habitual, something done regularly with little reflection. One young working man said: "Well, at first I didn't like it, [but] it doesn't bother me anymore. Just like getting up in the morning and brushing your teeth. It's just something you do".

But seizure control medications differ from 'normal pills' like vitamins or contraceptives. They are prescribed for a medical disorder and are seen both by the individual and others, as indicators or evidence of having epilepsy. One young man as a child did not know he had epilepsy "short of taking [his] medication". He said of this connection between epilepsy and medication: "I do, so therefore I have". Medications represent epilepsy: Dilantin or Phenobarbital are quickly recognized by medical people and often by others as epilepsy medications.

Medications can also indicate the degree of one's disorder. Most of our respondents do not know any others with epilepsy; thus they examine changes in their own epilepsy biographies as grounds for conclusions about their condition. Seizure activity is one such sign; the amount of medications 'necessary' is another. A decrease or increase in seizures is taken to mean that epilepsy is getting better or worse. So it is with medications. While two may be related—especially because the common medical response to more seizures is increased medication—they may also operate independently. If the doctor reduces the dose or strength of medication, or vice versa, the patient may interpret this as a sign of improvement or worsening. Similarly, if a person reduces his or her own dose, being able to 'get along' on this lowered amount of medication is taken as evidence of 'getting better'. Since for a large portion of people with epilepsy seizures are considered to be well-controlled, medications become the only readily available measure of the 'progress' of the disorder.

TAKING MEDICATIONS

We tried to suspend the medical assumptions that people take medications simply because they are prescribed, or because they are supposed to control seizures, to examine our respondents' accounts of what they did and why.

The reason people gave most often for taking medication is *instrumental*: to control seizures, or more generally, to reduce the likelihood of body malfunction. Our respondents often drew a parallel to the reason people with diabetes take insulin. As one woman said, "If it does the trick, I'd rather take them [medications] than not". Or, as a man who would "absolutely not" miss his medications explained, "I don't want to have seizures" (although he continued to have 3 or 4 a month). Those who deal with their medication on instrumental grounds see it simply as a fact of life, as something to be done to avoid body malfunction and social and personal disruption.

While controlling body malfunction is always an underlying reason for taking medications, psychological grounds may be equally compelling. Many people said that medication *reduces worry*, independent of its actually decreasing seizures. These drugs can make people feel secure, so they don't have to think about the probability of seizures. A 20 year-old woman remarked: "My pills keep me from getting hysterical". A woman who has taken seizure control medication for 15 years describes this 'psychological' function of medication: "I don't know what it does, but I suppose I'm psychologically dependent on it. In other words, if I take my medication, I feel better". Some people actually report 'feeling better'—clearer, more alert and energetic—when they do not take these drugs, but because they begin to worry if they miss, they take them regularly anyhow.

The most important reason for taking medication, however, is to insure 'normality'. People said specifically that they take medications to be more 'normal': The meaning here is normal in the sense of 'leading a normal life'. In the words of a middle-aged public relations executive who said he does not

restrict his life because of epilepsy: "Except I always take my medication. I don't know why. I figure if I took them, then I could do anything I wanted to do". People believed taking medicine reduces the risk of having a seizure in the presence of others, which might be embarrassing or frightening. As a young woman explained:

I feel if it's going to help, that's what I want because you know you feel uncomfortable enough anyway that you don't want anything like [a seizure] to happen around other people; so if it's going to help, I'll take it.

This is not to say people with epilepsy like to take medications. Quite the contrary. Many respondents who follow their medically prescribed medication practice openly say they 'hate' taking medications and hope someday to be 'off' the drugs. Part of this distaste is related to the dependence people come to feel. Some used the metaphor of being an addict: "I'm a real drug addict"; "I was an addict before it was fashionable"; "I'm like an alcoholic without a drink; I *have* to have them [pills]"; and "I really don't want to be hooked for the rest of my life". Even while loathing the pills or the 'addiction' people may be quite disciplined about taking these drugs.

The drugs used to control seizures are not, of course, foolproof. Some people continue to have seizures quite regularly while others suffer only occasional episodes. Such limited effectiveness does not necessarily lead these people to reject medication as a strategy. They continue, with frustration, to express "hope" that "they [doctors] will get it [the medication] right". For some, then, medications are but a limited ticket to normality.

SELF-REGULATION: GROUNDS FOR CHANGING MEDICATION PRACTICE

For most people there is not a one-to-one correspondence between taking or missing medications and seizure activity. People who take medications regularly may still have seizures, and some people who discontinue their medications may be seizure-free for months or longer. Medical experts say a patient may well miss a whole day's medication yet still have enough of the drug in the bloodstream to prevent a seizure for this period.

In this section we focus on those who deviate from the prescribed medication practice and variously regulate their own medication. On the whole, members of this subgroup are slightly younger than the rest of the sample (average age 25 vs 32) and somewhat more likely to be female (59–43%), but otherwise are not remarkably different from our respondents who follow the prescribed medication practice. Self-regulation for most of our respondents consists of reducing the dose, stopping for a time, or regularly skipping or taking extra doses of medication depending on various circumstances.

Reducing the dose (including total termination) is the most common form of self-regulation. In this

context, two points are worth re-stating. First, doctors typically alter doses of medication in times of increased seizure activity or troublesome drug 'side effects'. It is difficult to strike the optimum level of medication. To people with epilepsy, it seems that doctors engage in a certain amount of trial and error behavior. Second, and more important, medications are defined, both by doctors and patients, as an indicator of the degree of disorder. If seizure activity is not 'controlled' or increases, patients see that doctors respond by raising (or changing) medications. The more medicine prescribed means epilepsy is getting worse; the less means it is getting better. What doctors do does not necessarily explain what patients do, but it may well be an example our respondents use in their own management strategies. The most common rationales for altering a medication practice are drug related: the medication is perceived as ineffective or the so-called side effects become too troublesome.

The efficacy of a drug is a complex issue. Here our concern is merely with perceived efficacy. When a medication is no longer seen as efficacious it is likely to be stopped. Many people continue to have seizures even when they follow the prescribed medication practice. If medication seemed to make no difference, our respondents were more likely to consider changing their medication practice. One woman who stopped taking medications for a couple of months said, "It seemed like [I had] the same number of seizures without it". Most people who stop taking their medicine altogether eventually resume a medication practice of some sort. A woman college instructor said, "When I was taking Dilantin, I stopped a number of times because it never seemed to *do* anything".

The most common drug-related rationale for reducing dose is troublesome 'side effects'. People with epilepsy attribute a variety of side effects to seizure control medications. One category of effects includes swollen and bleeding gums, oily or yellow skin, pimples, sore throat and a rash. Another category includes slowed mental functioning, drowsiness, slurred speech, dullness, impaired memory, loss of balance and partial impotence*. The first category, which we can call body side effects, were virtually never given as an account for self-regulation. Only those side effects that impaired social skills, those in the second category, were given as reasons for altering doctors' medication orders.

Social side effects impinge on social interaction. People believed they felt and acted differently. A self-regulating woman described how she feels when she takes her medication:

I can feel that I become much more even. I feel like I flatten out a little bit. I don't like that feeling . . . It's just a feeling of dullness, which I don't like, almost a feeling that you're on the edge of laziness.

If people saw their medication practice as hindering the ability to participate in routine social affairs, they were likely to change it. Our respondents gave many examples such as a college student who claimed the medication slowed him down and wondered if it were affecting his memory, a young newspaper reporter who reduced his medication because it was putting

*These are reported side effects. They may or may not be drug related, but our respondents attribute them to the medication.

him to sleep at work; or the social worker who felt she 'sounds smarter' and more articulate when 'off medications'.

Drug side effects, even those that impair social skills, are not sufficient in themselves to explain the level of self-regulation we found. Self-regulation was considerably more than a reaction to annoying and uncomfortable side effects. It was an active and intentional endeavor.

SOCIAL MEANINGS OF REGULATING MEDICATION PRACTICE

Variations in medication practice by and large seem to depend on what medication and self-regulation mean to our respondents. Troublesome relationships with physicians, including the perception that they have provided inadequate medical information [14], may be a foundation on which alternative strategies and practices are built. Our respondents, however, did not cite such grounds for altering their doctors' orders. People vary their medication practice on grounds connected to managing their everyday lives. If we examine the social meanings of medications from our respondents' perspectives, self-regulation turns on four grounds: testing; control of dependence; destigmatization; and practical practice. While individual respondents may cite one or more of these as grounds for altering medication practice, they are probably best understood as strategies common among those who self regulate.

Testing

Once people with epilepsy begin taking seizure-control medications, given there are no special problems and no seizures, doctors were reported to seldom change the medical regimen. People are likely to stay on medications indefinitely. But how can one know that a period without seizures is a result of medication or spontaneous remission of the disorder? How long can one go without medication? How 'bad' is this case of epilepsy? How can one know if epilepsy is 'getting better' while still taking medication? Usually after a period without or with only a few seizures, many reduced or stopped their medicine altogether to test for themselves whether or not epilepsy was 'still there'.

People can take themselves off medications as an experiment, to see 'if anything will happen'. One woman recalled:

I was having one to two seizures a year on phenobarb . . . so I decided not to take it and to see what would happen . . . so I stopped it and I watched and it seemed that I had the same amount of seizures with it as without it . . . for three years.

She told her physician, who was skeptical but 'allowed' her this control of her medication practice. A man who had taken medication three times a day for 16 years felt intuitively that he could stop his medications:

Something kept telling me I didn't have to take [medication] anymore, a feeling or somethin'. It took me quite a while to work up the nerve to stop takin' the pills. An one day I said, "One way to find out . . .".

After suffering what he called drug withdrawal effects, he had no seizures for 6 years. Others test to see how long they can go without medication and seizures.

Testing does not always turn out successfully. A public service agency executive tried twice to stop taking medications when he thought he had 'kicked' epilepsy. After two failures, he concluded that stopping medications "just doesn't work". But others continue to test, hoping for some change in their condition. One middle-aged housewife said:

When I was young I would try not to take it . . . I'd take it for a while and think, "Well, I don't need it anymore," so I would not take it for, deliberately, just to see if I could do without. And then [in a few days] I'd start takin' it again, because I'd start passin' out . . . I will still try that now, when my husband is out of town . . . I just think, maybe I'm still gonna grow out of it or something.

Testing by reducing or stopping medication is only one way to evaluate how one's disorder is progressing. Even respondents who follow the prescribed medication regimen often wonder 'just what would happen' if they stopped.

Controlling dependence

People with epilepsy struggle continually against becoming too dependent on family, friends, doctors or medications. They do, of course, depend on medications for control of seizures. The medications do not necessarily eliminate seizures and many of our respondents resented their dependence on them. Another paradox is that although medications can increase self reliance by reducing seizures, taking medications can be *experienced* as a threat to self reliance. Medications seem almost to become symbolic of the dependence created by having epilepsy.

There is a widespread belief in our society that drugs create dependence and that being on chemical substances is not a good thing. Somehow, whatever the goal is, it is thought to be better if we can get there without drugs. Our respondents reflected these ideas in their comments.

A college junior explained: "I don't like it at all. I don't like chemicals in my body. It's sort of like a dependency only that I have to take it because my body forced me to . . .". A political organizer who says medications reduce his seizures commented: "I've never enjoyed having to depend on anything . . . drugs in particular". A nurse summed up the situation: "The *drugs* were really a kind of dependence." Having to take medication relinquished some degree of control of one's life. A woman said:

I don't like to have to *take* anything. It was, like, at one time birth control pills, but I don't like to take anything *everyday*. It's just like, y'know, controlling me, or something.

The feeling of being controlled need not be substantiated in fact for people to act upon it. If people *feel* dependent on and controlled by medication, it is not surprising that they seek to avoid these drugs. A high school junior, who once took medicine because he feared having a seizure in the street, commented:

And I'd always heard medicine helps and I just kept taking it and finally I just got so I didn't depend on the medicine no more, I could just fight it off myself and I just stopped taking it in.

After stopping for a month he forgot about his medications completely.

Feelings of dependence are one reason people gave for regulating medicine. For a year, one young social worker took medication when she felt it was necessary; otherwise, she tried not to use it. When we asked her why, she responded, "I regulate my own drug . . . mostly because it's really important for me not to be dependent". She occasionally had seizures and continued to alter her medication to try to 'get it right':

I started having [seizures] every once in a while. And I thought wow, the bad thing is that I just haven't regulated it right and I just need to up it a little bit and then, you know, if I do it just right, I won't have epilepsy anymore.

This woman and others saw medications as a powerful resource in their struggle to gain control over epilepsy. Although she no longer thinks she can rid herself of epilepsy, this woman still regulates her medication.

In this context, people with epilepsy manipulate their sense of dependence on medications by changing medication practice. But there is a more subtle level of dependence that encourages such changes. Some reported they regulated their medication intake in direct response to interventions of others, especially family members. It was as if others *wanted* them to be more dependent by coaxing or reminding them to take their medications regularly. Many responded to this encouraged greater dependence by creating their own medication practice.

A housewife who said she continues regularly to have petit mal seizures and tremors along with an occasional grand mal seizure, remarked:

Oh, like most things, when someone tells me I have to do something, I basically resent it If it's my option and I choose to do it, I'll probably do it more often than not. But if you tell me I have to, I'll bend it around and do it my own way, which is basically what I have done.

Regardless of whether one feels dependent on the drug or dependent because of others' interventions around drug taking, changing a prescribed medication practice, as well as continuing self-regulation serve as a form of *taking control* of one's epilepsy.

Destigmatization

Epilepsy is a stigmatized illness. Sufferers attempt to control information about the disorder to manage this threat [38]. There are no visible stigmata that make a person with epilepsy obviously different from other people, but a number of aspects of having epilepsy can compromise attempts at information control. The four signs that our respondents most frequently mentioned as threatening information control were seizures in the presence of others, job or insurance applications, lack of a driver's license and taking medications. People may try to avoid seizures

in public, lie or hedge on their applications, develop accounts for not having a driver's license, or take their medicine in private in order to minimize the stigma potential of epilepsy.

Medication usually must be taken three or four times daily, so at least one dose must be taken away from home. People attempt to be private about taking their medications and/or develop 'normal' pill accounts ("it's to help my digestion"). One woman's mother told her to take medications regularly, as she would for any other sickness:

When I was younger it didn't bother me too bad. But as I got older, it would tend to bother me some. Whether it was, y'know, maybe somebody seeing me or somethin', I don't know. But it did.

Most people develop skills to minimize potential stigmatization from taking pills in public.

On occasion, stopping medications is an attempt to vacate the stigmatized status of epileptic. One respondent wrote us a letter describing how she tried to get her mother to accept her by not taking her medications. She wrote:

This is going to sound real dumb, but I can't help it. My mother never accepted me when I was little because I was "different". I stopped taking my medication in an attempt to be normal and accepted by her. Now that I know I need medication it's like I'm completely giving up trying to be "normal" so mom won't be ashamed of me. I'm going to accept the fact that I'm "different" and I don't really care if mom gives a damn or not.

Taking medications in effect acknowledges this 'differentness'.

It is, of course, more difficult to hide the meaning of medications from one's self. Taking medication is a constant reminder of having epilepsy. For some it is as if the medication itself represents the stigma of epilepsy. The young social worker quoted above felt if she could stop taking her medications she would no longer be an epileptic. A young working woman summed up succinctly why avoiding medications would be avoiding stigma: "Well, at least I would not be . . . generalized and classified in a group as being an epileptic".

Practical practice

Self-regulators spoke often of how they changed the dose or regimen of medication in an effort to reduce the risk of having a seizure, particularly during 'high stress' situations. Several respondents who were students said they take extra medications during exam periods or when they stay up late studying. A law student who had not taken his medicine for 6 months took some before his law school exams: "I think it increases the chances [seizures] won't happen". A woman who often participated in horse shows said she "usually didn't pay attention" to her medication practice but takes extra when she doesn't get the six to eight hours sleep she requires: I'll wake up and take two capsules instead of one . . . and I'll generally take it like when we're going to horse shows. I'll take it pretty consistently". Such uses of medication are common ways of trying to forestall 'possible trouble'.

People with epilepsy changed their medication practice for practical ends in two other kinds of circumstances. Several reported they took extra medication if they felt a 'tightening' or felt a seizure coming on. Many people also said they did not take medications if they were going to drink alcohol. They believed that medication (especially Phenobarbital) and alcohol do not mix well.

In short, people change their medication practice to suit their perceptions of social environment. Some reduce medication to avoid potential problems from mixing alcohol and drugs. Others reduce it to remain 'clear-headed' and 'alert' during 'important' performances (something of a 'Catch-22' situation). Most, however, adjust their medications practically in an effort to reduce the risk of seizures.

CONCLUSION: ASSERTING CONTROL

Regulating medication represents an attempt to assert some degree of control over a condition that appears at times to be completely beyond control. Loss of control is a significant concern for people with epilepsy. While medical treatment can increase both the sense and the fact of control over epilepsy, and information control can limit stigmatization, the regulation of medications is one way people with epilepsy struggle to gain some personal control over their condition.

Medication practice can be modified on several different grounds. Side effects that make managing everyday social interaction difficult can lead to the reduction or termination of medication. People will change their medication practice, including stopping altogether, in order to 'test' for the existence or 'progress' of the disorder. Medication may be altered to control the perceived level of dependence, either on the drugs themselves or on those who 'push' them to adhere to a particular medication practice. Since the medication can represent the stigma potential of epilepsy, both literally and symbolically, altering medication practice can be a form of destigmatization. And finally, many people modify their medication practice in anticipation of specific social circumstances, usually attempting to reduce the risk of seizures.

It is difficult to judge how generalizable these findings are to other illnesses. Clearly, people develop medication practices whenever they must take medications regularly. This is probably most true for long-term chronic illness where medication becomes a central part of everyday life, such as diabetes, rheumatoid arthritis, hypertension and asthma. The degree and amount of self-regulation may differ among illnesses—likely to be related to symptomatology, effectiveness of medications and potential of stigma—but I suspect most of the meanings of medications described here would be present among sufferers of any illness that people must continually manage.

In sum, we found that a large proportion of the people with epilepsy we interviewed said they themselves regulate their medication. Medically-centered compliance research presents a skewed and even distorted view of how and why patients manage medication. From the perspective of the person with

epilepsy, the issue is more clearly one of responding to the meaning of medications in everyday life than 'compliance' with physicians' orders and medical regimens. Framing the problem as self-regulation rather than compliance allows us to see modifying medication practice as a vehicle for asserting some control over epilepsy. One consequence of such a reframing would be to reexamine the value of achieving 'complaint' behavior and to rethink what strategies might be appropriate for achieving greater adherence to prescribed medication regimens.

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