

# A qualitative study of medication-taking behaviour in primary care

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**Background.** Prescribed medication is a mainstay of primary care but it is clear that a large proportion of treatment is not taken correctly. Such 'non-compliance' is considered to be a major problem, but research to date has provided few solutions. There have been increasing calls for a change in approach in order to gain a deeper understanding of why the problem remains and new ways of addressing it.

**Objectives.** We aimed to investigate how adult primary care patients perceived medication-taking using a Grounded Theory methodology.

**Method.** Fifty general practice patients without major current mental health or recreational drug abuse problems were interviewed at home using a flexible interview schedule. Subjects' accounts of taking prescribed treatments were verified where possible by tablet counts or case-record review, six interviews being excluded as unreliable. Medication use was discussed for 159 prescribed treatments of which 34 were reportedly not taken as directed.

**Results.** The analysis is presented as a model of decision making which suggests that: (i) knowledge (about disease and treatment) combined with faith in the doctor produces the motivation to start using medicines; (ii) most patients test a medicine before accepting it fully; (iii) three types of medicine user exist: those who (a) passively accept treatment advice, i.e. try to take the medicine as they perceive the doctor wants them to, (b) actively use medicines, i.e. take it as they decide they want to, and (c) reject medication altogether; (iv) the process of accepting a treatment is closely linked to accepting the illness; and (v) practical problems are a late obstacle which only play a small part in the process.

**Conclusions.** These concepts have been organized within a comprehensive model of the decision-making process, which is discussed with reference to other current theories of medication use. Researchers and clinicians must move beyond compliance when assessing or trying to improve medication use. Making the medication-testing process explicit is proposed as one way of assisting patients to use treatments better.

**Keywords.** Adherence, compliance, medication use, primary care.

## Introduction

Prescribed medication is a central pillar of modern primary care and accounts for 10% of NHS expenditure in Great Britain.<sup>1</sup> Yet 14.5% of patients do not redeem their prescription,<sup>2</sup> and only around 60% of treatment is taken as prescribed.<sup>3</sup> To date, research on 'compliance' has been based on the professionals' agenda, tending to blame patients and failing to provide a sound understanding of the problem. Recent reviews

have highlighted the lack of successful management strategies available.<sup>4-6</sup> We remain unsure how to tackle patients who do not take their medicines sensibly even when the consequences, such as transplant rejection or leukaemia relapse, are severe.<sup>7,8</sup> One authoritative review has recently highlighted the need to move beyond the belief that patients should 'comply' or even 'adhere' to treatment regimes.<sup>6</sup> It is suggested that the roles and responsibilities of patient and prescriber must change to allow for a more constructive 'concordant' relationship to be established. This paper, using insights gained through patient interviews, will argue how this may be achieved within general practice.

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## Method

We aimed to investigate the factors which influence medication-taking behaviour in primary care and the process by which patients decide what to do with a prescribed medicine. The techniques of Grounded Theory were used to explore patients' experiences and rationale for their medication-taking behaviour.<sup>9</sup>

The study had two discrete data-collection phases:

- (i) themed interviews with general practice patients receiving a wide range of prescribed medication;
- (ii) themed interviews with patients who were perceived, by their GP, to operate damaging medication-taking behaviour.

### *Subject selection*

Sixteen doctors were involved in generating the two patient samples. The first was initially randomly selected from those receiving the full range of prescriptions issued, i.e. acute/repeat and single/multiple items. The second sample sought patients whose medication-taking behaviours were perceived, by their doctors, to be 'non-compliant' and causing clinical problems. Patients under 16 years old, those with major mental illness and known drug abusers were excluded.

### *Data collection*

In order to acquire the most open personal accounts of medication use possible, the researcher approached subjects by telephone to explain the study in person and arrange an interview in the patient's home. He introduced himself as 'a researcher from the university'. Interviews focused on current medication use and its relationship to their illnesses before addressing perceptions about their medications and conditions. Interviews were audio-taped and transcribed verbatim, except where tape failure occurred and when one subject did not wish to be recorded (pt 50), in which case immediate notes were made. Lastly, a tablet count or consent to view case records was obtained in order to verify the account given.

### *Analysis*

An iterative analysis of the first 27 interviews led to the development of eight decision-making themes with 39 subcategories.<sup>9</sup> A process of immersion was used to clarify these themes and produce a conceptual model which informed the remaining interviews and analysis.<sup>10</sup> Analysis was triangulated with two experienced researchers.

The initial analysis involved:

- checking and loosely coding the initial interviews in conjunction with two other researchers;
- listing and defining these codes whilst checking further interviews;
- coding relevant sections of text;
- collating the connected coded text;

- reflecting on text content;
- constructing more abstract conceptual categories;
- constructing the model whilst reviewing tapes for disconfirming examples;
- critical discussion about the model;
- refining the model further.

Analysis of the 17 second-round interviews focused on harmful medication use. Using the evolving model, each respondent's account was plotted and contradictory episodes were considered in more detail. The revised model was systematically checked against all original tapes before being accepted.

## Results

### *Subjects*

Initially, six doctors provided details of 50 patients of whom five declined to participate and 16 were excluded, as the elderly on chronic treatment were heavily over-represented. The 29 subjects interviewed included 16 recruited via an acute and 13 via a repeat prescription. Tablet counts provided additional information in 23 instances; in six cases this was not possible (e.g. the therapy was a cream or the course had finished). In 27 cases the tablet count or its impossibility confirmed the interview data; two interviews had to be excluded from the analysis.

Ten doctors provided details of 29 patients whom they considered 'non-compliant' for the second sample. A further 21 interviews were performed; eight patients declined. Case notes confirmed 17 of these accounts; four further interviews were excluded.

The 44 subjects included in the analysis received a total of 159 prescribed treatments. Of these, 108 preparations were taken in a 'compliant' fashion as traditionally defined (within 20%), 28 were taken less than prescribed, 6 taken more often than recommended and 17 were unclassified. The sample contained 24 women; 23 subjects were over 65 years old and 12 lived alone.

### *A Therapeutic Decision Model*

The findings are presented as a Therapeutic Decision Model (Figure 1) which aims to encompass the main influences on patients and illustrate the decision-making process. The model is presented and explained in stages using a single case study as the prime example. Each section is described with supporting quotations and reference to other examples where necessary.

### *Getting motivated*

Patients' motivation depended upon the combination of their understanding of the condition, the treatment and their faith in the doctor.

Jane was a 25-year-old asthmatic who demonstrated two extremes of behaviour, consuming twice the inhaled

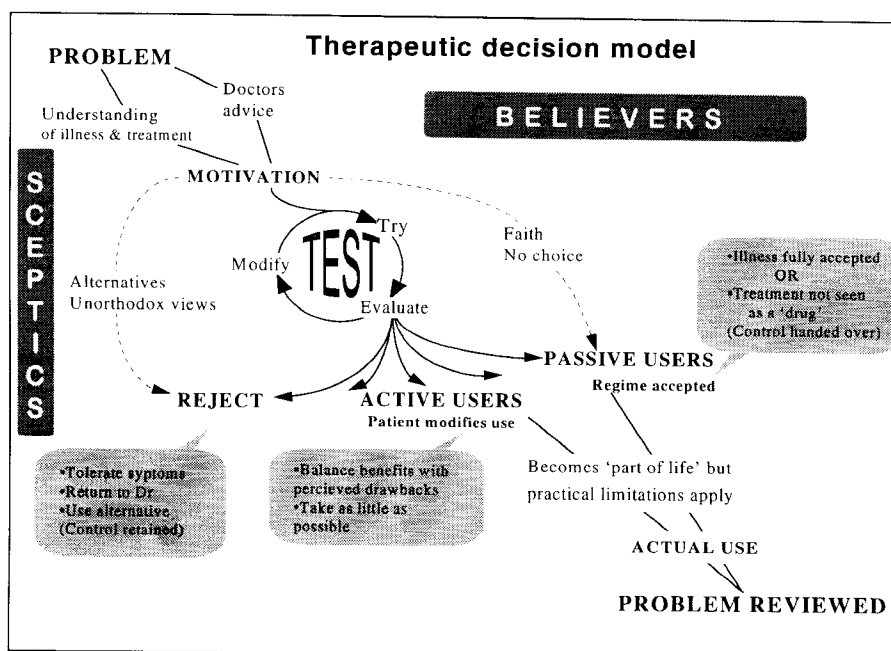


FIGURE 1 *Therapeutic Decision Model*

salbutamol (17 puffs/day) and under half the budesonide and salmeterol (1–2 puffs/day) recommended. In addition she was on the oral contraceptive pill, which she took appropriately.

She had suffered from asthma since the age of two and been hospitalized many times. She found asthma extremely unpleasant, was aware that it could be a life-threatening condition and acknowledged that it had limited her job prospects and social life. She perceived it as such a problem that she would pay 'whatever I could afford' or risk death during surgery if a lung transplant could cure it. Her partner would be willing to swap having children or 'offer a pound of flesh for it'.

Her understanding about asthma and her medication, based on her and her family's experience provided motivation to 'fight it' but not with the recommended therapy:

Jane: "Well basically the first stage of Asthma, so I've been told. I've to get an overproduction of glut and phlegm which gets into your lungs and blocks up all your tubes and then they start to narrow and you become wheezy." (pt 38/para 48)

Jane: "No, it's basically with my asthma I would say. The Ventolin's there in case of an emergency so I don't panic, I know it's there. It's just basically the overall fight is against my asthma and not letting it win on top of me. I know my Ventolin's necessary but sometimes you think there's always steroids if it's to be absolutely necessary." (pt 38/para 416)

She does not have great faith in her current GP's advice whose management she is ambivalent about:

Jane: "He's just a bit laid back about it all and he's quite happy just to stack you full of drugs. If you've got a problem, we'll give you something for it sort of thing. I prefer just to fight it more." (pt 38/para 557)

Faith helped patients to accept the doctor's view and could provide adequate motivation in itself for some patients, usually the elderly.

#### *Does it work? Test it*

Subjects had very clear opinions about the value of their treatments. These had been established through an explicit or subconscious testing process, and frequently influenced decisions about how a therapy was used. For instance, Jane, through subconscious testing, knew that her inhalers worked for her:

Interviewer: "And what was the bit about you saying . . . that you get bad if you don't take them [inhalers subject called steroids] for a few days?"

Jane: "Yeah if . . . you do recognize it, that you are a lot wheezier if you forget to take them. You notice a difference right away. It's like if you go away for a weekend or that and you forget them by the time you come back you're, you're a lot wheezier." (pt 38/para 166)

Another subject, Mrs R, used an explicit test despite having a good relationship with her doctors. She

suffered systemic lupus erythematosus for some years before trying to manage without her steroid therapy. Following this event, Mrs R described her steroids as her 'lifeline'. She was committed to the regime prescribed for steroids, though not for all preparations.

Mrs R: "Prednisolone, I felt that I could be off them, I thought you know I was feeling well at the time I didn't need to be taking this lot and, I wasn't adamant that I was coming off them, but you know, I more or less said to my doctor at Ninewells, the consultant and my doctor here, 'I really want to get off of these steroids' and err I mean I did it, they knew I was doing it but it didnae work and I mean I had to go back on them. I was off maybe about 6 months, I mean I was losing weight rapidly, I mean I lost maybe 3 stone in as many . . . less than that months you know." (pt 3/para 42)

Those on long-term treatments commonly tested out their therapy before accepting it. How it was tested depended on the patient's understanding of its function, e.g. an analgesic with a short-term, symptomatic effect can be easily assessed. An anti-hypertensive may be stopped with no symptomatic consequences. Unless blood pressure measurements are understood and seen as important then these tests may be misinterpreted. Some treatments are not monitored and have no symptoms by which they can be assessed, e.g. Didronel for osteoporosis (pts 8 and 15) or low-dose aspirin (pt 29). These were taken primarily in response to the doctor's advice but were still tested by conferring with other doctors or other sources of information such as friends or the media. Patients needed to know how to assess a treatment effect appropriately, otherwise they selected their own measures.

Medicines were taken within perceived limits. These were read from labels, dictated by doctors or established by experimentation. Although an upper limit was usually clear, subjects tended to establish their own lower limit, often through a testing process (pts 8, 23, 34, 38, 42, 45 and 47).

### *Reaching a decision*

Three categories of response emerged from the study patients. These were to reject, passively accept or actively modify the prescribed regime.

Jane was faced with a dilemma. To fully accept the recommended regime challenged her fight against asthma. Accepting treatment required a loss of autonomy or change in self-image which implied a failure or weakness on her part. Accepting treatment, especially long-term treatment perceived as powerful, required an acceptance of the illness. More treatment implied greater illness, not better care.

Interviewer: "You've mentioned this word lots of times but this is you isn't it, this is part of your character, this fight against your asthma?"

Jane: "Oh always, it's just the way my dad's brought me up 'cause he lost his brother through asthma, he had a bad heart attack through asthma so since then he's always told everybody to fight it. . . . So I think it gives you more of a chance if you're willing to fight what you've got." (pt 38/para 407)

This fight translated into a reluctance to use inhaled steroids, which she saw as the more powerful of her medicines. Consequently she was continually attempting to reduce the amount she consumed (also her long-acting inhaled beta-2 agonist, salmeterol, which she believed to be another steroid), despite the fact that she knew these improved her condition:

Jane: "It's just the way I've been brought up by my dad, like I said, it's just always fight it. He's never . . . it's just his attitude you never give in to anything, if you can help take as little as you can if you can get away with it."

Interviewer: "So would . . . would taking it, you know, regularly twice a day, would that be giving in?"

Jane: "If I'm bad no. Well in the summer when I'm feeling . . . I say what's the point 'cause I feel fine. It's hard to explain. If you're feeling good you don't need to depend on them. I think it's just having to depend on something all your life day in day out." (pt 38/para 328)

Patients could retain some control by becoming active users, modifying the regime as they perceived it suited best. Those who fully accepted the regime as prescribed assumed a more passive role and relinquished control to their doctor.

The barriers to accepting a drug could also be overcome by considering it as trivial or harmless, and therefore not a sign of illness. Medicine that was perceived to be weak was seen to be safer to use. This was demonstrated by subjects omitting to mention some long-standing therapies such as the pill or 'the wee white ones', which seemed no longer to be viewed as drugs. Jane saw salbutamol use, even to excess, as being less damaging than steroids. She accepted salbutamol, making it a part of life by denigrating its significance:

Interviewer: "What about the Ventolin are there any problems that you're aware of with that?"

Jane: "It's not such a strong inhaler. It doesn't have a long-lasting effect on your body. All it does is it opens your lungs up so you can get a breath when you're panicking. It doesn't stay in your

body for a long length time like a steroid inhaler does.” (pt 38/para 463)

The sentiment ‘I don’t take medicines unless I have to’ (pt 5/para 64) was commonly expressed. Subjects did not like taking drugs. It was apparent in many instances that taking treatment signified illness. The higher the dose or the perceived potency of drugs the greater the reluctance to consume them. Alternatively, illness acceptance could be assisted by the medication-testing process, for instance for Mrs R, whose test convinced her of the need for steroids.

#### *Making treatment ‘part of life’*

Once a treatment was accepted it became part of life, built into the daily routine and was no longer an issue. Practical problems would be overcome. For instance Jane kept one inhaler warm on cold days when working outdoors to prevent them freezing up. Recall was not the problem as her partner’s regular prompts were ignored. Others struggled, particularly to recall what they had already taken and resorted to elaborate laying-out routines to prevent overdosing.

#### *Reviewing the problem*

In Jane’s case she perceived her situation to be acceptable, though her GP was unhappy. There was little likelihood of her current doctor influencing her behaviour as she had little faith in his advice. Only when she accepted the true nature of her problem or understood better the mode of action of her inhalers could she fight her disease by appropriate active use of her medicines.

Medication use was not static. Patients’ symptoms, knowledge and attitudes changed, which sometimes led them to review their medication use, the cycle being re-entered when new information or treatment required evaluation.

#### *Sceptics and believers*

Patients sometimes bypassed the testing process. For example, some people do not accept the validity of the Western medical approach. Jim was recruited because he declined to use a non-steroidal anti-inflammatory preparation for a muscular strain, but happily took arnica, a homeopathic remedy, instead. He used doctors to ensure a serious diagnosis was not missed, then applied his own management. His scepticism extended as far as not having his children immunized.

Jim: “I went to the GP about, oh I can’t think what it was . . . anyway basically because there was some problem that I was aware of but I didn’t know what was causing it. Go and get diagnosis, find out what it is . . . now there’s been several times when where its ah bacteria, virus, whatever, something causing the problem so ‘I can give you a prescription for such and such for it’. My

response is ‘Well what’s going to happen if I don’t take anything’, and ‘oh . . . it’ll probably clear up’ . . . but the usual response is ‘but I’ll give you this anyway and that’ll make sure’. So in that case I would actually take (accept but not cash) the prescription and wait for two or three days to see if it does clear up ha ha.” (pt 46/para 8)

The balance between faith in the doctor and an understanding of the disease process or treatment varied widely. Some patients would almost blindly follow advice, reporting ‘I take my treatment religiously’. Most of these believers were elderly. For them an explanation or test was superfluous, for instance for Ethel, aged 71:

Ethel: “Well I feel if you don’t [comply] what’s the point in going to the doctor? If you’re not going to take whatever they give you, I mean you’re wasting the doctor’s time, you’re wasting your own time. No I, if I had, well if the doctor had said to me when I went for my shoulder you’ll have to go on tablets well I would have taken them, maybe I wouldn’t be keen to take them but I would have taken them.” (pt 15/para 132)

#### *Disconfirming cases*

Two patients were interviewed whose actions proved difficult to match with the proposed model and theirs should be recognized as disconfirming data. They demonstrate behaviours which were, by their own admission, irrational.

One was a 67-year-old man who consumed five times (100 mg) his prescribed dose of temazepam. He knew this drug was potentially dangerous, storing it separately, in a safer place than his other medicines. He acknowledged and openly discussed taking up to twice the amount that had been prescribed, but was shocked when a tablet count revealed the true level of consumption. He responded by returning to his doctor. It appears that he was in a state of denial, genuinely failing to acknowledge to himself how he used his medication (pt 2).

The second was a young insulin-dependent diabetic woman whose management was out of control. She openly discussed her use of insulin on a symptomatic basis, totally ignoring the advice from all doctors. She described herself as a ‘bad diabetic’, but could not motivate herself to change. She knew that she would develop major complications and had a friend who was now blind for the same reason. She knew how she should use insulin, knew it could work because of recent antenatal hospital care and expressed a desire to be better self-controlled. She had faith in her carers, believing they both wanted and knew how to help her. This was reflected perversely in her non-attendance at appointments because she was embarrassed and felt stupid. Her irrational medication use cannot be explained by the model presented: her explanation was ‘laziness’ (pt 50).

## Discussion

Qualitative methods have been recommended to explore people's beliefs and motivations for medication taking.<sup>4-6,11</sup> These methods offer the potential to understand why this has remained such a puzzle despite thousands of papers on the topic. However, their application needs to be considered critically.

Interviews and pill counts have been found to overestimate medication use, questioning the accuracy of the 44 accounts given.<sup>12,13</sup> However, the published data stem from trials in which subjects probably knew (rarely reported) their medication use was being studied. Some behaviours witnessed in these trials were bizarre, e.g. pill or inhaler 'dumping' prior to clinic visits, so it must be questioned whether these apply to normal practice. One value of qualitative methods lies in the potential to encourage honest responses, whose meaning is clarified through discussion. In this study, official accounts often gave way to more open discussion as the interview progressed. As the six subjects whose accounts could not have been true were excluded, it is suggested that the analysis is based upon accounts which are as accurate as reasonably possible and reflect how subjects believed they were using medicines.

The subjects were recruited through a wide range of practitioners with differing practice characteristics (e.g. rural/urban, single-handed/group practice) and were purposefully selected to include as wide a range of prescription recipients as possible. Access was carefully negotiated by the researcher in order to minimize the risk of being associated with their GP, and the medical status of the interviewer was not volunteered. A non-judgemental approach was used throughout which frequently succeeded in accessing details deliberately hidden from the doctor. The contrast between an open, unthreatening relationship with a researcher (who was often assumed to be a doctor) and the patient's GP must be highlighted. Patients felt obliged to play their part, to 'comply'. The doctor-patient relationship did not encourage openness or the establishment of a concordant approach to therapy.<sup>6</sup>

This study focused on the patients' perceptions and could be seen as excluding that of the doctors. The main researcher's medical training balanced this within both interviews and analysis, and may explain why the final output became based around a clinically applicable model. The analysis was challenged by two non-medical researchers.

The model of medication-taking behaviour developed from these data fits with many theories described previously. However, the concepts of patients testing, and becoming passive or active users, are novel. The model is able to accommodate apparently contradictory behaviours as well as unify a number of theoretical models, and so indicates future avenues of research.

For instance, how can clinicians distinguish those who will passively follow their guidance from those who will manage their medication themselves; or can the testing process be used therapeutically to establish better medication use?

The Health Belief Model is relevant to the establishment of motivation.<sup>14</sup> The balancing of perceived vulnerability, seriousness, benefits and drawbacks of treatment is part of this process. Assessing medication, however, depends upon appropriate knowledge and understanding. Attribution Theory, which suggests that beliefs stem from related past experiences, supports the importance of information sources other than the doctor.<sup>15</sup> However, those with considerable faith in their doctor accepted their explanations more fully and sometimes took treatment solely on the doctor's advice. Establishing the balance between faith in the doctor's advice and relevant understanding for each individual should form part of the prescribing process. Future research should consider how doctors should tune their intervention to best effect.

The Locus of Control Theory suggests that the balance of control over an individual's health is important.<sup>14</sup> This correlates with passive/active medication users found in this study. Passive use required control to be relinquished. Active use allowed patients to retain control by managing their medications. However, medication taking signified illness for patients, some choosing to minimize the amount of drug consumed at the expense of suffering symptoms or risking complications. This has been reported previously in asthmatics and diabetics, but appears to apply widely.<sup>16,17</sup> This conflict may be a central barrier to any 'compliant', or even 'concordant', medication use, a stark example being the estimated 80% of renal transplants rejected because immunosuppressant therapy is not taken.<sup>7</sup> This study, although conducted on subjects with lesser ailments, would predict that patients will attempt to deny their illness and can symbolically do so by reducing or stopping treatment. Emphasizing a drug's importance could, paradoxically, reduce the amount taken. Whilst problem-free, their own experience, which counts above advice from professionals, would reinforce this pattern of use. Understanding the symbolic role of medicines and how illness challenges an individual's identity are key to addressing these issues.

The various testing methods described concord with Leventhal's Self-regulatory Model.<sup>18</sup> This emphasizes the ongoing, cyclical nature of the evaluation process and the need for a medication-taking behaviour to be coherent with the patient's beliefs and biologically valid if it is to succeed. However, the authors' experience of assisting patients in performing their own treatment tests suggests that this may be a powerful tool for improving medication use. Supervised tests could be used for symptomatic conditions such as asthma or monitorable conditions such as hypertension to convince both

patients and doctors which level of treatment is necessary. When it is not clinically appropriate to test, e.g. in the case of immunosuppressants, it must be recognized that many patients will none the less attempt to do so, as they have a powerful drive to minimize treatment use. Indeed, the more powerful the drug, the more its importance is emphasized and the stronger may be the desire to reduce it.

Some patients have always rejected what is seen as 'sensible' medical advice. The Royal Pharmaceutical Societies report, *From Compliance to Concordance: towards shared goals in medicine taking*, places greater emphasis on an outcome which concords with both the patient's and the prescriber's objectives.<sup>6</sup> Accepting that patients will inevitably decide how to use their therapy would be a considerable advance. Acknowledging this will empower patients, encourage concordance and help establish truly patient-centred care.<sup>19</sup>

The model presented has been developed solely from the 44 interviews analysed, and will not encompass every situation. To establish its validity or potential for improving patient care, it must be tested further. However, the impact of new prescribing methods should be evaluated in terms of patient satisfaction, safe medication use, clinical outcome and perceived quality of life, rather than compliance.

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