PREDICTING COMPLIANCE WITH NEUROLEPTIC MEDICATION:

Developing clinically useful scales

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Abstract

The aim of the study was to determine the attitudes of patients towards neuroleptic medication in relation to compliance, in order to develop a measure that will allow clinicians to predict likely compliance difficulties.

A catchment area sample of 106 adult schizophrenics completed three new self-report measures, a rating scale of attitudes to medication (Drug Attitudes Scale - DAS), a scale based on the theory of planned behaviour (Theory of Planned Behaviour Scale - TPB) and a measure of compliance with medication (Drug Behaviour Scale - DBS). Keyworkers rated compliance, using an established measure (the Kemp Scale).

Three reliable variables from these scales were renamed positive, negative and conditional positive attitude and together named the Drug Compliance and Attitude Scale (DCAS). The DCAS predicted both keyworker (Kemp) and self-report (DBS) measures of compliance. The DCAS had modest concurrent validity and was superior in predictive power to the most popular established scale.

The non-compliance reported by patients was found to be mostly because they changed the time they took the medication rather than because of changing dosage and involved increasing as well as reducing frequency. Reasons for deviation from prescription included active manipulation of subjective state as well as passive non-compliance.
It has been shown that compliance with neuroleptic regimes is a complex set of behaviours which involves more than simply taking or not taking medication. Future research on enhancing compliance among this patient group will need to consider the complex nature of both attitudes to medication and behavioural responses.

Clinical implications of the study include the use of the DCAS to enhance compliance, to identify those patients for whom the medication may not be effective and to evaluate treatments combining drug and psychological interventions.

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Chapter 1

Introduction

1.1 Overview of introduction

This introduction begins with a psychological critique of the construct of schizophrenia, in order to set the context for the remaining discussion of research which is set within a medical paradigm. Next, the research to date on compliance with neuroleptic medication is reviewed, with special attention to the new research on subjective appraisal of medication by patients. After this the usefulness of the theory of planned behaviour for predicting compliance is examined. In the final section, potential predictor variables are proposed, drawn from subjective appraisal research and from theory of planned behaviour constructs.

1.2 Schizophrenia and antipsychotic medication

1.2.1 *Schizophrenia*

In 1962, Thomas Kuhn published an analysis of scientific enterprise over several centuries. His central ideas included the importance of the social scientific community, using the word paradigm to describe the body of knowledge which is acceptable to and acknowledged by the community at any given time. Over the years, paradigm shifts might occur, caused by multiple factors which together create a critical mass for change.

The relevance of this analysis to a psychological study involving the concept of schizophrenia is that the concept itself may usefully be viewed as the product of such a paradigm. As such, the thinking underpinning the concept follows somewhat different rules and criteria for acceptability than the dominant scientist-practitioner paradigm in Western psychology. This clash of scientific philosophies has produced certain difficulties for psychologists approaching psychiatric models, which will be briefly explored here.

The study of schizophrenia attracts enormous funds and a large volume of publications on the topic continue to appear every year. Most of these publications take the concept of schizophrenia for granted. Sarbin & Mancuso (1980) surveyed the Journal of Abnormal and Social Psychology for the years 1959 to 1978 and found that 374 papers totalling 2,742 pages

or 15.3 per cent of the journal space used the presence or absence of a diagnosis of schizophrenia as an independent variable. The trend over that period was for the proportion of papers devoted to schizophrenia to increase.

The central question for psychologists is whether the concept of schizophrenia is useful for scientific or other purposes.

Mary Boyle (1990) analysed the original work of Kraepelin and Bleuler. Medical research, she claimed, like all research, is concerned with the valid description of patterns or regularities. Unobservables (electricity, atoms, intelligence, learning) are usually inferred from these patterns. In psychology, one type of unobservable is the hypothetical construct and two conditions must be met if it is to be claimed as valid. Firstly, it must be derived from an observed pattern; this pattern then becomes the criterion for inferring the construct. Secondly, the construct must lead to new observations (e.g. Trisomy 21 (Down's syndrome) as a construct lead to the observation of chromosomal abnormalities). The necessary condition for asserting the validity of a hypothetical construct is that it be derived from a pattern, the sufficient condition is that the construct leads to new observations. The language of medicine tends to obscure the process of concept formation by talking of new diseases being 'discovered' which people are then said to 'have'.

The claim by Boyle was that Kraepelin, Bleuler and later Schneider have all failed to reliably observe patterns and that no new observations have stemmed from the construct of schizophrenia despite almost 100 years of effort and vast amounts of money poured into research.

In 1990 Bentall pointed out the poor predictive validity of the diagnosis of schizophrenia in terms of outcome, response to treatment and aetiology. The outcome of schizophrenia diagnosis appears to be largely a function of social, rather than biological variables Barham & Hayward (1990).

Claridge (1990) outlined a substantial body of evidence to show that the simple distinction between normal traits and schizophrenia is a false one and that the tendency towards psychotic behaviour is distributed along a series of continua which connect 'madness' to ordinary mental life.

The conclusion would seem to be that the assumption that forms of 'madness' can be subdivided into discrete diagnostic groups (for example those in DSM IV) "must be rejected as scientifically and practically useless" (Bentall, 1990, p. 284). People called schizophrenics seem to be a highly diverse group showing little in common. This leads to the further conclusion that studies comparing one group with a diagnosis of schizophrenia with another deemed 'normal' amounts to "the comparison of one group of people who in all probability have nothing in common with another group of people who also probably have nothing in common" (Bentall. 1990, p.293).

Alternative research strategies are recommended by Bentall (op. cit.) and others in the volume Reconstructing Schizophrenia, for example studying symptoms such as hallucinations and delusions; the study of schizotypal traits in normal individuals; exploring the illness careers of schizophrenic individuals. Yet the Medical Research Council of Great Britain (MRC, 1988) and the National Institute of Mental Health in the U.S. (Keith & Matthews, 1988) place major emphasis on prioritising neurobiological investigations, with until recently only the latter organisation giving some little acknowledgement to psychosocial factors.

The term 'negative symptoms' is used quite frequently in the literature and tends to mean deterioration or deficit in cognitive function, poverty of speech, lack of motivation, social withdrawal, lethargy and similar symptoms. It is contrasted with the 'positive symptoms' of delusions, hallucinations and thought disorder and much has been made within psychiatry of the debate about two types of schizophrenia (Crow, 1985). There is a lack of clear understanding about what negative symptoms are or how they are related. Although Andreasen (1979) has published reliable scales for their assessment, factor analysis by Gibbons, Levine, Davis, Schooler & Cole (1985) indicated three separate components. It was noted by Andreasen (1979) that there was confusion as to whether there really is an identifiable negative syndrome. Hallucinations, a 'positive symptom', occur widely in the normal population (Romme & Escher, 1989), do not always cause distress and are variously culturally interpreted (Al-Issa, 1978).

The terms positive and negative are subject to the same criticism as the schizophrenia construct itself.

The more radical psychological thinking about the construct of schizophrenia and its usefulness has been presented in an attempt to counterbalance what follows, since most of the research quoted and thinking discussed is couched within the medical paradigm and reflects medical ways of thinking. Rather than introduce caveats all along the route, I hope the reader will regard this discussion as the 'pinch of salt' with which all the rest should be taken.

Lengthy discussion has been avoided about 'positive' and 'negative' symptoms, genetics, neurobiology and classification systems, because the research is vast, confusing and overwhelmingly inconclusive. The reasons for this may lie in the deficits of the construct and the heterogeneity of the group.

These points are put forward not in order to dismiss all organic approaches to schizophrenia, but to argue for an informed and cautious approach to the literature and the maintenance of an open-minded attitude to all sources of information.

1.2.2 *Anti-psychotic medication: neuroleptic drugs*

1.2.2.1 *Classical and new neuroleptics:* One of the most important tasks for the physician in the treatment of schizophrenia with drugs is to maximise the antipsychotic response while reducing side effects.

The original National Institute of Mental Health trials of neuroleptics found treatment with this class of drug reduced both positive and negative symptoms (Cole, Klerman & Goldberg, 1964).

Neuroleptics are often divided roughly into two types. The first group, referred to as 'classical' or 'old' neuroleptics include the very first drugs discovered and represent the largest group of drugs available on the market. Depot, or injection, forms are available which are not currently available for newer neuroleptics.

Classical neuroleptics have side-effect profiles generally characterised as extra-pyramidal in nature and referred to as EPS (extra-pyramidal side effects) in the literature. The drugs act by binding to

dopamine receptors in the brain. There are currently thought to be five types of dopamine receptors with older neuroleptics found to block the D2 sites in particular (Farde, Wiesel & Nordstrom, 1989).

The site of drug action being dopamine receptors was a fact influential in the general 'dopamine hypothesis' of schizophrenia which has been through several transformations, one notable version being by Crow (1985) who put forward the 'two-syndrome hypothesis' of schizophrenia based on the dopamine connection: Type I schizophrenia with positive symptoms, dopamine - related pathology and favourable neuroleptic response; Type II with negative symptoms, pathology unrelated to dopamine and poor neuroleptic response. However, the literature in general supports the view that neuroleptics are effective for both types of symptom, positive and negative (Pickar, Owen & Litman, 1991).

A drug called clozapine, one of the group of newer or 'atypical' neuroleptics, was trialled in several European countries during the 1970s, but in 1975 a group of 13 Finnish patients developed severe blood disorders and eight died (Naber, Holzbach, Perro & Hippius, 1992). The drug was withdrawn from use. This experience, combined with the never-ending search for confirmation of the dopamine hypothesis, seems to have retarded the trials of drugs which act on a wider range of transmitters.

During the 1990s several drugs have come into regular use (e.g., respiridone, olanzapine, clozapine) at first under restricted conditions but more recently for general prescribing, which act not only on dopamine receptors but also on 5HT sites (affecting serotonin levels in the synapse) and in some cases on alpha sites (adrenergic receptors). This wider range of action appears to be associated with significant improvement in both positive and negative symptoms without EPS (at the correct dosage) and with beneficial effects on pre-existing tardive dyskinesia (Carman, Peuskens & Vangeneugden, 1995; Chouinard, Jones, Reminton, Bloom, Addington, MacEwen, Labelle, Beauclair & Arnott, 1993; Marder & Meibach, 1994a).

The advent of the new neuroleptics has been welcomed by Lindstrom (1994) and Naber *et al.*(1992). Both assume that EPS and affective and cognitive impairment associated with old neuroleptics are a major cause of non-compliance and are hopeful that better quality of life is

on offer for people with schizophrenia, associated with improved compliance.

1.2.2.2 *Side effects of neuroleptics:* The symptoms classed as extra-pyramidal side effects (EPS) include dystonia or involuntary muscle spasm (with prevalence reports from 10 per cent (Swett, 1975) to 64 per cent (Chiles, 1978)); akathisia or inability to sit still (prevalence from 20 to 75 per cent) (Braude, Barnes & Gore, 1983; Van Putten, 1975); parkinsonism or rigidity and tremor (15 to 35 per cent) (Marder & Meibach, 1994b); tardive dyskinesia or involuntary repetitive movements involving facial and other muscles (prevalence rising from five per cent after one year to 20 per cent after four years) (Kane, Woerner, Borenstein, Wegner & Lieberman, 1986). No generally effective treatment is available for tardive dyskinesia (Whitworth & Fleischhacker, 1995) and women and older people are more affected (Kane & Freeman, 1994). Cognitive and emotional parkinsonism is a term quoted by Lindstrom (1994) meaning rigidity of thought and affect which reduces motivation, tolerance for change and employability.

Classical neuroleptics can also produce a rare but potentially fatal condition leading to stupor and coma known as neuroleptic malignant syndrome, with prevalence reported from none at all to 2.2 per cent (Hermesh, Aizenberg, Weizman, Lapidot, Mayor & Munitz, 1992; Keck, Pope & McElroy, 1991; Modestin, Toffler & Drescher, 1992). Up to 10 per cent of chlorpromazine takers show photosensitive blisters and rashes (Baer & Harris, 1967; Bernhard, Pathak, Kochevar & Parrish, 1987) often in conjunction with parkinsonian symptoms (Binder & Jonelis, 1983). Opthalmological effects leading to obscured vision have been found with chlorpromazine (Bond & Yee, 1980) and thioridazine (Hamilton, 1985; Meredith, Aaberg & Willerson, 1978).

New or atypical neuroleptics do not carry these side effects but have their own side-effect profile including anticholinergic effects, which can be transient, such as dry mouth and hypersalivation, sweating and temperature regulation inhibition, blurred vision, constipation and sexual dysfunction. ECG alterations and increased arrhythmia may occur (Patterson, Pittman & Willis, 1983). Orthostatic hypotension causing falling in older women has a 41 per cent incidence in the first three days of treatment (Jefferson, 1974).

Both groups of neuroleptics have side effects such as weight gain (up to 38 per cent) (Klett & Caffey, 1960; Leadbetter, Shutty, Pavalonis, Vieweg, Higgins & Downs, 1992) and seizures (0.5 to 1.2 per cent) (Bartels & Heimann, 1985).

The main trials of newer neuroleptics have occurred quite recently (Carman *et al.*,1995; Chouinard *et al.,* 1993; Marder & Meibach, 1994a) and have tended to report on clozapine and risperidone. All have concentrated on treatment-resistant patients (those for whom classical neuroleptics seem unsuitable) who have switched from classical neuroleptics. Discussions of compliance are sketchy in these studies, using anecdotal and retrospective comparisons. Conclusions about improved compliance, (which imply that this results from improved side effect profile), are not warranted as yet and certainly cannot be held to be representative of the whole group of people diagnosed as schizophrenic.

Side-effects of medication is only one of many factors which have been explored as possible reasons for non-adherence to neuroleptic treatment regimes, as discussed in Section 1.3 below. To expect improved compliance because of changed side-effect and effect profile is to make as yet unsubstantiated assumptions about the nature and size of these variables' contributions to non-adherence. Although the side-effect pattern is different it is certainly too early to conclude that compliance with new neuroleptics is assured.

1.2.2.3 *Effectiveness of antipsychotics:* The definition of what may constitute a drug 'response' is controversial, different studies employing different definitions. Using various measures to establish baseline, some studies have used change of at least 50 per cent to define response, others used less change. Recent studies have tended to use 20 per cent reduction of the PANSS (Positive and Negative Syndrome Scale) score as the main criterion (Chouinard *et al.*, 1993; Marder & Meibach, 1994a); In a meta-analysis of research on new neuroleptics, Carman *et al.* (1995) noted that PANSS reduction was used as the main criterion for effectiveness. It should be noted that, although a 20 per cent symptom reduction may be clinically significant, there is no evidence that such a reduction is sufficient or satisfactory for the majority of patients.

In the meta-analysis reported by Carman *et al.* (1995), of 675 patients taking risperidone 56.3 per cent met this 20 per cent criteria in reduction of negative symptoms, compared with 45.8 per cent of patients taking a classical neuroleptic. The Canadian multicentre study by Chouinard *et al.*(1993) does not quote percentages so clearly, however it appears from a graph shown in their paper that around 70 per cent of patients were classed as 'responders' on total (positive and negative symptoms) PANSS.

Thus, the latest research indicates that just over half of patients meet 'response' criteria for negative symptoms and just under three quarters are 'responders' on total symptom score with the newest treatments. Long-term outcomes are not currently available.

Early clinical trials reported larger drug/placebo differences in females than in males (Goldberg, Schooler, Davidson & Kayce, 1966) and women seem to require lower doses of neuroleptics (Seeman, 1983). Gaebel (1989) reported that males may have more negative symptoms, which may be somewhat less responsive to neuroleptics than positive symptoms.

The literature on both effectiveness and side-effects of neuroleptics is fraught with methodological problems. In addition to the discordance between diagnostic criteria discussed in Section 1.2.1, the group of people diagnosed as schizophrenic is heterogeneous, with various classifications of symptoms creating various possible subgroups. It is impossible to tell from current research whether a relationship exists between neuroleptic effects and subtypes of schizophrenia (Awad, 1989; Wolkowitz, Bartko & Pickar, 1990).

Awad (1993) in an overview of methodological and design issues in trials of new neuroleptics focuses on several areas: multicentre trials can increase potential bias while increasing sample size; difficulties recruiting acutely disturbed patients may result in a study population skewed towards mild-moderate severity of symptoms; sex and age differences are often ignored. In terms of design issues, he notes that the lack of sedative and EPS effects in new neuroleptics compared with old can reduced the

'blindness' in trials; it is difficult to determine dose equivalency; trials are often too short (4 to 6 weeks) to yield information on long-term use.

Measurement problems discussed by Awad include low validity of measurement tools; a need to "objectify" clinical observations; omission of quality of life measures; inattention to therapeutic relationship and subjective feelings about neuroleptics; over inclusiveness in outcome measures and data collection.

Also, haloperidol is the old neuroleptic with most side-effects, using it as the criterion for comparison may exaggerate the relative benefits of new drugs. All studies seen by the present author use haloperidol as the comparison criterion. As noted above in the discussion on side-effects, sources of bias are present in comparisons of new versus old drugs because 'resistant' patients are recruited to trial new drugs.

Such (great) reservations about methodology notwithstanding, it is clear that while great benefits are available to some, not all schizophrenics benefit equally from medication and some may not derive any benefit from it at all (Davis, Schaffer & Killian, 1980; Leff & Wing, 1971; Prien, Levine & Switalsky, 1977). It has been questioned whether a subgroup of schizophrenics may even deteriorate in some aspects of their functioning (Hogarty, Goldberg, Schooler *et al.*, 1974; Judd, Goldstein, Rodnick & Jackson, 1973; Rappaport, Hopkins & Hall, 1978). Patients taking neuroleptics were questioned by Rogers, Pilgrim & Lacey (1993) who found that 56.8 per cent felt the medication to be very helpful but 27.7 per cent rated the medication as either harmful or very harmful. Davidhizar (1985) noted that some patients held both strongly negative and strongly positive opinions about medication at the same time.

In summary, both new and old neuroleptics have significant and potentially distressing side-effects. Neuroleptics are not effective for every patient and may cause worsening of symptoms for some. The '20 per cent rule' used to define drug effectiveness is not based on any information about patient satisfaction or quality of life improvement.

Some non-adherence behaviours may be seen as perfectly rational in the light of this background.

1.3 The problem of compliance

1.3.1 *Defining, measuring and comparing non-compliance levels*

The variety within reported rates of non-compliance amongst schizophrenic patients arises from differences in definition, measurement, and in population and treatment settings.

1.3.1.1 *Defining non-compliance:* It has been noted that 'non-compliance' can refer to many things (Blackwell, 1976), including failure to enter treatment, premature termination of treatment, and incomplete implementation of medical instructions. It has also been defined in terms of attendance at out-patient clinics, the promptness with which a patient seeks care, the degree to which the patient adheres to medical instructions, and willingness to remain in hospital after admission (Buchanan, 1996). Compliance with medication is inherently difficult to define.

Most researchers have proposed that patients are either compliant or non-compliant. This dichotomy creates the problem of defining the cut off which separates 'compliant' from 'non-compliant'. Across the studies conducted to date, many different ways of assigning individuals to compliant and non-compliant groups have been adopted. For example, Budd *et al.,* defined non-compliant patients as "those who had failed to attend and/or accept medication for one third or more of all scheduled appointments" over a twelve month period (1996, p.394), whilst Giron & Gomez-Beneyto opted for those patients who took "less than 75 per cent of the prescribed dose during one month, or the treatment was interrupted for one month or more" over a nine month period (1995, p.366).

A more fruitful approach than using a dichotomous definition may be to consider a patient's level of compliance along a continuum. Blackwell (1976) and Haynes (1976) both view compliance as being the extent to which the patient's behaviour coincides with medical advice. Non-compliance could similarly be defined in terms of deviation from prescribed treatment.

1.3.1.2 *Measuring compliance:* Direct methods of measuring compliance include analyses of blood and urine samples. Such methods prove to be expensive and inconvenient. Patient consent is often difficult to

obtain, particularly amongst non-compliant patients (Buchanan, 1996). Urine tests may over-estimate compliance when drugs have a long half life (Churchill, 1985), whilst serum assays are of limited value in assessing partial compliance (Babikar, 1986). All such direct methods are limited by the large inter-individual metabolic variations which exist (Dahl, 1986; Jann, Ereshefsky & Sahlad, 1985). Weiden, Dixon, Frances, Appelbaum, Hads & Rapkin, (1991) assert that whilst direct methods can reveal whether a patient has had recent exposure to neuroleptic medication, longitudinal data cannot be established.

Indirect methods which include physician's reporting, patient's reporting and tablet counts are easier to apply and more common, but not without limitations. Doctors are often poor judges of patient compliance (Gordis, 1979), whilst concerns are always raised over the reliability of self-reported compliance levels (Buchanan,1996; Weiden *et al.,* 1991).

Schizophrenic patients often lead disorganised and chaotic lifestyles, which may impact upon their ability to report upon their actions (Weiden *et al.,* 1991). The schizophrenic symptoms may interfere with the patients' ability to report compliance (Weiden *et al.,* 1991), and research suggests that patients may exaggerate their levels of compliance (Gordis, Markowitz & Lilienfield, 1969; Park & Lipman, 1964). To carry out tablet counts, schizophrenic patients are required to have high levels of organisation which may be beyond their capacity (Weiden *et al.,* 1991). There is no assurance that what has left the prescribed supply of tablets has been taken by the patient (Blackwell, 1976).

Measures of compliance are not consistent with each other, casting doubt on the validity of such approaches (Bergman & Werner, 1963; Gordis *et al.,* 1969; Park & Lipman, 1964). Ideally, measurement of compliance should involve the simultaneous use of various measures to correct for the limitation of any single measure (Weiden *et al.,* 1991).

1.3.1.3 *Population and treatment setting differences:* There is great variation amongst the treatment settings and patient populations used in the studies described in the published literature, making it extremely difficult to draw any conclusions from across the evidence to date. Different sampling methods have been used within the research (O'Shea, 1995). Comparisons

between studies involving patients from different settings makes no sense (e.g., comparing compliance rates in voluntary private hospitals with rates in forensic units). Concerns surrounding the treatment settings and patient populations used in the research to date are discussed further below (see Section 1.3.6).

1.3.2 *The consequences of non-compliance*

Despite problems with effectiveness, failure to comply with neuroleptic medication is seen as creating adverse consequences for patients, their carers, health services, and indeed the public at large. Non-compliance with neuroleptic medication has been reported to prolong psychoses (Mason, Forrest, Forrest & Butler, 1963), to cause sufferers to experience unnecessary levels of symptomatology (Budd, Hughes & Smith, 1996), and to increase the likelihood of relapse (Forrest, Geiter, Shaw & Steinbach, 1964; Johnson, Pasterski, Ludlow, Street & Taylor, 1983; Krucko, 1978), and frequent hospitalisation (Green, 1988; Kane, 1989). Neuroleptic non-compliance may increase the levels of stress upon the family members and carers who supervise and care for the affected schizophrenic patient (Budd *et al.,* 1996; Fadden, Bebbington & Kuipers, 1987). Relapses and hospital re-admissions are described as the revolving-door phenomenon (O'Shea, 1995), entailing great public expense (Bebbington, 1995; Green, 1988). Compliance in community settings may not be supervised as closely as in hospitals (Corrigan, Liverman & Engel, 1990). Non-compliance with neuroleptic medication may increase the potential for violence in the community (Tanay, 1987).

In summary, failure to comply with neuroleptic medication is seen as the cause of significant public health problems which have increased over the past two decades with the move from hospital to community care. This viewpoint does make the major assumption that if patients did comply, all of the above problems would disappear. This is somewhat simplistic as past research has shown that even with enforced compliance, dysphoric responders have negative clinical outcome (Falloon, Watt & Shepherd, 1978; Hogarty, Schooler, Ulrich, Mussare, Peregrino & Herron, 1979). There are obviously many factors affecting neuroleptic treatment outcome, and it is misleading to attribute all the problems to non compliance.

1.3.3 *The prevalence of non-compliance*

Studies of general medical populations suggest that approximately one third of patients fail to comply with their prescribed medical regimens (Becker & Maiman, 1975; Davis, 1966). Whilst some research suggests that psychiatric patients demonstrate similar compliance rates to general medical populations (Barofsky, 1977; Marston, 1970), most commentaries describe a higher prevalence of non-compliance amongst psychiatric populations (e.g., Buchanan, 1996; Connelly, 1982).

There is a great deal of variation in reported non-compliance rates within psychiatric populations. Rates from 18 to 60 per cent have been reported (e.g., Blackwell, 1976; Fitzgerald, 1972; Jamison *et al.*, 1979; Van Putten, 1974). In general, it seems that psychiatric populations show higher rates of non-compliance in comparison to general medical populations.

For schizophrenic patients, rates of non-compliance with treatment (e.g. neuroleptic medication) may be even worse. Whilst non-compliance levels of 40 per cent have been reported (Buchanan, 1992; Hogarty *et al.,* 1973), much research indicates the incidence of non-compliance may be as high as 80 per cent (see Corrigan *et al.,* 1990).

In summary, it is very difficult to estimate accurately rates of non-compliance amongst schizophrenic patients. Findings are not directly comparable and so do not improve our understanding of non-compliance. What is clear across studies is that despite the benefits of neuroleptic medication, high levels of non-compliance exist.

1.3.4 *Predictors of non-compliance*

Many factors which may contribute to non-compliance with prescribed treatments are cited in the medical and psychiatric literature (Blackwell, 1976; Buchanan, 1996). For the purposes of this study, discussion will focus upon the predictors of non-compliance with neuroleptic medication amongst schizophrenic patients. Many of the determinants of non-compliance amongst schizophrenic patients are similar to those within general medical populations (Buchanan, 1996).

1.3.4.1 *Side-effects of medication:* Neuroleptic medication is well known for producing particularly unpleasant side effects such as dystonia,

akathisia, parkinsonism, and dermatological, haematological, opthalmological, cognitive and emotional changes (as described above - see section 1.2.2). The most obvious reason proposed for non-compliance may be the negative attitudes resulting from the frequent and disturbing side effects. This is reflected in much of the research (Falloon, Watt & Shepherd, 1978; Nelson, 1975; Renton, Affleck, Arstairs & Forrest, 1963). An early dysphoric reaction (a severe feeling of discomfort which the patient attributes to the neuroleptics) shortly after receiving medication has been found to be predictive of non-compliance (Van Putten & May;1978; Van Putten, May, Marder & Wittmann, 1981).

However, some studies have cast doubt upon such a conclusion (Willcox, Gillan & Hare, 1965). Interestingly, Irwin, Weitzel & Morgan, (1971) assert that the presence of side effects may improve compliance since patients become aware that the drug is 'doing something'. Additionally, it has been shown that 'placebo side effects' are common in the form of adverse symptoms that cannot be explained pharmacologically (Gutheil, 1982). Such effects may result from a particular meaning the patient attaches to the drug (Guimon, 1995). Whilst an impact of side effects upon levels of compliance is recognised, the direction and explanation of impact is unresolved.

1.3 4.2 *Type of treatment and setting:* As might be expected, higher levels of non-compliance are found among out-patient populations in comparison to in-patient populations (Blackwell, 1976; Hare & Willcox, 1967; Irwin *et al.,* 1971). Clearly the degree of supervision patients receive affects compliance, (see 1.3.4.4 for further discussion).

Freeman (1973) reported that the use of depot medication given as injections improved compliance in comparison with oral medication. Whilst holding face validity, this should be viewed with caution given the surprising lack of research in this area.

The literature supports the view that more complex drug regimes are associated with decreased compliance (Haynes, 1976). It has been noted that complicated treatment directions and schedules and the jargon used by clinicians increase confusion and the likelihood of non-compliance Corrigan *et al.* (1990).

The length of treatment appears to be associated with compliance levels as the views of patients with regard to the treatment have been found to change over time (Seeman, 1974; Stimson, 1974). Wieden, Manevitz & Dixon (1989) report that while 48 per cent of schizophrenic patients are non-compliant within the first year of treatment, 74 per cent are non-compliant within their first two years. Dencker & Liberman (1995) suggest that an indefinite length of treatment with associated pessimism may lead to an increased likelihood of non-compliance.

Compliance levels may be affected by the delivery of medication in hospitals and clinics. For example, Corrigan *et al.* (1990) suggest that the conventional medication call in hospitals ensures that patients do not learn about their treatment, and are unprepared for unsupervised treatment regimes. In addition, Parkes, Brown & Monck, (1962) proposed that patients not being provided with clear instructions regarding clinic attendance, and being requested to arrange their own appointments for after care increases the likelihood of non-compliance. Having to wait a long time to see the doctor has also been associated with non-compliance (Craig , Huffine & Brooks, 1974; Raynes & Warren, 1971). Also, Leff & Wing (1971) reported the anxiety many patients experience whilst in the crowded clinic waiting room as being a reason for non-compliance. Finally, Weiden, Shaw & Mann (1986) assert that patients unable to pay for transportation to the clinic or hospital for medication will inevitably become non-compliant.

1.3.4.3 *Relationship with the prescriber:* The personality characteristics of the prescriber appear to affect compliance and treatment response. Research based upon rates of attendance at out-patient clinics showed that physicians rated as being aware of patients needs, task oriented, and flexible, warm, friendly, and competent, have less drop outs (Baum, Felzer, D'Zmura & Shumaker, 1966; Gibby Stotsky, Hiler & Miller, 1954). However, Howard, Rickels, Mock, Lipman, Covi & Bauman, (1979) asserted that compliance levels are related to what physicians did rather than what they were like, noting that improved compliance levels were attained when patient-prescriber contact had a clearer structure and focus.

Compliance with neuroleptic medication has been found to correlate with the strength of the prescriber's belief in medication, ambivalence on the part of the prescriber being predictive of non-compliance (Irwin *et al.,* 1971). The literature indicates that non-compliance is more likely when patients are not actively involved with the prescriber in the decision making process about medication (Eisenthal, Emery, Lazare & Udin, 1979; Hertz, Bernheim & Perloff, 1976; Schulman, 1979). Successful interaction may depend upon the combination of patient and prescriber characteristics: A combination of the authoritative patient and an accepting physician was reported as predictive of non-compliance by Davis (1968). A lack of rapport and restricted communication between the physician and patient, and lack of friendliness, understanding, concern and feedback on the part of the physician are factors considered by Gillum & Barsky (1974) as contributing to non-compliance.

1.3.4.4 *Patient characteristics:* The most important socio-demographic predictors of non-compliance have been cited as being lower socio-economic status (Buchanan, 1996; Winkelman, 1964), negative attitudes of relatives towards the patient (Gillum & Barsky, 1974), and a lack of family support (Buchanan 1996; Piatkowska & Farnill, 1992). Lack of supervision may be associated with non-compliance; both living alone (Blackwell, 1976) and social isolation (Mason *et al.,* 1963), have been found to be predictive of non-compliance.

The influence of other socio-demographic factors upon compliance is less clear cut. Some studies have found that younger patients are less likely to comply (Davis, Estess, Simonton & Gondoa, 1977; Tunnicliffe, Harrison & Standen, 1992; Zito, Routt, Mitchell & Roerig, 1985), whilst others have found no effect for age (Atwood & Beck, 1985; Buchanan, 1992, 1996). On gender effects, Sellwood & Tarrier (1994) and Tunnicliffe *et al.* (1992) have found that males are less likely to comply, other studies have found that gender has no predictive value (Atwood & Beck, 1985; Baekeland & Lundwall, 1975; Buchanan, 1996). In the same study, Sellwood & Tarrier (1994) have associated non-compliance with ethnicity, whilst other studies have not (Buchanan, 1992, 1996; Tunnicliffe, *et al.,* 1992). Marital status was not associated with compliance in Tunnicliffe *et*

al.'s (1992) study, whilst Altman, Brown & Sletten (1972) found in-patients who were single were more likely to drop out of treatment. Less socially stable patients were found to be more likely to drop out of treatment (Baekeland & Lundwall, 1975), yet Buchanan (1996) found occupational stability not predictive of compliance.

Several studies have found alcohol and drug abuse to be associated with non-compliance among populations with diagnoses of scizophrenia (Caspar & Regan, 1993; Drake, Osher & Wallach, 1989; Salloum, Moss & Daley, 1991; Soni and Brownlee, 1991).

Personal characteristics linked to non-compliance include dependency conflicts and hostility towards authority (Diamond, 1985), and a sense of humiliation about having a chronic mental illness (Terkelsen, 1985). Factors relating to the clinical symptoms of schizophrenia which contribute to non-compliance include grandiose and paranoid delusions (Van Putten, Crumpton & Coralee, 1976; Wilson & Eoch, 1967) and self rated depressed mood (Bossert, Dose, Emrich, Garcia, Junker, Raptis & Webber, 1990).

Relying upon the assumption that past behaviour predicts future behaviour, Buchanan (1992) reported that poor compliance in the past is predictive of future non-compliance. In-patients who were non-compliant were found to be less compliant later as out-patients (Nelson, 1975).

Poor insight or unawareness of illness has been commonly observed amongst schizophrenic populations (Greenfield, Strauss, Bowers & Mandelkern, 1989; Lin, Spiga & Fortsch, 1979; Nelson, 1975; Wilson, Ban & Guy, 1986), and consistently related to non-compliance (Bartko, Herczeg & Zador, 1988; McEvoy, Applebaum, Geller & Freter, 1989; Van Putten *et al.,* 1976). Similarly, denial of illness has been associated with non-compliance (McEvoy *et al.,* 1989; Modzierz, Macchitelli, Conway & Krauss, 1973). There is much debate surrounding the proposed relationship between compliance levels and the degree of knowledge about schizophrenia and its treatment (see Budd *et al.,* 1996).

The literature indicates that negative attitudes towards doctors, hospitalisation and treatment understandably contribute to non-compliance (Hoge, Appelbaum, Lawlor, Beck, Litman, Greer, Gutheil & Kaplan, 1990;

Marder, Van Putten, Mintz, Lebell, McKenzie & Faltico 1984; Rodenhauser, Schwenkner & Khamis, 1987). In addition to such global attitudes, more attention is now being paid to patients' subjective experiences of, and attitudes towards their neuroleptic medication as discussed in section 1.4.

1.3.5 *Improving compliance*

The identified predictors of non-compliance should be addressed when clinicians are aiming to improve compliance levels amongst schizophrenic patients. The following describes some of the interventions which may facilitate treatment compliance (for a fuller discussion see Corrigan *et al.,* 1990; Dencker & Liberman, 1995).

1.3.5.1 *Improving treatment settings:* Kane (1983) and Faraone, Cirelli, Curran & Brown, (1988) have shown that compliance can be improved by establishing low-dose side-effect free maintenance regimes. Improved compliance was demonstrated with a more informal setting by Liberman & Davis (1975). The remaining literature offers advice rather than experimental investigation. This includes reducing waiting time in clinic, giving patient reminders (Raynes & Warren, 1971) and giving refreshments in clinic (Masnik, Olarte & Rosen, 1981).

1.3.5.2 *Improving relationship with prescriber:* A collaborative relationship betwwen patient and prescriber has long been argued for (Corrigan *et al.,* 1990; Eisenthal *et al.,* 1979; Frank & Gunderson, 1990; Piatkowska & Farnill, 1992). Improved compliance has been found when doctors give positive feedback and encourage collaboration (Janis, 1983), Corrigan *et al.*, (1990) suggest this should be encouraged in medical training. Professor Bentall and his colleagues are currently conducting a large Medical Research Council funded project at Liverpool University investigating the efficacy of therapeutic alliance versus compliance therapy. Alliance therapy places emphasis on developing a collaborative relationship with the patient to design the most suitable treatment regime, as opposed to the usual type of intervention ('compliance therapy'), which assumes that compliance is a matter of patients following instructions and is essentially authoritarian in approach. Their prediction is that with greater involvement and empowerment on the part of the patient, both treatment efficacy and compliance will be enhanced (Bentall, personal communication).

1.3.5.3 *Modifying neuroleptic regime:* Suggestions to improve compliance include prescribing atypical neuroleptics (Awad & Hogan, 1994), using depot injections (Gerlach, 1994, 1995), using jargon-free language and repeated instruction (Dencker & Liberman, 1995) and prescribing holidays from treatment to avoid indefinite treatment (Carpenter & Heinrichs, 1983). Targeted pharmacotherapy involves withdrawing patients from their maintenance medication, monitoring clinical state and providing brief drug treatment at onset of signs of deterioration (prodrome) which often occur weeks prior to crisis induced readmission. This, if successful, would have great advantages for compliance levels since only intermittent medication compliance is required. Placebo versus active maintenance therapy were compared by Jolley, Hirsch, McRuik & Wilson, 1989 but they experienced problems with patients withdrawing from the study and with patients failing to identify early warning signs. They concluded that the brief training in prodrome identification received by participants was insufficient. Carpenter, Hanlon, Heinrichs, Summerfelt, Kirkpatrick, Levine & Buchanan (1990) in a similar study had many drop outs, all authors concluding that the high drop out rate was because of the distress experienced by patients and carers as a result of poor symptom control and high rates of relapse leading to readmission. Gaebel Frick & Kopcke(1993) found that maintenance plus targeted therapy was superior to targeted therapy alone which was superior to placebo in terms of therapeutic outcome and relapse prevention. Data on compliance are not reported for these studies. Certainly, simply placing patients on depot injections in response to non compliance is insufficient to address all the problems. As discussed earlier, therapeutic outcome may remain negative, there is a potential reduction in patient empowerment and choice and it is perfectly possible not to comply with depot. A very simple behavioural intervention targetted at adherence to drug regime itself is reported by Boczkowski, Ziechner & Desanto (1985), involving self-monitoring of medication routine and tailoring medication regime to personal habits and routine. This they report to be superior to an educational programme about neuroleptics and the need for compliance.

1.3.5.4 *Educational programmes:* programmes have been designed, aimed at families, to increase understanding of schizophrenia and neuroleptics and

to address negative attitudes and over or under concern (Anderson, Reiss & Hogarty, 1986; Falloon & Faddon, 1993; Guimon, 1995; Pakes, 1979). Kemp, Hayward, Applethwaite, Everitt & David, (1996) devised a four to six session course of 'compliance therapy' which they reported reduced patients' negative attitudes towards medication, increased patients' insight into their illness and improved compliance levels as measured by a keyworker rating scale. Such gains were found to persist for six months. Psycho-educational programmes can be effective in providing information and support whilst improving compliance levels, but very few programmes have been described and evaluated in the literature. More research is required into investigating the efficacy of such programmes and into which aspects are most effective. Falloon & Liberman (1983) warn that outcome can deteriorate as well as improve as a result of combining drug and psychosocial interventions, depending on the type of intervention, medication dose and other factors. Goldberg, Schooler, Hogarty & Roper, (1977) found that symptomatic patients suffered increased relapse with psychosocial plus drug treatment, whilst asymptomatic patients had reduced relapse rates. Alanen, Rakkolainen, Laasko, Rasimus & Kaljonen, (1986) found that low doses of medication combined with psychotherapeutic input improved outcome and reduced relapse. In general it is now accepted that for most (but not all) patients low dose medication and psychosocial therapy is the treatment of choice (Falloon & Fadden,1993).

1.3.5.5 *Cognitive and cognitive-behavioural interventions:* since Bentall *et al.*'s (1988) call for treatment of symptoms not syndromes, a great number of techniques and interventions have been developed by psychologists to treat symptoms, (e.g. voices, delusional beliefs, paranoia) and affective response to symptoms, enhance coping strategies and prevent relapse. Many of these have been within the cognitive therapy/ cognitive behavioural tradition and have proved fruitful in terms of increasing understanding of the psychological mechanisms involved in symptomatology and in terms of producing improvements in symptom profile, coping skills (Tarrier, Sharpe, Beckett, Harwood, Baker & Yusopoff, 1993), subjective experience of quality of life, family functioning and burden of care (e.g., Barrowclough & Tarrier, 1984; Falloon *et al.*, 1984; Tarrier, Barrowclough, Vaughn, Bamrah,

Porceddu, Watts & Freeman, 1988) relapse rates and self-monitoring skills (Birchwood, Smith & Cochrane, 1992). Outcome measurement is complex and has not included compliance with neuroleptics. Some studies have reported observed interactions between interventions and medication levels (Falloon *et al.*, 1985; Hogarty McEvoy, Muntz, DiBarry, Bartone, Cather, Cooley, Ulrich, Carter & Madonia, 1988). Prescribing techniques are another variable which may interact with medication level, cognitive or other intervention and compliance. For example, Birchwood (1996) discusses prevention of relapse using a combination of targeted prescribing (increasing drug levels at first signs of deterioration) plus maintenance prescribing during non crisis periods combined with cognitive interventions to identify, describe and modify affective and behavioural response to prodromes (a period of weeks before readmission when signs of deterioration are present).

Few studies have attempted to measure compliance with neuroleptics as an outcome of such interventions, but connections are tempting and have been drawn. One would expect better compliance with lower rather than higher levels of medication, for example. If cognitive interventions can control some aspects of the symptom picture, for example affective response to symptoms, the need for drug control may be reduced. One could venture further and say that cognitive interventions targeted directly at positive symptoms may even offer alternatives to drug therapy for those patients who are non compliant because the drugs are ineffective. Turkington & Kingdon (1996) describe a template for CBT with neuroleptic resistant psychotic symptoms, including using a normalising rationale, treating anxiety and depression, which they say can lead to poor compliance, and direct techniques to modify delusions, hallucinations, negative symptoms and thought disorder. There is a burgeoning literature on the cognitive treatment of psychotic and allied symptoms. For a comprehensive overview see Haddock and Slade (1996) and for a therapy handbook see Chadwick, Birchwood and Trower, (1996).

The lessons drawn from the cognitive therapy research so far seem to indicate the need to progress beyond symptom treatment into treating the person as a whole, understanding the maintenance of symptoms through

ordinary psychological processes and designing individual interventions in the light of general knowledge about these processes. It could be argued that the research on compliance would benefit from moves in the same direction.

1.3.6 *Concerns with compliance research to date*

The body of literature surrounding neuroleptic compliance is considerable . Unfortunately, the extent of contradictory results in some areas is also considerable. Drawing conclusions is hazardous since comparisons between studies are difficult to make. Different authors have employed different definitions for compliance, different ways of measuring compliance, and included different patient populations and treatment settings. It is therefore impossible to generalise many of the findings.

The population of people diagnosed as schizophrenic is a heterogeneous group, comprising of people with various clusters of symptoms adding to concerns over generalisability. Individual studies are generally noted for small sample sizes and suffer from the effects of uncontrolled variables such as the duration, severity, and nature of illness, neuroleptic dosage, and tolerance levels. Such flaws are amplified when attempts are made to draw conclusions from across the various studies. The research has mainly focused upon the clinical outcome measures of neuroleptic compliance such as symptom rates, hospital admission rates, and clinic attendance rates. These are limited means for evaluating compliance levels.

1.4 Subjective appraisal and compliance

1.4.1 *Recent developments in compliance research*

As can be seen from the preceding section, the majority of researchers have focused on clinical outcomes of neuroleptics and the many hypothesised reasons for non-compliance have similarly been centred on patient or drug variables.

Recent interest in patients' subjective experiences of and attitudes to neuroleptics has stimulated a new and seemingly fruitful avenue of study.

The earliest attempt found to explore psychological factors is by Irwin, Weitzel & Morgan (1971) who found compliance rates higher if prescribers believed neuroleptics were essential in treatment and lower if prescribers were ambivalent.

From the patient's point of view work by Van Putten, May & Marder, 1984; Van Putten & May, 1978; and Van Putten *et al.*, 1981 found that an initial dysphoric response, assessed by four questions, was a powerful predictor of both immediate and eventual drug refusal by schizophrenic patients. Van Putten questioned whether patients' subjective responses to medication really 'have some meaning' or whether the responses can be dismissed as aberrations of 'sick minds'. This concern with whether people with schizophrenia can answer questions reliably was specifically addressed by Davidhizar (1985), mentioning thought disorder, social withdrawal, personalised communication and affective disturbance as potential factors which could interfere with reliable responding. Using Fishbein's expectancy - value model to measure attitude toward taking medication, an approach that is expanded upon in the present study and discussed further in section 1.5, she quotes a study where 50 patients answered open-ended and fixed response questions and were able to stay on subject and share information and to rate strength of beliefs and feelings. Clients responded positively to the exercise and reported a range of beliefs and feelings about medication: 20 per cent only negative, 16 per cent only positive; 64 per cent both positive and negative feelings.

In a similar study, Rogers, Pilgrim & Lacey (1993) found that 56.8 per cent of patients felt neuroleptics had been helpful, versus 27.7 per cent who rated them as harmful. Work by Finn, Bailey, Scultz & Faber (1990) attempted to measure the subjective utility ratings of patients and significant others for neuroleptics (for a discussion of subjective utility see section 1.5.2.1). In this study no significant difference was found between the distress caused by symptoms and the distress caused by side-effects of the medication as rated by both patients and psychiatrists. The psychiatrists saw side effects as the lesser of the two evils when costs to society were taken into account. Psychiatrists overestimated the distress associated with some adverse reactions such as akathisia, dystonia and hypotension, but

underestimated distress resulting from constipation, painful urination and weight gain.

From a psychoanalytic viewpoint, Josephs (1987) hypothesised that the treatment of schizophrenia often founders "due to a failure to ameliorate the pervasively demoralised, alienated and mistrustful attitudes which preclude the patient's genuine involvement in the treatment regimen" (p.1). Detached and passive compliance by patients means prescribers "end up in the business of attempting to bolster a socially appropriate public facade while unwittingly confirming the patient's inner cynicism, which had made social adaptation seem such a pointless endeavour in the first place" (p. 1). Josephs' paper derives its thesis from observations of patients in the course of individual and group therapy. It would seem to indicate the need to take care to involve patients in decisions and plans regarding their drug treatment.

Quantitative explorations by Awad & Hogan (Awad & Hogan, 1994; Hogan & Awad, 1992; Hogan, Awad & Eastwood, 1983) demonstrated relationships between neuroleptic dysphoria measured by a 30 item or 10 item scale (the Drug Attitude Inventory (DAI)), compliance (though it is unclear how this was measured), DAI scores and less favourable therapeutic outcome. They suggest future research comparing new and old neuroleptics in terms of subjective appraisal.

Reviewing work to date on subjective appraisal of neuroleptics Awad, Voruganti, Heslegrave & Hogan (1996), conclude that "the physician [should] develop specific or additional approaches to the management of such dysphoric patients on neuroleptics at the time of discharge." (p. 58).

Methodologically, the subjective appraisal research suffers from problems of defining and measuring negative subjective response. The measures themselves are discussed below in 1.4.2 but in general there is confusion between dysphoria, which often appears to be a combination of negative physical and psychological reactions reported by the patient or rated by the physician, and subjective appraisal, which would be the patient's opinions or judgements about their whole experience of neuroleptic treatment.

Even when this distinction is adequately made, the decision about how wide to cast the net of 'patient experience' is difficult - are we asking about experience of admission, sectioning, ward staff and the like, or just about the drugs themselves?. Is it unreasonable to try to separate drug experience from the rest of the patient's experience? Davidhizar's use of a subjective expected utility model begins to make more sense here, in that at its best such an approach may allow evaluation of the balance of pros and cons of those factors relevant to each individual patient. Other methodological problems include the classification of participants, definition of compliance and selection of items to include as independent variables.

A philosophical and political objection to the research on compliance is that it seems to reflect a paternalistic attitude, so that 'good' patients comply, while 'bad' patients don't. An examination of the DAI 10 and DAI 30 items, for example (Appendices F and G respectively) will show that the compliant patient does not think independently, always does as the doctor says and would never change their drugs of their own accord. The use of the term 'adherence' by some authors has been a way of attempting to stress the autonomy of the patient, yet considerably more change than this will be required to genuinely empower patients.

The lack of symptom relief for some patients and the worsening of symptoms for others, discussed in 1.2.2, means it can be a rational and sensible decision not to comply, especially in view of the damage which may be done by some of the drugs themselves (tardive dyskinesia, for example, is currently irreversible).

1.4.2 *Measures of subjective appraisal*

Four measures of subjective appraisal of neuroleptic medication representing different approaches are reviewed below.

1.4.2.1 *The ND:* Van Putten and his colleagues (1981) used four questions to measure neuroleptic dysphoria. This form is known as the ND and is interviewer administered. The questions are:

How does the medication agree with you?

Did it make you feel calmer?

Did it affect your thinking?

Do you think this would be the right medicine for you?

For each question the patients gave a rating of -11 to +11. Total scores of ten or more were classed as 'syntonic' responses. Scores less than ten were denoted 'dysphoric'. The author states a dysphoric categorisation was a powerful predictor of both immediate and eventual drug refusal.

This assessment takes little time and can be given to acutely psychotic inpatients, but there is no reliability or validity information and no attempt to objectively measure compliance in terms of drug refusal or other creteria.

1.4.2.2 *The SWN:* Naber (1995) developed the Subjective Well-being under Neuroleptic treatment scale (SWN) to measure 'neuroleptic-induced deficit syndrome', which he and others (e.g., Lindstrom, 1994) describe as reduced quality of life with restrictions of emotionality, straight thinking and spontaneity. The scale is a self rating scale and thus can be described as subjective appraisal, but the content is restricted to Naber's criteria for neuroleptic-induced deficit syndrome. It is thus much more pre-determined and narrower than the other scales.

The scale was carefully developed, although it is unclear from where the original items for inclusion came. Confirmatory scale-structure analysis was used on results for 280 schizophrenic patients. Good test retest reliability, sensitivity and concurrent validity with other self-rating scales was shown.

The SWN was completed at a second time point by 48 patients six months post-discharge. The responsible physician rated compliance with a yes or no response to the question 'Does your patient regularly take his/her neuroleptic drug?'. The 14 non-compliant patients had shown significantly worse SWN scores at first testing, showing the scale to have predictive validity as regards compliance, though the numbers for this part of the study were low.

The scale is 'user friendly' though negatively biased and takes 20 minutes to complete. Similar scales (Liddle & Barnes, 1988; Jaegar, Bitter, Czobar & Volavka, 1990; Selten, Sijben, van den Bosch, Omloo-Vissen & Warmerdam, 1993) exist, though they are interview based self-rating assessments, not purely self-rating. All scales focus on 'drug-induced deficit syndrome' as described in the medical literature. The main problem

with these scales is that they are prescriber appraisals using patient's report, rather then ascertaining the patients' own constructs and views about the drugs. Single measures of compliance using physician ratings are another limiting feature.

1.4.2.3 *The ROMI:* The Rating of Medication Influences (ROMI) reported by Weiden, Dixon, Frances, Applebaum, Hads & Rapkin (1994) was developed to assess perceived influences on compliance with maintenance neuroleptics. Unlike the other two scales, this one is targeted directly at compliance.

Item set was selected from a review of the literature, revealing seven 'compliance domains'. Group discussions (between the researchers, presumably) led to the proposal of specific interview items, which were then refined by informal testing of items with well-known patients.

A prospective three centre study used patient, family and clinician interviews to obtain ratings of medication influences on compliance. The rater judgment section of the ROMI completed by family and clinicians was found to be unreliable and dropped. Patient report sections were satisfactory. Validation was thorough. Three 'compliance' and five 'non-compliance' subscales emerged on exploratory factor analysis.

The predictive power of the subscales was not explored, although the authors say they are currently testing the ability of the ROMI to predict compliance and non-compliance. This is a major unknown about the instrument at present.

The scale requires 'an understanding of compliance theory and a clinical familiarity with schizophrenia and neuroleptics. The ROMI rater should also know how to administer a Brief Psychiatric Rating Scale' (Weiden *et al.*, 1994, p 303). A three hour training is required for experienced psychiatrists to administer the ROMI.

The main problems with this instrument are the high level of expertise and additional training required to administer it and the current lack of research into its actual predictive power.

1.4.2.4 *The DAI:* In 1983, Hogan, Awad & Eastwood reported on the development of the Drug Attitude Inventory (DAI). The scale consisted of 30 items (Appendix F) with a seven factor structure established by

exploratory factor analysis. The factors reported are subjective positive, subjective negative, health and illness, physician, control, prevention and harm. It is not clear who administered the scales. Later papers (e.g., Hogan & Awad, 1992) specify psychiatric nurses and most of the studies have used newly admitted inpatients. In 1992 Hogan & Awad published a study comparing Naber's ND scale and a new short, 10 item version of the DAI (Appendix G). They reported good correlations (0.75 and 0.74) between the two scales administered to a group of 52 patients.

The 10 item DAI is based on the first two factors (subjective positive and subjective negative) of the longer scale. These factors are most similar to Naber's concept of dysphoria. The DAI is the most popularly used of the scales available and has been translated into several languages. It is short, easy to score and user friendly, requiring little rater training. Responses are given 'true' or 'false' then scored -1 (negative subjective response (SR)) or +1 (positive SR). A total of between -10 and +10 is possible. Dysphoric patients are those who score below 0 (Hogan, 1998, personal communication). The authors succeeded in allocating correctly, blind, 92 per cent of participants to 'compliant' or 'non-compliant' categories on the basis of scores on the DAI (Hogan *et al.*, 1983). They do not report how compliance was measured independently.

Thus, the DAI appears to be the best of the scales available in terms of predicting compliance. It does not, however, give any clues as to why a given participant is behaving in the way s/he is, has a paternalistic approach and compliance prediction may be subject to bias in that the experimenters themselves rated compliance: their ratings may have been based on patients statements about compliance.

1.4.3 *A Q-sort approach to subjective appraisal*

A separate section has been devoted to this one study because the present study links in closely and builds on this work.

Day, Bentall & Warner (1996) used Q-methodology to explore the experiences of 50 people with a diagnosis of schizophrenia taking neuroleptic medication, in response to Awad & Hogan's (1994) call for innovative methods for researching subjective response.

Q-methodology is a method of sorting statements according to degree of agreement, producing a Q-sort (a forced normal distribution of statements along the agree-disagree continuum) for each participant (McKeown & Thomas, 1988). Factor analysis is then used to extract prototypical sorts which represent 'domains' or groups of individuals. This contrasts with traditional attitude scaling in that the participant considers all items at once in relation to each other, reflecting real-life situations. Items are not given externally defined objective meanings, so that attitudes can be sampled without a prior structure of beliefs about neuroleptics or compliance being imposed by the researcher.

Interviews with nine people, four with a diagnosis of schizophrenia, three community psychiatric nurses and two psychiatrists, were tape-recorded. Statements about neuroleptics were extracted from the discourse: 127 statements were initially identified. The three investigators working together reduced this number to 45 by amalgamating similar and eliminating idiosyncratic statements.

The 45 statements were typed onto cards and were given to the 50 participants. Participants were asked to split them into three piles along an agree - undecided - disagree continuum. They then further sorted the cards along a -5 to +5 continuum, with a forced number of cards in each pile, producing a quasi-normal distribution.

The factor analysis of the resulting 50 sorts shows relationships between individuals rather than items. These clusters are known as domains (of people) rather than as factors. A domain represents a typical patient appraisal. Four domains were identified:

A. **Unquestioning, Uncomplaining, Dependent**

These people expressed dependence on neuroleptic medication, agreeing strongly with statements such as 'I can't do without my medication'. Participants also had strong reliance on the doctor and disagreed with the negative statements about medication.

B. **Autonomous, Sceptical**

These people agreed with negative statements about medication and endorsed ideas that they should make their own decisions about medication. They were neutral about side-effects.

C. **Balanced Appraisal**

People loading positively on this domain did feel strongly about side-effects but were concerned that they could not manage without the medication.

D. **Autonomous, Responding**

These people perceived benefits from taking the medication but were not dependent upon it.

Domain D was dropped from other reports (e.g., Bentall and Day, 1994) because only three participants loaded positively and one negatively on this factor.

The authors conclude that subjective experience of medication is not simply positive or negative but a complex set of reactions and responses. They recommend that clinicians take this into account when delivering treatment and suggest that the most effective prescribing strategy in terms of compliance and treatment outcome will be the one which is consistent with the patient's own viewpoint. Further research into patients' subjective responses to neuroleptic medication is also recommended to enable the design of treatment protocols which accurately match the needs of individual patients.

The strengths of this study are its starting from the patients' discourse and the use of a technique, Q-sort, which minimises the imposition of the investigator's viewpoint. The major drawback is that the Q-sort technique takes vast amounts of time to administer and is not clinically immediately useful.

The present study aims to produce a scale which accurately describes a given individual's subjective experience in simple terms and suggests treatment strategies. One way in which it aims to do this by using the statements used in the above study to create a questionnaire which is quick and easy to complete.

It is further intended to investigate whether the resulting scale is predictive of compliance.

1.5 Can attitudes predict compliance behaviour?

1.5.1 *Attitudes do not predict behaviour very well*

It will be noted that the scales discussed in the last section are in fact attitude scales, often constructed more or less in the classic tradition of social psychology.

The study of attitudes has been exceedingly important in the history of social psychology, dominating the field in the 1920s and 1930s (Allport, 1935) and remains a major theme (McGuire, 1986).

The research on attitudes is vast and complex, and notable at times for great sophistication in abstract discussion paralleled by oversimplification in practical application. Over a number of decades, a concept of attitude as an evaluative tendency has emerged, so that Eagly & Chaiken (1993) can offer a definition, "a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour"(p.21). So attitude is a hypothetical construct, an internal state which predisposes an individual towards favourable or unfavourable responses. These responses "can be cognitive, affective or behavioural and overt or covert. The importance of attitudes thus lies in their presumed power to influence responding." (Eagly, 1992, p 695.).

Progress in the study of attitudes has been uneven, from Allport's confident beginning to the nadir of social psychology's crisis of confidence during the 1960s and 1970s. A major complaint during this time was the questionable status of attitudes as a predictor of behaviour.

In 1969, Wicker's review of 42 studies reporting attitude - behaviour relations produced an average correlation of approximately 0.15. In response to this review, Fishbein & Ajzen (1974) carried out an aggregation analysis which showed that the lowest values are typically obtained for correlations between general attitudes and specific behaviours. Multiple-act behavioural criteria correlate much better with general attitudes. Such generalities however did not impress those whose interests lay in the hypothesised causal relationship of attitude to behaviour, the ultimate aim being to predict specific behaviours.

1.5.2 *Improving prediction*

In an attempt to set out more clearly the exact nature of potential pathways between an individual's attitudes and specific individual behaviours, researchers turned to theoretical approaches which described the nature of the relationship between the two.

1.5.2.1 *Subjective expected utility (SEU):* Subjective expected utility theory (SEU), having its roots in Peak's (1955) decision-making theory, was brought into play to help solve the causal relationship problem. Such theories assume that human beings make decisions based on probability estimates of likely outcomes of a given decision, combined with value judgements about the relative utilities of each outcome, then act to maximise this combination, called 'expected utility'. For example, in deciding whether to go out for a picnic on a given day, an individual might make probability judgements about the likelihood of rain, of warm temperatures, of whether friends are likely to join in, then consider the value of each outcome (a downpour, a sunny day, a picnic with friends, a picnic without friends), lastly, the final decision will be based on the course of action (to picnic or not to picnic) which maximises the probability of a valued outcome (a picnic with friends on a warm day, for example). The choice of outcomes to consider and the value system against which it is judged is idiosyncratic to the individual.

In a volume reviewing current research with SEU theory, Norman & Conner (1996) compare five theories which have been used to predict health behaviours. These are the Health Belief Model (Becker & Maiman, 1975), Protection Motivation Theory (Rogers, 1975; 1983), Health Locus of Control Theory (Wallston & Wallston, 1982), Self-Efficacy Theory (Bandura, 1977) and the Theory of Planned Behaviour (TPB) (Ajzen, 1991). All of the theories have been applied to health behaviours such as adhering to a healthy diet, avoiding hazardous behaviours such as smoking, preventative behaviours such as using condoms. They have had only limited application to attitudes to illness or medication. Norman & Conner (1996) compare the theories on several grounds. Firstly, they found the models to be comparable in terms of predictive validity, although there is very little research available which directly addresses this. They also conclude that

the self-efficacy construct appears to be a key predictor of health behaviour. Secondly, they discuss the theoretical constructs underlying each model and find a considerable degree of overlap between them. Each theory includes perceived consequences of behaviour constructs and control perceptions constructs. The TPB does not appear to include emotional arousal constructs, in contrast to the others. However, only the TPB includes normative influences on behaviour. Both the TPB and PMT contain a hypothetical intervening variable which mediates the relationship between the other social cognitive variables and behaviour. Norman and Conner (1996) draw out the importance of including normative influences and perceived threat, believe there is a strong case for including self-efficacy in all models of health behaviour and stress the usefulness of behavioural intention as a mediating variable. The two theories which are preferred in their analysis are Bandura's Self-Efficacy model and the Theory of Planned Behaviour (TPB). The latter was preferred for the present study, firstly because of the ease of operationalisation of the constructs and the clear examples provided by Conner and Sparks (1996), secondly because this was the theory proposed as useful and discussed by Davidhizar (1982) in her work and thirdly because its predecessor, the Theory of Reasoned Action, has been applied to prediction of intention by people with a diagnosis of manic depression to take lithium (Cochran & Gitlin, 1988), which is the closest application found to the present study on neuroleptics.

1.5.2.2 *The theory of reasoned action (TRA):* Fishbein & Ajzen's theory of reasoned action (TRA) is a particularly well-known example of SEU theory (Ajzen & Fishbein, 1980; Fishbein, 1980; Fishbein & Ajzen, 1975). The proximal cause of behaviour here is not attitude but intention to act in a particular way. Intention mediates between attitude and behaviour and is also influenced by subjective norm, which is one's perception of the extent to which significant others think that one should engage in the behaviour. The reasoned action principle states that if person x thinks that a behaviour will achieve good outcomes and that other people want x to do it, then x intends to carry out this behaviour and does so.

Another feature of this approach is that the authors insist on applying a rule that both attitude and behaviour should be measured at the same

levels of specificity in order to achieve higher correlations. So, attitude in the case of neuroleptic compliance would mean attitude towards the act of taking neuroleptic medication (rather than attitude towards the drugs themselves as in the subjective appraisal research). Fishbein and Ajzen would criticise the subjective appraisal research as not specific enough and as not including subjective norms.

The theory of reasoned action has had utility in predicting health behaviours largely under volitional control, such as smoking initiation, frequency and cessation, alcohol consumption, oral contraception and condom use, exercise, food choice, breast and testicle self-examination (for comprehensive reviews see Sheppard, Hartwick & Warshaw, 1988 and van den Putte, 1993). A major criticism of the TRA is that it assumes that if one intends to do something one can. This is obviously not true, as putting intention into action often depends on one's available resources, the co-operation of others and many other factors (Liska, 1984).

1.5.2.3 *Theory of planned behaviour (TPB):* In response to this criticism, Ajzen (1987, 1988, 1991) revised the model to incorporate a perceived behavioural control factor, that is, one's perception of how easy or difficult it is to perform the behaviour, as an additional predictor of both intention and behaviour. This is the theory of planned behaviour (TPB) (see Figure 1.1). The theory assumes, like the TRA, that all important variables subsumed by the general categories 'demographic variables' and 'personality traits' can be systematically reduced to fewer, in this case four, variables, namely attitude to behaviour (AB), subjective norm (SN), perceived behavioural control (PBC) and behavioural intention. This reduction is achieved by a process of multiplying the more distal factors together to produce the proximal factors (in addition to directly measuring the proximal factors). This process of generating multiplicative composites eventually condenses the many factors discussed earlier into the four more easily measurable factors. The process produces simplicity and specificity, which are simultaneously the main strengths and weaknesses of the model. Ease of operationalisation and clarity of hypotheses generated must be balanced against the narrow focus which may prematurely eliminate relevant variables.

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1.5.2.4 *Criticisms of subjective expected utility:* Frisch & Clemen (1994) criticise the SEU approach whereby one can construct probability functions (representing a person's beliefs) and utility functions (representing a person's values) on two counts. Firstly, they say research based on these models has produced inconsistent results (e.g., Janz & Becker (1984)).

Secondly, Frisch & Clemen (op. cit.) and other authors have noted that SEU describes how one makes a decision once it is structured but does not describe how one generates options, determines which consequences to consider or identifies the relevant risks. One the above basis, Frisch & Clemen argue that utility theory is not the type of descriptive theory psychologists need and argue for psychological attempts to describe the processes involved in decision-making.

In a recent article, Evans and Over (1997) discuss rationality in decision-making and argue for logical versus adaptive/effective rationalities, the latter based on past experience. SEU, they argue, is based on logical rationality whereas most everyday decisions are based on adaptive rationality. Past behaviour and experience are therefore important variables which are ignored by SEU (though SEU theorists might argue that these are incorporated in variables such as beliefs and expectations).

1.5.2.5 *Criticisms of TPB:* In addition to these general criticisms of the whole class of SEU theories, there are specific issues for the TPB. It can be seen that the theory of planned behaviour is a proposed complete theory of human behaviour. Figure 1.1 shows how it starts with the most general and distal epidemiological and personality factors, proceeds through beliefs, expectations, etc., to the proximal factors of attitudes (to behaviour) (AB), subjective norm (SN) and perceived behavioural control (PBC).

Liska (1984) criticised the assumptions and structural equations underlying the theory of reasoned action (TRA), predecessor of this model, showing that causal interactions can exist between attitudes and social norms, whereas the TRA (and TPB, though it wasn't around then) conceptualises them as separate. He puts forward a whole set of models describing potential interactions between the proximal factors and suggests including other important predictive variables.

Other authors have suggested the addition of other moderating variables. Level of moral reasoning (Rholes & Bailey, 1983) and a moral dimension of choice (Raats, Shepherd & Sparks, 1995) have been shown to influence the magnitude of predictive validity of TRA and TPB respectively. Past behavioural experience with the attitude object has been shown to increase consistency between an attitude and relevant behaviours (Regan & Fazio, 1977). A number of studies have suggested direct impact of past behaviour on current (e.g., Bagozzi, 1981; Bentler & Speckhart, 1979, 1981). Accessibility from memory of such attitudes, based on past experience of the object, was proposed as the important feature increasing the attitude-behaviour correlation by Fazio and his colleagues, who showed both that direct experience produces more accessible attitudes (e.g., Fazio, Chen, McDonel & Shearman, 1982) and that more accessible attitudes are more highly correlated with behaviour, that is, that accessibility is a mediating variable between attitudes & behaviour. This brings us back to the general criticism made by Evans & Over (1997) that SEU excludes past experience.

None of the above additions feature in the current theory of planned behaviour, although the whole field is still developing and the theory cannot be regarded as entirely resolved.

Lastly, both the TRA and the TPB may be described as deliberative processing models, in that they appear to imply that individuals make behavioural decisions based on a careful consideration of available information (Conner & Sparks, 1996). The assumption that multiplicative operations in some way mirror or represent human decision making processes is also questionable. No evidence is put forward to justify either of these assumptions in terms of what is known about human processing of information. In fact, information processing theory generally reflects parallel processing of information within many inter-related complex structures, with a significant role for emotional valences associated with inputs along with rapid subliminal processing systems for threat recognition. There is evidence that the subliminal information processing system can in turn affect the outcome of conscious decision-making (Williams, Watts, Macleod and Mathews, 1997).

1.5.2.6 *Applications of TRA and TPB to drug compliance:* Despite these criticisms, the TPB remains probably the most influential expected utility theory (Eagly, 1992; Conner & Sparks, 1996). Its predecessor, the TRA, has been extensively applied to many different behaviours, mostly relatively simple to define, such as blood donation, voting, consumer behaviour and dental hygiene behaviour. Meta-analyses of the literature (e.g., Sheppard, Hartwick & Warshaw, 1988) have shown quite successful predictive validity for the model.

The newer TPB has been less well researched but has generally shown improvements over the TRA in predictive validity for more complex, less volitional behaviours. The mean multiple correlation between behavioural intentions (BI) and attitude to behaviour (AB), subjective norm (SN) and perceived behavioural control (PBC) was reported by Ajzen (1991) to be 0.71 across the 16 studies he reviewed. The mean correlation was competed at 0.64 for the TRA by Van den Putte (1993) but this author notes a large variation in results between behaviours.

The theory of reasoned action (TRA) has been applied to lithium compliance in people with manic-depressive disorders by Cochran & Gitlin (1988). In this study 48 outpatients completed attitudinal, behavioural and normative measures along with a self-report five point compliance scale. Results indicated that subjective norm and behavioural attitudes predicted behavioural intention. Some modification of the TRA model was required to best account for results. The more compliant extreme of the patient population was probably over-represented in the sample and the self-report compliance measure was likely to be biased in favour of reporting high levels of compliance. These are the usual problems in such research and need to be borne in mind throughout the present study.

The TRA and the health belief model (HBM) were applied to the study of drug compliance in females with urinary tract infections by Reid & Christensen (1988). This study is also unusual in the field in that it includes an attempt to directly measure compliance behaviour, rather than just intention to comply. One hundred and thirteen patients completed measures of both HBM and TRA hypothesised predictor variables. Compliance was measured using self report concerning whether the patient

had finished all her medicine and, if not, instructions to the patient to count how many pills were left. The HBM variables predicted 10 per cent of the compliance variance; adding the TRA variables raised the total explained variance to 29 per cent. Anecdotal evidence suggested that some non-compliant patients took their medication until their symptoms subsided, then stopped. The behavioural intention (TRA) variable was neither the sole predictor of compliance (as the TRA model specifies) nor the strongest predictor - belief strength and outcome evaluation being the most powerful predictors: Compliant patients believed more strongly that taking the pills would reduce their symptoms and had more negative feelings about their symptoms. Barriers to taking medication (HBM) were the next most important predictors, increasing family or work commitments as recovery progressed could signal onset of non-compliance. However, the authors urge caution about generalising these findings to other populations.

Two papers specifically apply the TPB to drug taking: one, by Conner & Sherlock (1993) used the TPB to predict ecstasy-taking behaviour and found the TPB to predict 49 per cent of previous behaviour and 55 per cent of the variance in the future intention measure. The second, by Hounsa, Godin, Alihonou, Valois & Giraro (1993) attempted to identify psychological factors influencing mothers' intentions to use oral rehydration therapy in a rural area of Benin. Results suggested ways to improve compliance. Both these papers (and many others in the field) measured correlations between AB, SN and PBC and behavioural intention (BI) not the behaviour itself. Very few studies using the TPB have actually attempted to measure behaviour (Ajzen, 1991).

Davidhizar (1982) suggests using "the Fishbein expectancy-value model" to explore the "unusual resistance" of people with schizophrenia to participation in a treatment regimen. She reviews the need for concrete questions and recommends the use of a bipolar scale for responses so that the patient can express disagreement using negative numbers and agreement using positive. She reports that the usual 7-point scale appeared too complex for use with this population but did not say she had specifically tested this out.

In summary, no published studies or other studies known to the author have as yet applied the TPB to compliance with neuroleptic medications. Applications in similar fields suggest care should be taken in selection of subjects and the operationalisation of measures, compliance being the most difficult variable to measure. The ability of people with schizophrenia to participate with full understanding has also been questioned.

1.5.2.7 *Operationalising the TPB - some considerations:* TRA questionnaires have been criticised as being 'transparent' to respondents who may understand the need to produce consistent responses between items representing the same construct and between constructs such as attitudes towards a behaviour and intention to perform the behaviour (Gergen, 1973; Semin, 1987). Investigating the impact of questionnaire format, Budd (1987), compared the standard Ajzen & Fishbein (1980) format (where items measuring variables hypothesised to relate to given behaviours were presented consecutively for each behaviour) with a format where items were randomly presented. She found statistically significant differences between the levels of correlations produced using the different formats, the random format yielding much lower correlations. This appeared to be due to much lower reliabilities for measures in the random presentation condition. However, Sheeran & Orbell (1996), using protection motivation theory constructs (a similar model) showed no effect of format on reliability of measures although there was some variation in significance and strength of correlation. They discuss the debate between social cognitivists (questionnaire administrators) and discourse analysts (e.g., Potter & Wetherell, 1987) who might regard answers to questionnaires as entirely determined by context and would question researchers' capacity to reliably infer cognitions on the basis of questionnaire responses. They conclude that their respondents' answers were a product both of their health beliefs and the reporting context. They recommend paying greater attention to item desirability but do not recommend randomising format, since subjects found random format difficult and time-consuming to complete. Quantitative health psychologists, they say, can have a good deal of confidence in

making inferences about health beliefs on the basis of questionnaire responses.

These considerations focus on the sophistication of questionnaire respondents, as opposed to their potential lack of ability to fill in forms as discussed by Davidhizar (1982). The problem as regards operationalising the TPB would be the question of balancing simplicity, ease of responding and user-friendliness against the respondents' tendencies to produce linguistic formulations tuned to the context at hand (Potter & Wetherell, 1987) so that they give responses where attitude, behavioural intention and behaviour are all consistent.

The operationalisation of the TPB with regard to two studies of breast self-examination is discussed by Young, Lierman, Powell-Cope, Kasprzyk & Benoliel, (1991). The TPB can be operationalised by developing measures of the hypothesised antecedents to attitude (beliefs about outcome and evaluation of outcome), then summing the products of these measures. A similar procedure can be applied to subjective norm. Yet Young *et al.* found problems when participants answered complex questions - for example, about beliefs and evaluation of beliefs: "My performing breast self-examination would be difficult" (belief) followed by "Performing an examination that is difficult for me would be good .....bad" (evaluation) was a peculiar question for those who had disagreed with the first statement. Many responded to the latter (evaluation) items by saying they had already answered that question. Ajzen & Fishbein recommend this procedure but also recommend that attitude be measured directly using semantic differential scales for attitude to behaviour and social norm (Ajzen & Fishbein, 1980). A direct measure of perceived behavioural control (PBC) is also recommended (Ajzen & Madden, 1986).

In addition to the practical complexities for researchers and most importantly participants in using multiplicative scales, there are considerable statistical problems when using simple correlational analysis to assess the relationship between a multiplicative composite (such as AB, SN or PBC arrived at as outlined above) and a single outcome variable. Evans (1991) reports 'pervasive' misuse of correlational analysis in this context and warns sternly against it.

In conclusion, the measurement of hypothesised distal factors of the TPB such as beliefs and evaluations of beliefs and summing their products to give more proximal factors appears to offer no advantage over the direct measurement of the more proximal factors AB, SN, PBC and BI, and does produce practical and statistical problems for experimenter and responder.

1.6 Rationale for the present study

1.6.1 *The need for further investigations into variables affecting compliance*

The literature reviewed has highlighted some areas where further work might prove beneficial to those involved in the prescription and monitoring of neuroleptic regimes and to those in receipt of this treatment. Firstly, existing medical research appears to unequivocally assume that compliance is a good thing and that ensuring compliance would produce better therapeutic outcome. Whilst this is undoubtedly true in many cases, it has been shown to be an over-simplistic set of assumptions, so that there is a need for more research in the subjective appraisal tradition which tries to describe the patients' perceptions of and motivations for taking or not taking medication. Secondly, many articles demonstrate paternalistic approaches to patients, which seem to be sequelae of the assumptions about compliance and of the power relationships between prescriber and patient, so that prescribers provide instructions (overt authority), but patients can exercise power by not following the instructions (covert resistance). If this paternalistic approach continues to be reflected in the literature, there is a risk of failing to notice what seems a fairly central theme, namely that patients' perceptions differ markedly from those of prescribers. There is therefore a need for research which is as free as possible from paternalistic or authoritarian stances. Thirdly, compliance has often been assumed to be a dichotomous variable, so that it is assessed as either present in or absent from patient behaviour. In fact there appears to be a continuum of compliance behaviours, so that compliance should be measured as a matter of degree. Fourthly, there is evidence that patients augment as well as reduce their medication by altering their drug taking behaviour, so that

compliance measures should be able to pick up deviation from prescription in either direction. Fifth, approaches from discourse analysis in the first instance, such as the Day *et al.* (1996) Q-sort study, have produced useful constructs to inform this kind of future research, while another source of theoretical constructs might be health behaviour models, in particular the theory of planned behaviour (TPB) (Ajzen, 1991).

In summary, further work on patient drug-taking behaviour is needed which avoids value judgements about the behaviours and thus is free of the paternalistic viewpoint, which is sensitive to the many different topographies seen in the behaviours and which seeks to explore links between subjective appraisal, drug characteristics, prescriber characteristics and other variables identified in the literature and compliance. The definition of the latter should reflect awareness of complex drug taking behaviour patterns rather than just whether the patient adheres to the prescription.

1.6.1.1 *The need for a screening tool:* As outlined in the review of existing measures, there is no screening tool available which might tell clinicians both whether and why a given patient will comply with medication. Existing interventions to improve compliance do not differentiate between individuals and make fundamental assumptions such as that all patients wish to be in partnership with prescribers and to have information about their drugs. A screening tool which could differentiate patient attitudes towards their drugs would provide constructs for both prescribers and patients to use in discussing subjective appraisal in a non-authoritarian way. If such a screening tool could further inform both parties of the drug-taking behaviours likely to be associated with particular attitudes, compliance with prescription could also be discussed in a way which might enhance mutual understanding and respect rather than lead to frustration and potential conflict.

1.6.1.2 *The need for better compliance measures:* Existing self or observer report measures of compliance tend to be dichotomous or single item rating scales, which give little information about the subjective reasons for compliance behaviour. Practical measures such as pill counts or blood tests have drawbacks such as that they may be susceptible to manipulation by the patient, are often not measures of long term compliance, may be

intrusive and require compliance in themselves so that the measures can be taken. While self report measures are desirable in order to ascertain patients' own perceptions of their compliance behaviours, information from other sources is necessary to minimise positive bias. Measures of compliance need to be collected from multiple sources and should reflect complexity as described in 1.6.1. The literature would indicate the wisdom of expecting considerable differences between compliance ratings from different sources. Rather than aggregating the diverse information, it may be informative to explore the differences. In other words, it is time to move away from the search for a 'true' single measure of compliance towards sets of perceptions which are expected to be different depending on the source.

1.7 Aims of the research

This study aims to develop a scale predictive of compliance and non-compliance among people prescribed neuroleptic medication. The scale should have statistical validity and reliability and have clinical utility. The study further aims to explore patients' reasons for deviating from prescribed drug-taking behaviour.

1.8 Hypotheses

Hypothesis 1: Valid measures of seven variables thought to be predictive of compliance can be developed.

Hypothesis 2: These measures will predict compliance and non-compliance among people prescribed neuroleptic medication, in the following ways: For the three variables from Day *et al's* (1996) study, *high* scores on unquestioning compliance will correlate with *high* scores on compliance and *low* scores on non-compliance; *high* scores on autonomous scepticism will correlate with *low* scores on compliance and *high* scores on non-compliance; scores on balanced appraising will not correlate with compliance or non-compliance scores. For the four variables from the theory of planned behaviour, attitude to behaviour, subjective norm and

perceived behavioural control will be associated with scores on behavioural intention. Behavioural intention will in turn correlate with compliance and non-compliance measures. There will be a further direct association between perceived behavioural control and compliance.

CHAPTER 2

Method

2.1 Development of measures

2.1.1 *Operational considerations*

The literature review above lead to the following decisions in the conduct of the present study:

- Operationalisation of the four most proximal factors of the theory of planned behaviour;
- Interviewer-administered questionnaires (to minimise incomplete forms and ensure comprehension of task);
- Presentation of a rating scale -3 to +3 in large print on card to the interviewees (to reduce response ambiguity and allow disagreement, neutrality or agreement).

It was hoped that these methods would address the balance between potential interviewee impairment and potential interviewee sophistication.

A pilot study to investigate these and other practicalities was also indicated.

2.1.2 *Developing screening tools*

Two potential routes to developing an informative screening tool suggest themselves. The first involves converting Day *et al.*'s (1996) complex Q-sort procedure into a questionnaire format which can be rapidly and simply administered by a clinician with no special training in the area. The second route involves applying the model outlined in the theory of planned behaviour to the problem. This would mean operationalising the four 'predictor' variables, Attitudes to behaviour (AB); Subjective Norm (SN); Perceived Behavioural Control (PBC); Behavioural Intervention (BI) and testing their power in predicting compliance variables.

If either (or both) routes were successful it should be possible to give a standard score (z score or centile) for each predictor variable so that a 'patient profile' could be produced for any given patient after screening. Such visual presentation of information may assist the clinician to decide how best to address the issue of compliance for each individual.

In accordance with these intentions, two new scales were developed to measure factors which might be predictive of compliance, the Drug

Attitude Scale (DAS), based on Day *et al*'s results and the Theory of Planned Behaviour Scale (TPB), from Ajzen's work.

2.1.2.1 *Development of the Drug Attitude Scale (DAS):* This new scale was constructed by selecting from the 45 items used in Day *et al.*'s Q sort study those which produced the most extreme responses in that study (ratings of -5 or -4 and +4 or +5) along with those which best discriminated between domains found in the study. This produced a 30 item scale (Appendix D) with 10 items for each hypothetical factor corresponding to the Q sort domains. The hypothetical factors were unquestioning compliance (UC), balanced appraising (BA) and autonomous scepticism (AS). Item order was determined by pulling papers out of a hat. Half of the items were negatively phrased and half positively.

2.1.2.2 *Development of the Theory of Planned Behaviour Scale (TPB):* This new scale was constructed using Conner & Sparks' (1996) recommendations for operationalising the concepts of the Theory of Planned Behaviour. Four variables, attitude to behaviour (AB), subjective norm (SN), perceived behavioural control (PBC) and behavioural intention (BI) were operationalised, producing a 19 item scale (Appendix E). Items were randomly ordered and half phrased negatively. The literature on issues relevant to the patient group was taken into consideration when constructing the items, as recommended by Conner & Sparks and other authors. For example, when deciding on 'important others' to include in the subjective norm (SN) measure, the importance of the patient-physician relationship highlighted in the literature lead to the inclusion of the item 'my psychiatrist would approve of me taking my drugs'. The general format and phrasing of the questionnaire was kept similar to those recommended, because of literature indicating significant effects of format changes and because particular items have been found to maximise the likelihood of obtaining reliable measures (Conner & Sparks, 1996).

2.1.3 *Developing compliance measures*

The existing measures could be improved by operationalising the compliance construct to reflect the complexities of compliance behaviours. Operationalising the concept requires a definition allowing measurement. Usually this has translated as 'does the patient take medication?'. Asking

the question in this closed format may be responsible for the yes/no or single-item measures produced previously. Rephrasing the question to ask 'how does the patient take the medication?' allows investigation of the patterns of compliance behaviour.

A drug prescription consists of several implicit instructions to the patient by the prescriber, namely: take x number of pills (dose) at y times a day (time) for z number of days (completion). In the case of neuroleptic medication, there is usually no completion criterion, the patient being expected to continue on a maintenance dose unless/until instructed differently. This is still an important variable even though it cannot be measured directly in the case of neuroleptics, because it has been shown to affect compliance in other areas (e.g., Reid & Christensen 1988) and it may well be part of a patient's past experience that one generally stops taking medication when one is better.

Compliance may be measured by asking about deviation from these instructions (on time and dose in the case of neuroleptics) which may produce more useful information than asking whether or not a patient takes medication. Self-report measures are subject to bias from various sources and additional sources of information may be needed: Keyworkers have regular contact with patients and are responsible for ensuring day to day compliance. The Kemp *et al.* (1996) scale offers a simple, single-item keyworker rating scale of compliance which is not demanding of time and does not ask questions about deviation which may be too difficult for keyworkers to answer.

2.1.3.1 *The development of the Drug Behaviour Scale (DBS):* This new outcome measure was designed to tap the degree to which the participant's drug taking behaviour deviated from the behaviour prescribed by the psychiatrist. It included items designed to allow patients to rate their own usual deviation from the *time* the drug was supposed to be taken, deviation from the prescribed *dose* and whether the dose was *missed* out altogether (it is possible to deviate from depot prescriptions in all these ways, by not turning up at clinic, for example, or by requesting a reduced dose from the depot nurse). A *total deviation* score is obtained by summing these three. This is a self-report non-compliance questionnaire which

attempts to measure more than simply whether or not a patient adheres to prescription, by asking in what way deviation from prescription occurs (Appendix H). Further items including open-ended questions were included in the DBS for the reasons outlined below.

2.1.4 *Ascertaining reasons for deviation from prescription*

Since a main interest of this study is why patients don't comply, qualitative information is of interest as well as quantitative. Asking the patient why is the most direct and simple method of finding out, although the demand characteristics of the situation and the problems we all have in analysing our own motivations must be borne in mind when considering the replies. Additional items asking for reasons for reported deviation from prescription were added to the DBS (Appendix H). Participants were also asked whether they added over the counter or street drugs to their prescription drugs, in order to investigate whether compliance might be associated with substance abuse as reported in the literature.

2.2 Participants

Inclusion criteria were as follows: All patients currently prescribed neuroleptic medication and resident on the Isle of Wight whose symptoms conformed with the DSM IV diagnostic criteria for schizophrenia or schizoaffective disorder (American Psychiatric Association, 1994). Exclusion criteria: patients whose keyworker believed they were unfit to participate; patients who refused consent; those under 18 years old.

Through keyworkers' caseload lists and verbal information from keyworkers, followed by psychiatric case note reviews by the interviewers, 172 patients were identified who met the inclusion criteria. Of these, 106 patients agreed to take part in the study. The group of 56 patients who did not participate consisted of 50 who were considered too unwell by the keyworker to be approached for consent and six who refused personally, the majority of these having paranoid delusions which concerned being interviewed or questioned or concerned the medication itself.

The participating group consisted of 53 men and 53 women. The mean age of participants was 43 years old, most having left full-time

education at 16 years old. Most (68 per cent) were single, none had paid employment. The mean length of illness, as represented by length of time since first diagnosis, was 14 years, although this data was available for only 82 participants, there being no indication of date of onset in the notes of the remaining 24 people.

2.3 Materials

2.3.1 *The New Scales: Drug Attitude Scale, Theory of Planned Behaviour Scale and Drug Behaviour Scale*

As described in sections 2.1.2 and 2.1.3 above, these new scales were designed to measure a total of seven independent variables (three within the DAS and four within the TPB), and four self-report of compliance (dependent variable) measures (deviation from time, deviation from dose, missing doses altogether and a total score for the DBS). Each item can be rated from -3 through to +3. Each scale is scored by summing the ratings for items constituting each variable. For example, the DAS items which make up the Unquestioning Compliant variable are summed to produce a score on the UC subscale of the DAS. The study investigated the reliability and validity of these variables in various ways as outlined in the detailed data analysis description in section 2.5 below.

2.3.2 *The Drug Attitude Inventory (DAI)*

This is the most popular scale for measuring attitude and is reported to have good validity and reliability (Awad and Hogan, 1994). It was administered to randomly selected subsamples of the participant group because of concerns expressed by interviewers about maintaining concentration of some participants. Two versions of the scale exist, a 30 item scale (Appendix F) and a 10 item scale (Appendix G). Initially the 10 item scale was administered for brevity, but following a conversation with Professor Awad after the experiment had begun, to the effect that he considered the 10 item scale unsuitable for research use, this was changed to the 30 item version. The purpose of administering this scale was to check the concurrent validity of the new scales the DAS and the TPB.

2.3.3 *The Kemp Scale*

This is a rating scale completed by the keyworker to describe his/her assessment of the patient's compliance (Kemp *et al.*, 1996). A score of one means the patient is felt to be not at all compliant, seven means the patient is very compliant (Appendix I). The scale was developed by Roisine Kemp and colleagues and reported on in her studies on improving compliance. It is not validated but there is as yet no satisfactory valid measure of compliance. This scale was chosen to meet the need for observer ratings of compliance, and scores constituted the fifth dependent variable in the study, alongside the four self-report measures.

2.3.4 *Instructions to interviewers and participants and demographic data sheet*

Instructions to interviewers were provided in written form (Appendix J) to standardise their actions as far as possible and were used in the role-play training sessions. Interviewers had additional information as a result of the training sessions: It was decided that interviewers could use the words 'drugs', 'neuroleptics', 'medication', 'tablets' and 'injections' interchangeably as appropriate to the case and to reflect the patient's preference. Interviewers could also help the patient decide how her/his response should be expressed on the rating scales if they were confused (e.g., some were unsure how to rate disagreement with a negative statement). In order to standardise procedure as far as possible, written instructions were provided to be read to the participants by the interviewers (Appendix K). A single sheet for collection of basic demographic data was provided, for use by interviewers in checking patient notes and prior to questionnaire administration at the beginning of the interview (Appendix L).

2.4. Procedure

2.4.1 *Recruitment and informed consent*

Consent to the participation of each patient in the study was first obtained from the relevant consultant psychiatrist. The patient's keyworker was then approached for advice about the most effective way of contacting the patient. The keyworkers (community psychiatric nurses) undertook to

explain the study to their patients and invite them to participate. The keyworkers advised the experimenters on the patients' preferred timings and settings for interview. Patients were offered feedback about the over all findings of the study. All patients received an information sheet (Appendix B) and signed a consent form (Appendix C) before participating.

2.4.2 *Interviewers*

Three community nurses and one psychology assistant who were all familiar with the needs of the patient group volunteered to administer questionnaires. Care was taken that the one nurse who was also a keyworker did not interview any of her own patients.

Training took place over two sessions when all interviewers and the experimenter role played the administration of the questionnaires, paying attention to consistent style and answers to queries, to scoring and recording protocols and to the probability of maintaining patient interest over the total interview.

2.4.3 *Confidentiality*

Patients were assured of confidentiality which was protected by a number coding system, the key to which was held in a locked drawer in the psychology department. Only the demographic data sheet contained the patient's name and address. After completion of all questionnaires including the keyworker ratings, the names and addresses were removed from the demographic data sheets, so that only the number code remained for use in data entry.

2.4.4 *Demographic data collection*

This was completed before interview for each patient by the interviewer by looking through the psychiatric notes for evidence about DSM IV diagnostic criteria and demographic variables. Current medication was also recorded from the notes. This record was later compared to the patient's report of what medication s/he was currently prescribed.

2.4.5 *Interviews*

After being approached by the keyworker and giving consent each participant was interviewed individually in the setting advised by the keyworker (own home, outpatient clinic, inpatient setting, day centre). The

participant was again asked whether s/he wished to proceed with the study and whether there were any questions. The interviewer checked the details recorded on the demographic data sheet with the participant. The instructions to participants were read aloud by the interviewer and a copy given to the participant. The questionnaires were administered in a pre-set order, namely DAS, TPB, DAI (when administered), DBS. Questions were again invited and answered. Participants were offered information about the results of the study at a later date.

2.4.5.1 *Presentation method:* To assist in clarity of presentation and response to questionnaires, the response options (minus three to plus three) for each of the new scales were drawn onto card so that patients could point to the relevant number as well as giving a verbal response to each question. Anchor points were placed at the extremes of the scale only, to indicate the meaning of the ratings (i.e., strongly agree to strongly disagree for the DAS and TPB attitude scales; 'always' to 'never' for the DBS deviation from prescription/non-compliance scale). Each item was presented to the participant both visually (the participant had a copy of the questionnaire to read) and verbally (the interviewer read out each item). After the participant had given a verbal response as well as pointed to their chosen rating, the response was recorded by the interviewer. This ensured all questions were answered. Papers were partly spoiled for two of the participants, because of a confusion between the scoring of the DAS and the Drug Attitude Inventory (DAI) which was given to assess concurrent validity of the new scales. For this reason, data from the DAS is only available for 104 participants.

2.4.6 *Keyworker ratings*

Keyworkers were approached by the interviewers within two days of administering the above scales to the participants and asked to provide a one to seven rating for the participant on the Kemp scale.

2.4.7 *Repeated measures*

In order to assess test-retest reliability twenty randomly selected participants were interviewed again at one month's interval. Keyworkers were asked to rate again in the same way as before.

2.4.8 *Inter-rater reliability*

For twenty randomly selected participants two interviewers scored the responses to each questionnaire, one administering the scales and recording responses, one simply recording responses. The two swapped roles so that each performed each role for half of the time. Since there were four interviewers altogether this meant that each interviewer saw ten participants in this fashion. Given the transparency of the procedure, where participants both say and point to their response, 100 per cent agreement was expected.

2.4.9 *Pilot study*

To check that all practical and data analysis arrangements were satisfactory, a pilot study was conducted involving six randomly selected participants. This showed several flaws in the communication with the participants through the keyworker route, so this was tightened up in the main study. Although there could be no statistically useful results, data collected was entered into the database and analysed according to plans for the main study. The arrangements for data entry and analysis appeared satisfactory. The feedback from participants was that they understood the information about the study and felt the task of responding to the questionnaires was manageable. The data from the pilot was included in the final database.

2.5 Data analysis

The description of the data analysis is given in detail below with the aim of clarifying the process of developing reliable and valid scales as well as of investigating the predictive utility of the scales. Both of these are essential in testing the hypotheses, firstly that such scales can be developed and secondly that they will have predictive validity in terms of compliance.

2.5.1 *Descriptive data*

The characteristics of the whole group of participants were described in terms of age, sex, diagnosis, length of illness, ethnicity, residential and marital/partner circumstances, type of neuroleptics prescribed, method of administration of drugs, drug dose. The latter was calculated using

information from the British National Formulary (1998) except for olanzapine, the equivalents for which were supplied by the manufacturers, Eli-Lilley pharmaceuticals (1998).

2.5.2 *Internal validity*

The internal reliability of the seven variables measured by the two new scales was analysed using Cronbach's *alpha.* Items which negatively affected reliability were dropped. Variables with poor internal reliability were dropped. The three variables remaining after the internal reliability procedures were re-named positive attitude, negative attitude and conditional positive attitude.

2.5.3 *Statistical assumptions*

These three remaining variables and the outcome variables were examined for normality of distribution and efforts made to normalise non-normal distributions using logarithmic and other transformations. The dependent variables from Kemp compliance and DBS non-compliance were similarly treated. Not all variables could be normalised, indicating the use of non-parametric statistics for data analysis. The correlations between the three variables along with the mean, standard deviation and minimum and maximum values for each were calculated.

2.5.4 *Inter-rater reliability*

The 100 per cent agreement expected between raters was checked by counting number of agreements versus number of disagreements.

2.5.5 *Test retest reliability*

The correlations between time I and time II scores on the three variables were examined using Spearman's *rho*.

2.5.6 *Concurrent validity*

The three variables were compared individually with the Drug Attitude Inventory (DAI) versions 10 and 30 using Spearman's *rho*.

2.5.7 *Predictive validity*

The relationships between the three variables and the outcome measures (DBS self report of non-compliance and Kemp keyworkers' ratings of compliance) was investigated using Spearman's *rho* to test for association. . A multiple regression analysis was performed, but results from this should be viewed with caution as the test assumptions concerning normality of

distributions were violated. The predictive validity of the DAI for the compliance measures was calculated to allow comparison with that of the new scales.

2.5.8 *Factor structure*

The factor structure of the new scale (the Drug Compliance and Attitude Scale-DCAS) made up of the three variables was examined using principal components analysis. Oblimin rotation was used because the hypothesised factors were moderately intercorrelated.

2.5.9 *Clinical utility*

Profiles for each participant using centiles to create a criterion for comparison were prepared, showing the different patterns of responding which may be found in a variety of patients and how this information may be useful to prescribers and keyworkers.

2.5.10 *Drug characteristics*

Features of the drugs themselves, such as type of drug, dose, method of administration, were examined in relation to both compliance and attitudes, using Spearman's *rho* for ordinal data and Mann-Whitney *U* or Kruskal-Wallis *H* for categorical data.

2.5.11 *Effects of demographics*

Relationships between demographic characteristics and scores on the three attitude variables and on the two compliance measures were explored in the same way as the drug data.

2.5.12 *Open-ended data*

Participants' reports of the reasons for non-compliance were allocated to categories developed by two undergraduate volunteers. The whole information set was categorised twice, once by each volunteer and the few disagreements as to category allocation settled by discussion between the two. This data is presented as numbers of participants endorsing each category along with sample statements from each category.

2.5.13 *Non-participants' characteristics*

Demographic data and keyworker ratings of compliance for the fifty six non-participants were compared using Mann-Whitney *U* to compare ordinal data and Chi-square to compare categorical data.

CHAPTER 3

Results

3.1 Descriptive data

The characteristics of the whole group of participants were described in terms of age, sex, diagnosis, length of illness, ethnicity, residential and marital/partner circumstances, occupation, type of neuroleptics prescribed, method of administration of drugs. Figures 2 consists of pie charts showing group demographic characteristics and medication, Table 1 briefly summarises group statistics. Only one participant was of ethnic origin other than Caucasian; only twenty one participants were married or living with a partner; none had a paid occupation. The majority of patients were in their twenties, thirties and forties, with an equal number of males and females (53 in each group). The date of onset (first diagnosis) of illness was only available in the notes of 82 participants, average length of illness for these was around 14 years; 35 patients (33 per cent) had a primary diagnosis of schizoaffective disorder, 71 (67 per cent) had a diagnosis of schizophrenia. All of the group had left education by nineteen and the majority (N = 84; 79 per cent) at sixteen. In short, this was a group with established illness histories, with greatly reduced access to further education, supportive relationships and paid employment, typical, except in terms of ethnicity, of many outpatient populations of schizophrenics found around the country, whose main treatment is neuroleptic medication and whose support from services is mainly delivered by Community Psychiatric Nurses.

Old, or classical, neuroleptics were being taken by 70 participants (66 per cent), while new, or atypical neuroleptics were taken by 29 people (27 per cent), of these, 24 were prescribed respiridone, the remainder taking olanzapine. A combination of old and new drugs was taken by seven people (seven per cent). Medication was administered by depot route only for 47 patients (44 per cent), while 49 people (46 per cent) took only tablets. A combination of tablets and depot was prescribed for seven patients (seven per cent). Chlorpromazine equivalent doses allow rough comparison of amount of medication taken by patients, although these can only be calculated for the 49 people on tablets.

Figure 2 Pie charts showing group demographic and medication details

Figure 2.1

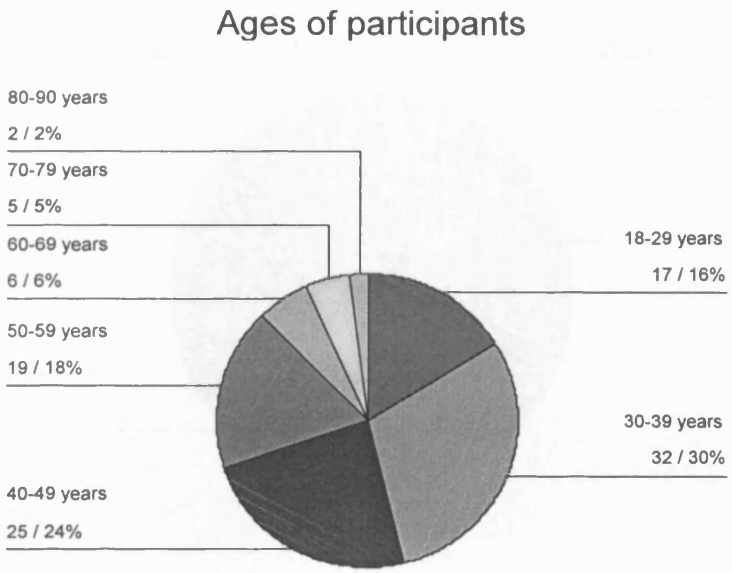
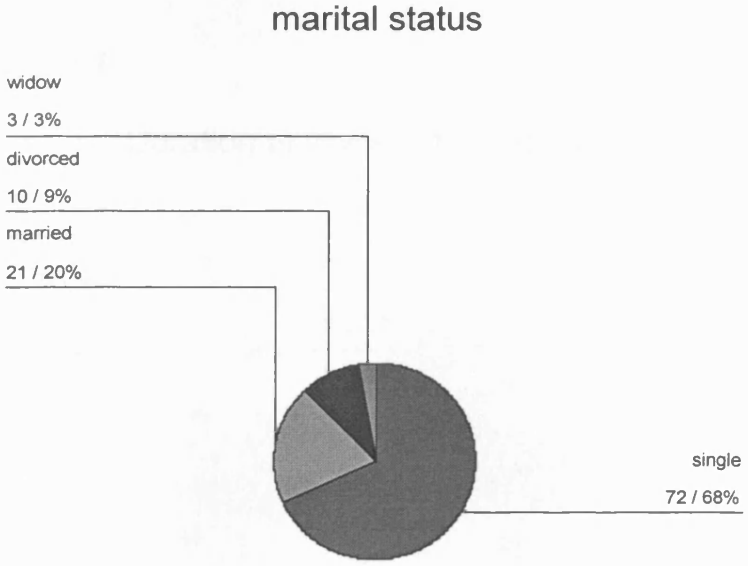


Figure 2.2



'married' = relatively permanent partnership

Figure 2.3

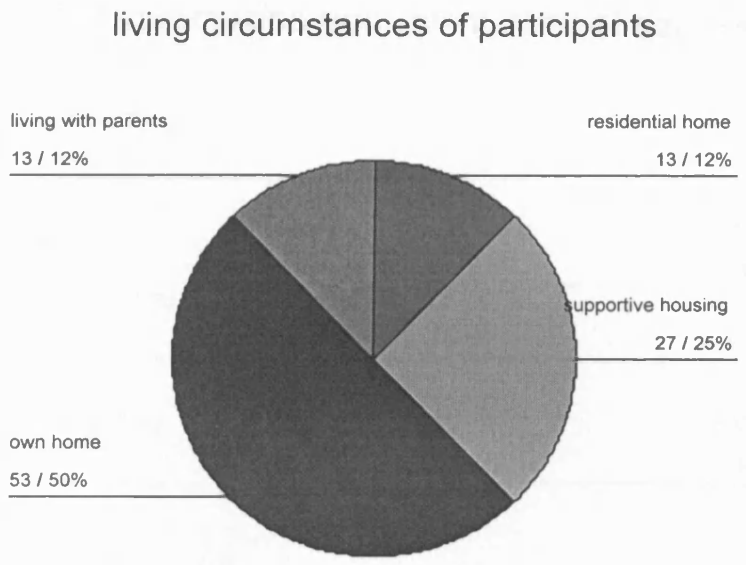


Figure 2.4

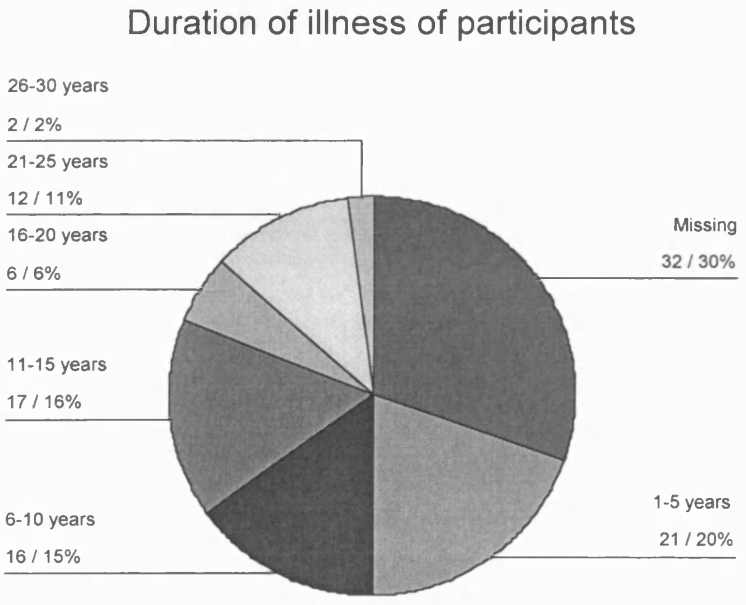
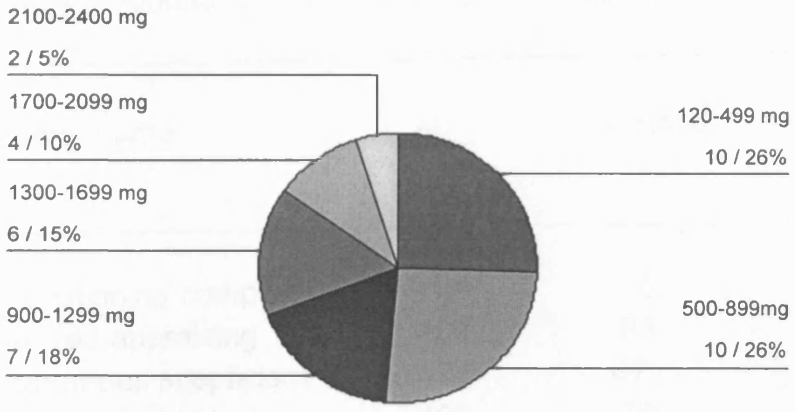


Figure 2.5

Chlorpromazine equivalent dose of neuroleptic



Chlorpromazine equivalents from British National Formulary (1997) and Eli Lilly & Co. Ltd. (1998).

Table 1 Age, education and length of illness of participants

	N	X	s. d.	min.	max.
age	106	42.9	14.17	21	81
education post 5yrs.[a]	106	11.11	.81	8	14
length of illness [b]	82	13.8	10.27	1	47

a number of years in full-time education after age five
b number of years since first diagnosis

3.2 Internal validity

The internal reliability of the seven variables measured by the two new scales was analysed using Cronbach's *alpha*. Table 2 shows all seven variables' initial *alpha* statistics and *alpha* after items which negatively affected reliability were dropped.

Four variables with poor internal reliability (final alpha less than 6.5) were dropped. These were unquestioning compliance (UC) from the Drug Attitude Scale (DAS) and three variables from the Theory of Planned

Behaviour scale (TPB), namely, subjective norm (SN), perceived behavioural control (PBC) and behavioural intention (BI).

Table 2 Cronbach's *alpha* for the seven predictor variables

Variable name	*N*	initial α	final α
unquestioning compliance	104	.30	.53
balanced appraising	104	.65	.70
autonomous scepticism	104	47	.65
attitude to behaviour	106	.70	.70
subjective norm	106	-.46	.46
perceived behavioural control	106	.52	.52
behavioural intention	106	.58	.58

Three variables with satisfactory reliability remained. For ease of reference and to simplify the presentation, these were renamed as follows: from the DAS, balanced appraising (BA) was renamed conditional positive attitude (CP) and autonomous scepticism (AS) was renamed negative attitude (N); from the TPB Scale, attitude to behaviour (AB) was renamed positive attitude (P). This process had the effect of reducing the two initial questionnaires (DAS and TPB) to one scale with three subscales, namely positive (P), conditional positive (CP) and negative attitude (N). The new combined scale was renamed the Drug Compliance and Attitude Scale (DCAS) (Appendix M). An examination of the item content of the three independent variables should show why the new names were chosen: Positive attitude (P) consists of positive statements about the act of taking medication; conditional positive (CP) contains positive statements about the effect of the drugs, but also has two conditional items, one endorsing the idea that the person should have the minimum dose necessary and the other indicating that the person does experience side effects from the

medication; negative attitude (N) contains unqualified negative statements about both taking the medication and its effects.

Table 3 Item content of the three reliable predictor variables

P attitude to behaviour (AB) (renamed positive attitude) (P)
• taking my drugs is unpleasant (-) • taking my medication is enjoyable • taking my medication is foolish (-) • taking my drugs is harmful (-) • taking my medication is good *α = .70
CP balanced appraising (BA) (renamed conditional positive) (CP)
• my drugs make me happier • my medication makes me less tense • I should have the minimum dose needed • my medication makes me see reality better • my drugs aren't good for me (-) • I don't have any side effects (-) • my drugs make my brain work better • my medication makes me think clearer * α =.70
N autonomous scepticism (AS) (renamed negative attitude) (N)
• it's hell taking this medication • this medication drains my energy • I'm frightened of my medication controlling me • I've lost interest in things since I've been on my drugs * α = .65

3.3 Statistical assumptions

The five dependent variables consisted of one representing the keyworker's perception of the patient's compliance on the Kemp Scale (referred to as 'Kemp keyworker' or 'Kemp') and four representing Drug Behaviour Scale (DBS) patient ratings of their own non-compliance, namely deviation from prescribed time of taking the drug (referred to as 'DBStime'), deviation from prescribed drug dose ('DBSdose'), a rating of how often the dose was missed out altogether ('DBSmiss') and a total deviation from prescription score ('DBStotal'). Thus, a high score on the Kemp variable represents high compliance, whereas a high score on the DBS variables represents low compliance, because it measures deviation from prescription.

The three independent variables P, CP and N were examined for normality of distribution and efforts made to normalise non-normal distributions using logarithmic and other transformations. The five dependent variables were similarly treated. Transforming the non normal variables did not normalise the distributions. Table 4 outlines descriptive statistics for each variable. Appendix N shows the distributions with normality tests. Only negative attitude (N) was normally distributed, the majority of the rest showing positive skews, with the exception of conditional positive (CP) which was bimodally distributed.

Table 4 Distributions and descriptive statistics for three independent and five dependent variables

Variable	*N*	X	s.d.	min.	max.	Distribution normal?
Positive attitude (P)	106	4.16	6.70	-14	15	no
conditional positive (CP)	104	10.01	8.19	-7	24	no
negative (N)	104	-1.63	6.10	-12	12	yes
Kemp (keyworker)	106	5.13	1.34	1	7	no
DBStime	106	1.7	2.09	0	6	no
DBSmiss	106	.75	1.42	0	5	no
DBSdose	106	.59	1.4	0	5	no

It is noticeable that, among the three attitude variables, conditional positive stands out as having a minimum value that does not reflect the full possible range of potential total scores: This variable is made up of eight items, giving a potential negative extreme of -24, yet the most negative score is -7, suggesting that participants tended to agree with the CP items.

All variables from the DBS self report measures show marked positive skew, indicating an unsurprising tendency for participants to report themselves as compliant. The keyworker ratings in the Kemp scale show normal distribution when eleven outliers are omitted. However, since these are the extremely non-compliant individuals it would seem foolish to leave them out. Because the distributions could not be normalised despite transformations the use of non parametric statistics was indicated for correlational and comparative analyses. Table 5 shows analyses of the relationships between the three variables using Spearman's *rho*. The three are moderately intercorrelated, with negative correlations between negative attitude and the other two.

Table 5 Correlations between the three predictor variables (N = 104)

	positive attitude	conditional positive	negative attitude
	r_s	r_s	r_s
positive attitude	-	.51**	-.67**
conditional positive	.51**	-	-.36
negative attitude	-.67**	-.36**	-

**p = < 0.01 (1-tailed for P and N, 2-tailed for CP).

3 4 Predictive validity of the DCAS

Table 6 shows correlations between the three attitude variables and the five outcome measures using Spearman's *rho*. A significant positive correlation was found between positive attitude and compliance as rated by keyworkers (Kemp). A significant negative correlation was found between self report of non-compliance (DBS time and DBStotal) and positive attitude. Conditional

positive attitude was not correlated with keyworker (Kemp) ratings, but people who scored highly on conditional positive attitude were more likely to report themselves as compliant as shown by their DBS time and total scores. Negative attitude was significantly associated with self reported non compliance and negatively associated with keyworker ratings of compliance. In summary, people scoring *high* on positive attitude were *compliant* on both keyworker and self report measures, those scoring *high* on negative attitude were *non compliant* on both measures and those scoring *high* on conditional positive *reported themselves as compliant* but were not rated so by keyworkers.

Table 6 Predictive validity of the Drug Compliance and Attitude Scale (DCAS): Correlations with compliance ratings.

DCAS attitude		Kemp (keyworker)	DBS time	DBS miss	DBS dose	DBS total
positive *N*=106	r_s (1-tailed)	.201*	-.29*	-.17*	-.08	-.32**
conditional *N*=104	r_s (2-tailed)	.148	-.27**	-.20*	-.11	-.31*
negative *N*=104	r_s (1-tailed)	-.288**	.21*	.09	.10	.24**

*p = < 0.05 (1-tailed for P and N, 2-tailed for CP).
**p = < 0.01 (1-tailed for P and N, 2-tailed for CP).

The measure of changing drug dose was not correlated with any variables and correlations for the deviation on time measure (DBS time) were similar to correlations for DBS total, suggesting that participants deviated from prescription mainly by changing the time the drug was taken. Missing doses altogether could be regarded as an extreme form of deviation from prescribed time.

A multiple regression analysis regressing the three predictor variables against Kemp keyworker ratings showed that the model predicted 9 per cent of the Kemp variance (R^2 = .09, S E 1.30). The only significant semipartial correlation was that between negative attitude and Kemp

(B = -.25, t = -2.0, p = <.05) suggesting that the single important predictor variable was negative attitude. The model as a whole was significantly predictive of the Kemp outcome variable (F = 3.26, d. f. 3, p = < .05). A multiple regression analysis regressing the three predictor variables against DBStotal self-report ratings showed that the model predicted 10 per cent of the DBStotal variance (R^2 = .10, S E 3.51). There were no significant semipartial correlations, but the model as a whole was significantly predictive of the DBS outcome (F = 3.73, d. f. 3, p = < .05). These latter results are of course subject to the caveat that multiple regression is a parametric technique and so results may be invalid.

3.5 Concurrent validity of the DCAS

The three variables positive (P), negative (N) and conditional positive attitude (CP) were compared individually with both versions of the Drug Attitude Inventory (DAI 10 and DAI 30) using Spearman's *rho*. Table 7 shows the correlations.

Table 7 Concurrent validity of the DCAS: Correlations with the DAI versions 10 and 30

	N	positive attitude (P) r_s	conditional attitude (CP) r_s	negative attitude (N) r_s
DAI 10	29	.39*	.34	-.37*
DAI 30	39	.48**	.61**	-.45**

*p = < 0.05 (1-tailed for P and N, 2-tailed for CP).
**p = < 0.01 (1-tailed for P and N, 2-tailed for CP).

Both versions of the DAI yield a single score, which proved difficult to interpret. Hogan, Awad & Eastwood (1983) reported using scores below the median to indicate dysphoria and scores above the median to indicate 'syntonia'. Following a request for guidance from the author, Hogan (1998, personal communication) suggested a scoring system where "incorrect" answers (i.e., those answers not indicating compliant attitudes) were given a negative score while "correct" answers gained a positive score. This is the

system that was used to produce the DAI results in Table 7. Thus, high scores on the DAI indicate agreement with compliant attitudes as defined by the DAI authors.

Positive attitude (P) was significantly related to high scores on both versions of the DAI, negative attitude (N) was significantly negatively correlated with both versions of the DAI and conditional positive was significantly associated with the DAI 30, but not with the DAI 10 ,although a trend towards association can be observed, suggesting that the positive and negative scales are measuring similar constructs to those measured by high and low ends of the DAI respectively, and that conditional positive attitude is measuring something similar to the DAI 30 also. The association is greater with the DAI 30, suggesting that some useful information may be lost if the DAI 10 is used alone.

3.6 Predictive validity of the DAI

The predictive validity of the DAI was tested in order to compare its power with that of the DCAS. Table 8 shows correlations between the DAI 10 and DAI 30 and the Kemp keyworker and DBS self report measures.

Table 8 Predictive validity of the DAI: Correlations with compliance ratings

	Kemp (keyworker) r_s [a]	DBStime r_s	DBSmiss r_s	DBSdose r_s	DBStotal r_s
DAI 30 N=29	.16	-.04	.01	-.19	-.09
DAI 10 N=39	.24	-.02	-.20	-.01	-.13

a Spearman's *rho* (1-tailed in each case).

There are no significant correlations, although the DAI 30 may be approaching significance as regards the Kemp scores. The DCAS appears superior in terms of predictive power and also in its ability to distinguish those patients (scoring high on conditional positive attitude) who say they are compliant but are not so according to the keyworkers.

3.7 Factor structure of the DCAS

The factor structure of the DCAS was examined using principal components analysis with oblique rotation because the hypothesised factors (the predictor variables) were moderately intercorrelated (Child, 1990). A scree graph gave a slope which became markedly shallower after four factors, although there were seven factors with eigenvalues greater than one. Suppression of more than three factors therefore appeared a reasonable course of action in an effort to confirm the hypothetical factor structure. This produced three factors which together accounted for 49 per cent of the scale variance. Table 9 shows the eigenvalues, factor loadings and item content of each factor.

The first factor contains five of the initial eight conditional positive items, the second includes all four negative attitude items. The third has only one item loading greater than .5, 'taking my medication is foolish (-)'. This is from the positive attitude scale. One other item from the positive attitude scale, 'taking my drugs is unpleasant (-)' appears to have 'migrated' into the second factor, loading negatively as part of negative attitude.

Table 9 Factor structure of the DCAS and item content of the factors

	DCAS item no.	loading [a]	content
Factor 1	9	.97	neuroleptics aren't good for me(-)
	6	.84	neuroleptics make me less tense
	17	.76	I don't have any side effects from my medication(-)
	1	.75	neuroleptics make me happier
	11	.56	I should have the minimum dose needed to keep my symptoms under control
Factor 2	8	.83	I'm frightened of my medication controlling me
	3	-.75	taking my drugs is unpleasant(-)
	2	.69	this medication drains my energy
	13	.61	I've lost interest in things since I've been on the neuroleptics
	4	.60	it's hell taking this medication
Factor 3	10	.75	taking my medication is foolish(-)

a only items with loadings > .5 are listed

Extraction method: Principal Component Analysis

Rotation method: Oblimin with Kaiser Normalisation

Rotation converged in 10 iterations

Total Variance Explained

	Initial Eigenvalues			Rotation
Component	Total	% of Variance	Cumulative %	Total
1	5.307	31.217	31.217	4.770
2	1.606	9.448	40.665	4.126
3	1.387	8.160	48.824	1.408

Extraction Method: Principal Component Analysis.

a. When components are correlated, sums of squared loadings cannot be added to obtain a total variance.

These three factors were saved as variables and correlated with the keyworker ratings and self report outcome measures. Table 10 shows the correlations. The same predictive validities were obtained as previously for conditional positive and negative attitudes. Positive attitude correlations were in the right direction but ceased to be significant. These results

suggest only two underlying factors, conditional positive and negative. The results are also consistent with the multiple regression analysis, in that negative attitude seems to be the best predictor of compliance scores from both sources.

Table 10 Predictive validity of the DCAS factors: Correlations with compliance ratings

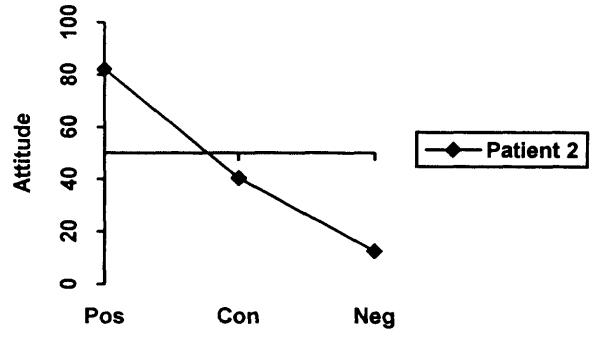
Factor	Kemp (keyworker) r_s	DBStotal (self) r_s
1 (conditional positive)	.13	-.28**
2 (negative)	-.27**	.28**
3 (positive)	.16	-.101

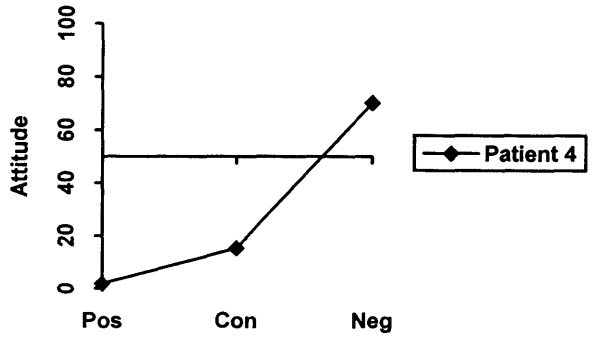
**p = < 0.01.

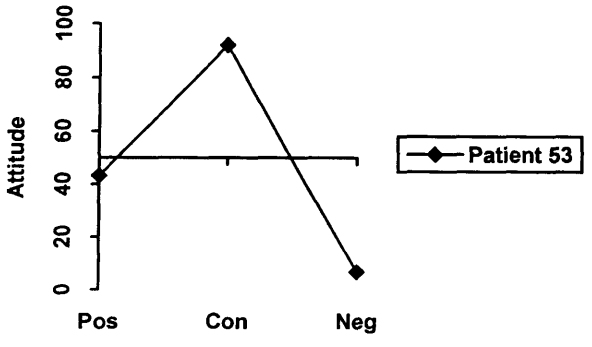
3.8 Clinical utility of the DCAS

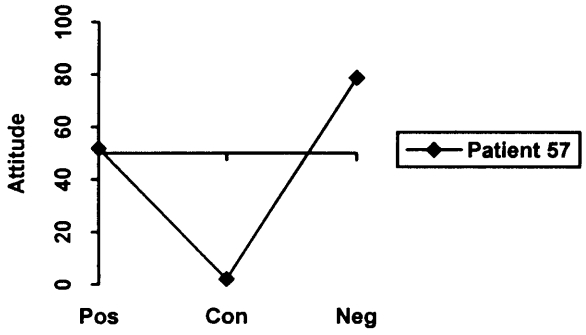
Profiles for each participant using centiles to allow comparison against the group as a whole were prepared (Appendix O), showing the patterns of responding which may be found in a variety of patients and how this information may be useful to prescribers and keyworkers. Figure 3 contains the individual profiles of five participants, the first, patient 2, is an individual with a strong positive attitude, the second, patient 4, is a person with a tendency towards being conditionally positive, the third, patient 53, is an individual high in negative attitude, the fourth, patient 57, has high scores on positive and negative attitude simultaneously, the fifth, patient 68, has roughly equivalent attitude scores on all three variables, and this patients attitude levels are average for the group, all falling roughly at the 50^{th}. centile. Appendix O shows the full range of patients' profiles, in general there are interesting differences between the three subscale scores for the majority of patients. It can be seen that there are two informative aspects of the profiles, firstly the pattern of the subscales, secondly, the centile score which allows comparison of the scores with those of the rest of the group.

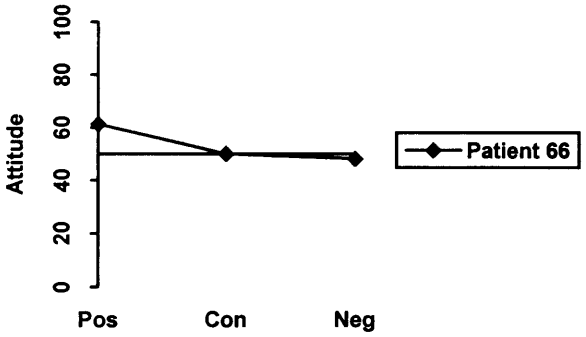
Figure 3 Sample patient DCAS profiles











3.9 Inter rater reliability

For twenty randomly selected participants two interviewers scored the responses to each questionnaire, one administering the scales and recording responses, one simply recording responses. The two exchanged roles so that each performed each role for half of the time. Since there were four interviewers altogether this meant that each interviewer saw ten participants in this fashion. Given the transparency of the procedure, where participants both say and point to their response, the 100 per cent agreement found between interviewers was to be expected.

Another form of inter-rater reliability is the degree of agreement between the keyworkers and the patients on the ratings of the patients' compliance. The correlation was calculated between the Kemp and DBStotal variables, representing keyworker ratings and patient self-report respectively. The correlation was not significant (r_s. (106) =.116, p = .237). It should be borne in mind that a significant correlation was neither expected

or desirable here, the differences between the two sets of ratings being most interesting.

3.10 Test retest reliability

Correlations between scores on time I and time II, one month later, for each of the three attitude variables were calculated as follows: Positive attitude (r_s.(20) = .91, p = < .001); Conditional attitude (r_s.(20) = .82, p = < .01); Negative attitude (r_s.(20) = .71, p = < .05); indicating good to satisfactory test-retest reliability for the scales.

3.11 Compliance ratings

Only 16 patients were assigned the highest compliance rating by their keyworkers. This rating is defined as 'Active participation, e. g., patient readily accepts medication and takes responsibility for their treatment'. The majority of patients (N =37) were assigned a rating of five, defined as 'passive acceptance'. Frequent questioning of treatment, partial or complete refusal produced ratings of three or less for 11 patients. In general, the picture is of a group of people who have limited enthusiasm for their treatment and amongst whom those who actively comply without prompting are a minority (28 patients were rated as moderately (rating = 6) or actively (rating = 7) participating). Outright refusal is also rare (two patients' compliance levels were rated as 1). The majority of non-compliant behaviour appears to occur among the middle scoring group, showing 'passivity and occasional reluctance' (ratings of 4 and 5 were assigned to the behaviour of 53 patients).

Although the Kemp ratings are somewhat negatively skewed, indicating a tendency for keyworkers to rate towards the compliant end of the scale, the DBS self-report measures are all extremely positively skewed, indicating a very strong tendency for patients to report that they deviate very little from the prescribed behaviour. The DBS total represents the sum of all the possible ways patients could deviate from prescription. A score of zero indicates complete compliance and 44 patients' reports fell into this

category. This is in contrast with only 16 whose compliance was rated highest by the keyworkers.

3.12 Effects of drug characteristics

Table 11 shows relationships between drug variables and compliance measures. Those on atypical neuroleptics (*N* = 29) were neither more nor less compliant on either measure compared with people taking classical neuroleptics (*N* = 70) or those on both types (*N* = 7), as shown by Kruskal-Wallis *H* results for the Kemp keyworker ratings and for the Drug Behaviour Scale self report scale. In response to concerns that this might be because 47 patients taking old neuroleptics received their drug through the depot route, the analysis was run for those people taking only tablets. No significant difference was found between those on old neuroleptics and those on new neuroleptics on Kemp compliance ratings (Z = -1.6, p = .11, 2-tailed), or on DBS self-report of compliance (Z = -.62, p = .54, 2-tailed).

Table 11 Drug variable relationships with compliance

drug	test	N	Kemp (keyworker)	DBS time	DBS miss	DBS dose	DBS total
old/new /both	H (χ^2)	106	3.4	.30	1.48	2.10	.59
tab/dep /both [a]	H (χ^2)	106	2.6	9.9**	19.16**	12.56**	24.35**
dose [b]	r_s (2-tailed)	40	.15	-.14	-.08	-.30	-.31

*p = < 0.05, **p = < 0.01.
a tablets > both > depot.
b chlorpromazine equivalents

Those on depot injections were rated neither more nor less compliant on Kemp keyworker ratings than other patients. On the DBS total score those on tablets reported themselves as less compliant than those on both depot and tablets, who in turn reported themselves as less compliant than those

on depot. Supervision of drug taking was not associated with greater compliance on the Kemp measure (χ^2 = 2.6, d.f. 2, p = .24), or on the DBS self-report measure (χ^2 = .63, d.f. 2, p = .71).

Spearman's *rho* showed that a tendency to add over the counter drugs to the prescribed medication was associated with a tendency to report oneself as less compliant (r_s (106) = .38, $p < .05$), but keyworker ratings did not confirm this, as shown by the correlation between self-ratings of adding over the counter drugs and Kemp keyworker ratings of compliance (r_s (106) = .14, p = .28). Self-report ratings of adding illicit (street) drugs to one's medication was not related to compliance on either measure, as shown by correlations between self-report of adding street drugs and Kemp keyworker ratings of compliance (r_s (106) = 11, p = .32) and by correlations between self-report of adding street drugs and self-report of compliance (r_s (106) = .09, p = .38).

3.13 Demographic variables and compliance

Relationships between demographic characteristics and scores on the three variables and on the two compliance measures were explored using Mann-Whitney *U* or Kruskal-Wallis *H* procedures to test for differences between groups and Spearman's *rho* to test for association between variables. Table 12 shows that females were more likely to be rated as non compliant. DBS self-report scales showed women did not report themselves as non compliant. Those with a longer illness history were more likely to report themselves as compliant but keyworkers ratings did not support this, suggesting that the people with most experience of being a patient may have learned to report themselves as compliant over time. Older people said they were more compliant and keyworkers agreed.

Marital status was not related to either compliance measure. No effect was found for living circumstances (supported lodging, own home, etc.), psychiatrist or diagnosis (schizophrenia or schizoaffective disorder).

Table 12 Demographic variable relationships with compliance

Variable (N = 106)	test	Kemp (keyworker)	DBStime	DBSmiss	DBSdose	DBStotal
age	r_s (2-tailed)	.59**	-.22*	-.13	-.20*	-.29**
education post 5yrs.	r_s (2-tailed)	-.00	.07	-.09	-.17	-.05
Length of illness	r_s (2-tailed)	-.02	-.12	-.28*	-.14	-.27*
sex	Z	-2.32*	-.01	-1.47	-.82	-.64
diagnosis	Z	-1.68	-.95	-.63	-.07	-.83
negative symptoms	Z	-.11	-.01	-.04	-1.20	-.44
residence	$(\chi^2)^a$	7.63	5.50	.05	1.35	2.61
marital status	$(\chi^2)^a$	3.22	3.56	2.47	.79	3.35

*p = < 0.05, **p = < 0.01.
a df = 3

The relationships between the three attitude variables and demographic data were investigated in a similar way. Table 13 shows the results. There were significant differences for gender, women having more negative attitudes, which seems consistent with the keyworker ratings of lower compliance among women. These attitudes may be reflected in women's non-compliance behaviour, even though women report themselves as no more or less compliant than men.

Older patients showed more positive attitudes towards the medication, this considered alongside their reporting of greater compliance seems to indicate more positive and compliant behaviour and attitudes in general.

Although diagnosis was not associated with compliance, it was associated with attitude, people with a diagnosis of schizoaffective disorder showing more negative attitudes and less positive and conditional attitudes than those with a diagnosis of schizophrenia.

Table 13 Demographic variable relationships with attitudes

Variable (N = 106 (P), N = 104 (CP and N)	test	positive (P)	conditional (CP)	negative (N)
age	r_s (2-tailed)	.21*	.14	-.18
education post 5yrs.	r_s (2-tailed)	.08	-.04	-.08
Length of illness	r_s (2-tailed)	.16	.13	-.16
sex [a]	Z	-.92	-.99	-2.53*
diagnosis [b]	Z	-2.75**	-2.46*	-2.92**
negative symptoms	Z	-.45	-.86	-.37
residence [d]	χ^2	2.88	4.24	1.21
marital status [e]	χ^2	9.55*	.63	8.45*

*p = < 0.05, **p = < 0.01.
a females > males
b schizophrenic diagnosis has more positive, more conditional and less negative attitude
c married people have more negative attitudes than single, who have more than divorced. The exact reverse is true for positive attitudes.
d df = 3
e df = 2

Marital status was significantly associated with positive and negative attitude, but not with conditional attitude. Married people had significantly more negative attitudes than single, who had more negative attitudes than divorced people, the exact reverse being true for positive attitude.

Further exploration of the relationships between gender, marital status and diagnosis was carried out Excluding divorced and widowed people left a group of 93 people, 47 male and 46 female. Within this group, women are significantly more likely to be married than men, (Z (93) = -2.658, p = <.01), and people with a diagnosis of schizoaffective disorder are significantly more likely to be married than those with a diagnosis of schizophrenia (Z (93) = 3.140, p = <.01. There is a non-significant trend showing that women are more likely to be assigned a diagnosis of schizoaffective disorder than to be assigned a diagnosis of schizophrenia (Z (106) = -1.439, p = .150).

These results taken together seem to suggest that women may display more 'mood' among their symptoms, leading to a greater likelihood of schizoaffective diagnosis (see DSM IV criteria, Appendix A). The mood referred to is most often a depressed mood, so that the negative attitudes reported towards drugs by women may be part of a larger picture where all aspects of life are viewed negatively, or may reflect particularly negative experience of drug treatments.

3.14 Open-ended data: Reasons for non-compliance

Participants' reports of the reasons for non- were allocated to categories as described in section 2.5.12. This data is presented in Table 14. Some patients gave several reasons which fell into several categories, so that numbers cannot be summed.

The major reasons given for non compliance were: inconvenience (*N* = 18), this category included embarrassment at taking medication in front of other people; forgetting (*N* = 17); subjective state (*N* = 16), including stopping medication when feeling better as well as failing to take medication because of side effects or confusion; idiosyncratic reasons (*N* = 21). Not everyone could articulate why they deviated from prescription, 39 patients, representing 37 per cent of the sample, could give no reason for non compliance. Reducing or increasing sedation and disorganisation, reasons which have been thought important in the literature, were each cited by only four patients.

It is notable that reasons given for non-compliance include manipulations perceived by the patient to increase as well as decrease drug effects and side effects, for example wanting to sleep more or taking extra medication because of increased symptoms or "feeling unwell". The Drug Behaviour Scale was not structured to allow collection of data about deviation from prescription by increasing as opposed to decreasing dose, so that it is not possible to find out how many people are 'augmenters' rather than 'reducers'.

Table14 Reasons given by patients for non-compliance

no. of patients giving reason	reason for non-compliance (category)	example of response
17	forgetting	I forget (usual response) It depends on reminders I only remember at tea time
18	inconvenience	I don't like to take (drugs) in front of my friends whenever it's convenient when it's convenient to go to the Centre (for depot)
16	subjective state	I take what I think I need Sometimes I feel I don't need it Thought I'd feel better without the drugs Depends on how I feel If I'm well I don't take them
4	disorganisation	keeping to time isn't important I oversleep I'm too busy to get to the clinic
4	sedatory effects	If they make me tired I might take them later In case I want to sleep To feel less sleepy
21	idiosyncratic reason	To avoid mixing (drug) with alcohol To lessen the strength If I'm feeling ill, someone's telling me not to take them The drugs screwed up my brain If I run out of tablets I get paranoid and can't get to the doctor's for a prescription If the tablets don't work, don't stop the voices
59	no reason	don't know (majority response) no reason, really it's just me can't say hmmn god knows

It is also interesting that so many people could not give a reason for not taking their drugs. This could reflect inability to report on the patients' parts. Alternatively it may reflect the strong tendency observed throughout these results for patients to report themselves as compliant, so that even when the participant has given ratings showing they are not completely compliant, they are not prepared to go further by discussing why this might be.

3.15 Non-participants' characteristics

The demographic and drug characteristics of the 56 patients whose keyworker thought unfit to participate or who refused to participate were compared with participants' scores, along with the keyworker ratings of their compliance. Mann-Whitney and *Chi*-square analyses (see Appendix P) showed no significant differences on any variable, suggesting that this group was not different from the participants group. The results give confidence to drawing conclusions from the data about the catchment area sample as a whole. It is likely however that the groups did differ on severity of symptoms, this being the main reason for keyworker advice not to involve the patient in the study. Severity of symptom data was not collected in this study.

Chapter 4

Discussion

4.1 Overview of discussion

The discussion begins with a summary of results and then the study hypotheses are used as a framework for a discussion of the predicted and actual outcomes. Findings from the analyses of data on drug characteristics, demographic characteristics and open-ended data are discussed next. The theoretical implications of the findings are discussed with particular reference to the theory of planned behaviour. In the next section, clinical implications of the findings are explored, including use of the DCAS to collaboratively improve compliance and how to identify and support those who choose not to comply. A critical analysis of the strengths and weaknesses of the study follows, with indications as to how it could be improved upon, especially in terms of the development of the DCAS and additional data collection. Recommendations for future research are outlined next and then conclusions end the chapter.

4.2 Research findings

4.2.1 *Summary of results*

The aim of the study was to develop a measure of subjective appraisal of neuroleptic medication which would tell the clinician and the patient something about the patient's attitude and the patient's likely compliance behaviours. This was not only to help the clinician and patient improve compliance but also to potentially alter the interactions between patient and prescriber away from an authoritarian or paternalistic discourse and towards open and frank discussion of all aspects of the patient's experience of neuroleptic treatment and behavioural, cognitive and affective responses to the treatment. For this to be fully achieved, it would be necessary that choosing not to take the drugs be entertained as a genuine option for patients.

The results of the study fall into two categories, relating to the first hypothesis that attitude scales could be developed from seven potential 'predictor' variables and the second hypothesis that the scales would predict

compliance behaviour. The study had the twofold purposes of simultaneously developing and applying the scales.

In terms of developing reliable and valid measures of patient subjective appraisal, three variables were derived from the seven contained within the two initial questionnaires, through an analysis of internal reliability. Cronbach's *alpha* was .7 for the positive (P) and conditional attitude (CP) variables and .65 for the negative attitude variable (N). These three variables together were named the Drug Compliance and Attitude Scale (DCAS). As well as internal reliability, test-retest reliability was assessed by repeating the questionnaires with 20 participants after a one-month interval. Test-retest reliability was satisfactory (*rho* = .91, .82 and .71 for P, CP and N respectively).

The factor structure of the DCAS was explored using principal components analysis and three factors found which accounted for 49 per cent of the scale variance. The third factor had only one item with a loading greater than .5. The five items loading on the first factor were all from the conditional positive (CP) variable. The five items loading on the second factor were the four items from the negative (N) variable and one from the positive (P) variable, this last item loading negatively on factor 2. The one item loading on Factor 3 was from the P variable.

The concurrent validity of the DCAS was assessed by correlating each subscale (the predictor variables) with the DAI scores. Significant correlations were found between positive attitude (P) and both versions of the DAI (DAI 10: r_s (29) = .39, p = < .05; DAI 30: r_s (39) = .48, p = < .01); significant negative correlations between N and both versions of the DAI (DAI 10: r_s (29) = -.37, p = < .05; DAI 30: r_s (39) = -.45, p = < .01;) and significant positive correlation between CP and the DAI 30 (r_s (39) = .61, p = < .01) but not between CP and the DAI 10 (r_s (29) = .34, p => .05). The DCAS was moderately correlated with the DAI.

The predictive validity of the DCAS was assessed by correlating subscale scores with keyworker ratings of compliance (Kemp) and with self-report ratings of non-compliance (DBStotal). A significant correlation was found between positive attitude (P) and Kemp (r_s (106) = .20, p = < .05) and P and DBStotal (r_s (104) = -.32, p = < .01). The correlation between

negative attitude (N) and Kemp was also significant (r_s (104) = -.29, p = < .01) as was the correlation between N and DBStotal (r_s (104) = .24, p = < .01). However, there was no significant association between conditional positive (CP) and Kemp (r_s (104) = .15, p = > .05). Thus, *high* scores on P predicted *high* compliance on both measures; *high* scores on N predicted *low* compliance on both measures; *high* scores on CP predicted *high* scores on self-report of compliance but not on keyworker ratings. The factors from the factor analysis of the DCAS were saved as variables and correlated with the Kemp and DBStotal compliance measures. Significant correlations were seen in the same direction as for the corresponding variables (CP corresponds with Factor 1, N corresponds with Factor 2). Factor 3 (corresponding with P) correlations failed to reach significance. The predictive validity of the DAI was assessed by the same method as the DCAS but no significant associations were found with either DBS or Kemp compliance ratings. The DCAS was found to be superior in predictive power to the DAI for this group.

In assessing the predictive validity of the DCAS, as well as developing the scale, the scale itself was being used to test the second hypothesis about predictive power of the 'predictor' variables. Since only three were effectively developed the first hypothesis was only partly supported. They were however predictive of compliance and in the directions set out in hypothesis two.

Analyses of data concerning drug characteristics showed that there was no difference in compliance levels associated with new compared with old neuroleptics as assessed by keyworkers (χ^2 (106) = 3.4, d. f. 2, p = >.05) and by self-report (χ^2 (106) = .59, d. f. 2, p = >.05). People taking tablets reported themselves as more compliant (χ^2 (106) = 24.35, d. f. 2, p = <.01) although keyworker ratings did not bear this out (χ^2 (106) = 2.6, d. f. 2, p = >.05). No significant effects of drug dose were found on either the Kemp or DBS compliance ratings.

People who deviated from prescription did so mainly by changing the time they took the drugs, rather than the dose. Only 16 people were rated as fully compliant by their keyworkers, in contrast to 44 people who rated themselves as fully compliant, confirming the expectation that participants

would tend to over-rate their compliance when compared to keyworker opinions. The inter-rater correlation between self-report total score and keyworker compliance ratings was non-significant (r_s (106) = .12, p = .24, 2-tailed), emphasising the different viewpoints of the two sets of people. Profiles for each individual in the sample were prepared, showing their DCAS score patterns to be varied and to represent many different score combinations (Appendix O).

Descriptive data showed that the 53 male and 53 female participants represented a socially disadvantaged group of people with long-term symptoms, receiving community care, typical of many populations of people taking neuroleptics, with the exception of ethnicity.

Associations between demographic variables, compliance and attitudes were as follows. Older people reported greater compliance on the DBS (r_s (106) = -.29, p = < .01) and keyworkers agreed (r_s (104) = .59, p = < .01). Older people also scored higher on positive attitude (r_s (106) = .21, p = < .05). People who had been diagnosed for longer rated themselves as more compliant (r_s (106) = -.27, p = < .05), but keyworkers disagreed (r_s (106) = -.02, p = > .05). Women showed more negative attitudes towards the drugs (Z (104) = -2.53, p = < .05) and were rated as less compliant by keyworkers (Z (106) = -2.32, p = < .05), but they did not report themselves as less compliant on the DBS (Z (106) = -.64, p = > .05). Diagnosis did not interact with compliance on either the Kemp (Z (106) = -1.68, p = > .05), or the DBS (Z (106) = -.83, p = < .05). However, there were significant relationships between diagnosis and all three attitude variables, P (Z (106) = -2.75, p = < .01), CP (Z (104) = -2.46, p = < .05), and N (Z (106) = -2.92, p = < .01), indicating that people with a diagnosis of schizoaffective disorder have more negative and less positive and conditional positive attitudes than those with a diagnosis of schizophrenia.

Married people had significantly more negative attitudes than single, who had more negative attitudes than divorced people (χ^2 (104) = 8.45, d. f. 2, p = <.05), the exact reverse being true for positive attitude (χ^2 (106) = 9.55, d. f. 2, p = <.05). Excluding divorced and widowed people leaves a group of 93 people, 47 male and 46 female. Within this group, women are significantly more likely to be married than men, (Z (93) = -2.658, p = <.01),

and people with a diagnosis of schizoaffective disorder are significantly more likely to be married than those with a diagnosis of schizophrenia (Z (93) = 3.140, p = <.01. There is a non-significant trend showing that women are more likely to be assigned a diagnosis of schizoaffective disorder than to be assigned a diagnosis of schizophrenia (Z (106) = -1.439, p = .150).

Reasons for deviation from prescription included intention to manipulate drug effect as well as more passive reasons. It was not possible to calculate how many people increased, rather than decreased, the dose, but it was clear from the responses that some people augmented their drug use. Thirty nine people who had agreed that they altered their drugs to some extent could not or wished not to give a reason for their behaviour.

4.2.2 *Findings from hypothesis testing*

The first hypothesis stated that valid and reliable measures of seven variables thought to be predictive of compliance could be developed. Only three measures proved to have reasonable internal reliability, so that the hypothesis was only partially supported. From a health behaviour perspective, Conner & Sparks (1996, pp. 134-141) allude to difficulties with internal reliability in their discussion of how to operationalise the theory of planned behaviour. They recommend the format followed in the present study as a way of minimising these problems. Cramer (1998, personal communication) has suggested that the selection of only a subset of 30 items from the 45 used in the Day *et al.* (1996) Q-sort study may have resulted in unnecessary loss of data, but the worst problems lay within the theory of planned behaviour constructs rather than those drawn from the Q-sort study. Conner & Sparks (op. cit.) report few difficulties among a range of other studies with behavioural intention and attitudes, but limited reliability data is available on multiple-item subjective norm measures. These authors report many difficulties with the reliability of perceived behavioural control in other studies. One obvious difficulty with subjective norm as this study has measured it, is that it tries to accumulate many potentially conflicting influences into one variable (what one's psychiatrist is perceived to want may not be the same as what family wants or what friends are seen to approve of). Future research will need to pay particular attention to this problem.

The three remaining variables proved to have modest predictive validity, though this was superior to that of the established scale, the DAI, in terms of correlations with scores on both keyworker and self report rating scales. The CP scale differentiates better between self-report and keyworker ratings than P or N. This feature of the CP subscale might be most useful clinically in identifying those people who may be reluctant to discuss their difficulties with the prescriber, assuming that keyworkers are good judges of compliance behaviour.

Concurrent validity with the DAI was just satisfactory, with moderate but significant correlations between positive attitude and high scores on both DAI 10 and DAI 30 and between negative attitude and low scores on both versions of the DAI. It should be noted that although this was the best available scale to use for concurrent validity, high correlations might not be expected in view of the very different approaches reflected by the two scales. The DAI item content (Appendices F and G) and scoring system both reflect a paternalistic approach to compliance, including items such as 'it is up to the doctor when I go off medication' (DAI 30, Appendix F), which is scored as 'correct' if the patient replies 'true' and as 'incorrect' if the patient replies 'false'. The finding of a significant correlation between conditional positive (CP) and the DAI 30 but not between CP and the DAI 10 is interesting. The DAI 10 is a selection of items from the DAI 30 and is reported to represent only two of the seven factors found in the DAI 30, namely, the 'subjective positive' and 'subjective negative' factors (Hogan & Awad, 1992). CP may be measuring something similar to one of the seven DAI 30 factors, while P and N have obvious similarities to the two DAI 10 factors.

The failure of the DAI to predict compliance in this study may be because it was developed to discriminate between groups of 'compliant' versus 'non-compliant' patients, rather than to reflect a compliance continuum as in the present study. In their 1983 paper reporting the development of the DAI 30, Hogan, Awad and Eastwood imply that the allocation of patients to compliant or non compliant categories was based upon their own ratings. To quote, they define compliance as 'a clinician's global assessment of a patient's regularity in taking his pills over the

duration of their therapeutic relationship' (Hogan *et al.,* 1983, p.181). Physicians' ratings of compliance have been shown to be often poor (Gordis *et al.*, 1969), so it is possible that both the DAI 30 scale and the doctors rating compliance were over inclusive in categorising some patients as compliant, especially if they showed conditional positive attitudes and may have reported themselves to be compliant in discussion with their physician. Another factor which is worth considering is that the DAI was developed with inpatients as participants, in contrast to the present study where only two participants were inpatients. Factors important in long term drug use by patients in the community may be different from those important for compliance by inpatients.

The question of whether there are three, two , or one scale contained within the item set is raised by the results of the factor analysis. Baggaley's formula, quoted in Child (1990), suggests that for a scale with 17 variables a sample size of around 30 is required for factor analytic techniques to be of use in this instance, while other authors (e.g., Kline, 1994) suggest five participants per item, in this case 85 would be needed, so that it seems more than satisfactory to have 104 participants. The weak presence of a third factor with only one item loading strongly, may mean that there are only two meaningful factors, conditional positive and negative. The multiple regression, though viewed with caution, suggested that the three variables together only accounted for 8 to 10 per cent of the variance, with negative attitude as the single significant predictor. The individual correlations suggested a similar percentage of the total variance accounted for by each individual variable, so that one could interpret the data as representing only one underlying evaluative factor, with positive and negative extremes However, the reasonable internal reliability of the positive attitude variable (α = .7) and the fact that many subjects endorsed the positive attitude items without endorsing the conditional positive (see individual profiles, Appendix O) suggests they may not be measuring the same portion of the variance and so should be kept separate for the time being. Similarly, a few subjects held highly positive and highly negative beliefs simultaneously, suggesting that the two are not mutually exclusive and that to agglomerate them would be to lose clinically useful material. A two variable scale could probably be

used to good clinical effect but the power of the CP variable to discriminate between the self-report and keyworker ratings would be lost. There is a moderate negative correlation between positive and negative attitude, suggesting they might be opposite ends of a continuum, but the correlation (r_s (106) = -.67, p < .01, 1-tailed) while highly significant, only accounts for around half the variance. In addition, it is most informative clinically to keep the constructs separate, as discussed earlier. Likewise, the correlation between conditional positive and positive attitude (r_s (106)=.51, p < .01, 1-tailed), while significant, still leaves room for differences between the two, as supported by the fact that positive attitude predicts keyworker ratings, whilst conditional positive does not. The low over all internal reliability of the scale (*alpha* = .46) compared with higher *alphas* for each subscale (*alpha* = .7 for P and CP and *alpha* = .65 for N) also supports differentiation between the subscales. An examination of the item content of conditional positive shows patient concerns as to the positive effects (e.g., helps me think more clearly, makes me less tense) versus some negative effects (I have side effects) and an endorsement that the patient should have the minimum dose, compared to the item content of positive attitude (e.g. taking my drugs is enjoyable, taking my medication is good) which are value statements about the act of taking medication being an excellent thing. In summary, the scale structure is debatable but there are insufficient statistical grounds to abandon the assumed three factor structure and good statistical and clinical reasons to keep it at present.

Hypothesis two stated that each variable would predict compliance in specific ways. For the variables from the theory of planned behaviour the predictions were in line with the theoretical model, with attitude to behaviour (AB), subjective norm (SN) and perceived behavioural control (PBC) as factors predictive of behavioural intention (BI), which was hypothesised to act as a mediator variable in predicting compliance behaviour. Because all variables except AB had to be dropped because of inadequate internal reliability, it was not possible to test these predictions. The variable attitude to behaviour (AB) modified and renamed as positive attitude (P), did predict compliance on both measures as hypothesised. For the three variables

from Day *et al.'s* (1996) research, it was hypothesised that autonomous scepticism, from which six items were dropped before it was renamed negative attitude (N), would predict non compliance, which it did on both measures. Balanced appraising was hypothesised to be unrelated to compliance, because a tendency to weigh up pros and cons as described by Day *et al.* (1996) might result in a decision to behave in either way. In fact, re-named as conditional positive (CP) attitude after two items were dropped, it predicted self reporting of compliance while being unrelated to keyworker ratings. This is most interesting as it may reflect the tendency observed by others, for patients to exaggerate their levels of compliance compared to observer ratings (Buchanan, 1996). The different distributions of the Kemp keyworker compliance ratings (less skewed) and the DBS self-report ratings (much more strongly skewed towards compliance) also support this observation. In view of this and of the fact that the item content of this scale is largely positive, with the exception of statements about preference for minimum dose and endorsement of experience of side effects, the balanced appraising variable was renamed conditional positive. The unquestioning compliance variable from the Day *et al.* study, hypothesised to predict compliance, was unreliable and dropped. Fortunately, the theory of planned behaviour variable, attitude to behaviour, renamed as P, seemed to serve a similar function to that of unquestioning compliance. Over all, there seems to be support for Day *et al.'s* findings of three typical approaches to medication, positive, negative and conditional. However, the conditional variable appears to reflect generally positive opinions with caveats, rather than a neutral stance.

It is important to remember that this is a cross sectional study showing correlations between variables for the most part at one time. Causality cannot be inferred from such relationships, so that the use of the term predictive validity does not imply that attitudes cause behaviour but merely implies that those people who hold particular attitudes tend to behave in certain ways towards their medication and vice versa. There are so many variables which have been considered important in this field (Buchanan, 1996) that it is perfectly possible that both effects may be caused by other interactions, as discussed by Bentler & Speckhart (1979;

1981). The same is true for the demographic and drug relationships with compliance discussed below.

In general, it has been possible to find variables predictive of compliance in the directions hypothesised. The correlations, although significant, are relatively weak in that they account for low amounts of the compliance variance. This means a good start has been made, but there are many other factors waiting to be explored.

4.2.3 *Findings from drug characteristics data*

The most exciting finding from the data on type of drug is that people taking the atypicals show no differences in their levels of compliance on either self-report or keyworker measures compared with those taking the classical neuroleptics, despite widespread speculation that they should show improved compliance (e.g., Lindstrom, 1994; Naber *et al.*,1992). The recent major trials of new neuroleptics do not directly address compliance, any discussion which occurs tends to be retrospective and anecdotal (e.g., Chouinard *et al.*, 1993). In addition, studies use haloperidol as the comparison classical neuroleptic, a drug which has particularly pronounced side effects, and select 'resistant' patients for inclusion in the groups taking new neuroleptics (Carman *et al.*, 1995), features which might have biased compliance outcome if it had been measured. The participants in the present study were placed onto new neuroleptics some six months beforehand as part of another study, and were not selected on the basis of treatment resistance but at random. This finding may be a disappointment to the medical and pharmaceutical communities and needs replicating before firm conclusions could be drawn, but it is certainly worth further attention. Drug dose appeared unrelated to compliance on all measures, although chlorpromazine equivalents could only be calculated for those patients taking tablets. This is a surprising finding as the expectations would be of increased side effects and reduced compliance with increased dose (e.g., Falloon *et al.,* 1978) and much effort has been devoted to maintaining patients on the minimum dose (e.g., Hogarty *et al.*, 1988; Tarrier *et al.*, 1993).

The remaining data of interest are those regarding method of administration of the drugs and behaviours involving adding other drugs to

those prescribed. Although depot administration is widely held to be the method of choice to improve compliance (Freeman, 1973), there is a surprising dearth of research in this area. Awad *et al.* (1996) recommend specific approaches including the use of depot medication for patients who show a dysphoric response to neuroleptics at discharge. In the present study, those patients on depot were considered similar in compliance levels to others by their keyworkers (χ^2 (106) = 2.6, d. f. 2, p = >.05). It may be that people who were initially non compliant have self-selected for inclusion in the depot group because non compliant behaviour in the past has lead their psychiatrists to place them on depot injections, so that by increasing their compliance in this way, they have become similar to other groups. However, other researchers have found that depot drug administration methods do not necessarily improve therapeutic outcome (Falloon *et al.,* 1978) and keyworkers' ratings of compliance may be based in part on their observations of symptom control for each patient. It is interesting that on patients' own self reports, but not on key workers', those on tablets are less compliant than those on both tablets and depot, who are in turn less compliant than those on depot only. Perhaps those on depot have learned to report themselves as more compliant to avoid further interventions. In view of the fact that those on tablets tend to report themselves as less compliant, even though these reports are not confirmed by keyworkers' views, a response on the part of the prescriber to place the self-reported non-complier onto depot may be ill-advised. It is possible to see an inexorable march of the population of people with a diagnosis of schizophrenia towards receiving depot methods as a result of prescriber response to their reported non-compliance. Of course, participants may have shared with the researchers things they might not share with their consultant because of different perceived consequences. In any event, more subtle ways of determining who is and is not likely to take their medication have utility, especially if they can be combined with more sophisticated ways of enhancing compliance if the drugs have favourable effects and of identifying and supporting those for whom the drugs do not have favourable effects.

4.2.4 *Findings from demographic data*

All of the patients in the study were of Caucasian ethnic origin, reflecting the population characteristics of the Isle of Wight. This could be problematic in terms of generalisability of the study to other groups which include significant ethnic groups. Sellwood & Tarrier (1994) found ethnicity and compliance to be related, whilst other studies found no relationship (Buchanan, 1996; Tunnicliffe *et al.*, 1992). Another predictor from past research appears to be socio-economic status (Buchanan, 1996; Winkelman, 1964), although it is unclear how this was measured. In the present study occupation was the only indicator of socio-economic status. Since none of the participants had paid work, it seems that in general they are a financially deprived group. Another factor which should be considered when generalising from these results is that the group was almost exclusively outpatients and included people recently diagnosed as well as those who had been diagnosed for a very long time.

The effect of gender found in this study is not in line with findings from past research. The findings that females have more negative attitudes and are significantly less compliant according to keyworkers but do not report themselves to be so, have not been reported before in the literature. Previous studies have found no effect of gender (Atwood & Beck, 1985; Baekeland & Lundwall, 1975; Buchanan, 1996) or that males are less likely to comply (Sellwood & Tarrier, 1994; Tunnicliffe *et al.*, 1992). The sample in this study may not be directly comparable to those in previous studies (for example, Tunnicliffe *et al.* studied depot administration only) and the finding needs to be replicated. There is evidence, however, that women are more affected by extra-pyramidal side effects (Kane & Freeman, 1994), that women show larger drug/placebo differences than men (Goldberg *et al.*, 1966) and that women seem to require lower doses of neuroleptics for therapeutic effect (Seeman, 1983). Prescribers may be unaware of this information, since the majority of drug trials do not report gender details, and prescribers may be prescribing similar levels of drug to both sexes. This would produce more marked effects and side effects in the women patients.

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The findings that women are more likely to be married than men, that people with diagnoses of schizoaffective disorder show more negative attitudes and that there is a (non-significant) trend for women to be diagnosed in the schizoaffective category more often than men are not conclusive evidence of anything, but are consistent with the following speculations. Firstly, that it may be easier for a socially disadvantaged woman to marry than for a similarly disadvantaged male and this may be a reason for the differences in marital status between the sexes in the study. Secondly, that women habitually express more emotion than men, emotionality being the differentiating element between schizophrenic and schizoaffective categories, so that women may be more likely to receive a diagnosis of schizoaffective disorder. The emotions in question are usually negative, so that there may be a general bias towards negative perceptions and cognitions being expressed by women, which affects their subjective appraisal of neuroleptics along with other things.

In summary, women's perceptions of neuroleptics and their subjective experiences of their effects on all aspects of their lives remains an unexplored but very important area.

Social isolation has been shown to be associated with non compliance (Blackwell,1976). Living circumstances in the present study were not associated with compliance. Findings for marital status have been contradictory in past research, Tunnicliffe *et al.* (1992) reported that marital status is not related to compliance, whilst Altman *et al.* (1972) found in-patients who were single more likely to drop out of treatment. This study found no effect for compliance of marital status, in terms of attitude being married was associated with more negative and less positive attitude. One can only speculate on possible reasons for this. Perhaps gender is a third factor as discussed above, perhaps married people are more exposed to conflict within their families and blame problems on their drugs. Certainly, divorced people seemed very positive in their attitudes (although they were a very small group)!

The lack of effects for consultant psychiatrist on both keyworker and DBS self-report measures may indicate that who the prescriber is has no

effect on compliance, but in view of past research (e.g., Baum *et al* 1966; Gibby *et al.*, 1954; Howard *et al.*, 1970; Irwin *et al.*, 1971), it would seem more likely that more subtle measures about the match between patient and prescriber characteristics are needed (Davis, 1968). The five consultant psychiatrists responsible for the treatment of the study participants had very different styles and personalities. These styles may be ideally suited to particular types of patient attitude profiles. In addition it is noteworthy that treatment was often delivered by registrar and senior house officer psychiatrists, so that the patient had contact with several different styles and attitudes.

4.2.5 *Findings from open-ended data*

The data consisted of the reasons given by people reporting themselves as non compliant for why they changed the time of taking their medication. The reasons 'forgetting' and 'disorganisation' imply an accidental failure to comply, for reasons difficult for the patient to control. Only 21 patients gave these reasons. Reasons involving inconvenience, reducing or increasing sedation, altering subjective state, are reports of intentional manipulation of the medication to meet the perceived demands of the external environment (e.g. keeping up appearances in front of friends) or the internal environment (mental and physical states). These are useful clues for clinical use and also strong indications that patients are attempting to actively manipulate their medication to maximise its usefulness. This supports the notion that patients are not only trying to reduce dysphoria (Van Putten & May, 1978; Van Putten *et al.*, 1981) but also to achieve other quite varied objectives by manipulating their drugs (e.g., Guimon, 1995; Gutheil, 1982; Irwin *et al.*, 1971; Willcox *et al.*, 1965). One difficulty is that patients are attempting to alter the drug effects without fully understanding the ways in which the drug effects are mediated. Drugs with a longer half-life, for example, may be less easy to adjust on the basis of current subjective state. The fact that around half of the people who agreed that their behaviour deviated from prescription at times did not give a reason for this may reflect inability to do so because of lack of awareness of their own motivation, which might in turn be produced by unawareness of illness (e.g. Greenfield *et al.*, 1989) or denial of illness (e.g. McEvoy *et al.*, 1989) or by factors such as the

cognitive impairments discussed by Davidhizar (1982). Alternatively or additionally this fact may be a result of reluctance on the part of participants to discuss their non-compliant behaviours further. It must be remembered that the interviewers themselves represented a part of the mental health system and therefore may well have been perceived as authority figures or at least on the side of the 'establishment'.

4.3 Theoretical implications

The two original questionnaires were derived from two different approaches to predicting compliance behaviour. The first approach is based on Day *et al*'s (1996) work, which started from the discourse by categorising statements from tape recorded conversations about neuroleptics and using these as elements in a Q sort study. The DAS items were drawn from these elements. This method helps prevent the imposition of the investigator's own viewpoint on the data, something from which the more medical research on compliance seems to suffer. The second approach is based on an existing theory, the theory of planned behaviour (Ajzen, 1991), which is itself an example of subjective expected utility theory, a form of decision analysis theory (Peak, 1955). This approach offers a rationale for choosing between the many variables identified as relevant in the literature and a model of how they might relate to compliance.

The severe problems with reliability encountered in operationalising three of the four theory of planned behaviour variables call into question the utility of the theory for this field of research. The theory has not been applied in this area before, although it has been considered to show promise by other authors (Davidhizar, 1982). Applications in related areas are few, but the study by Cochran & Gitlin (1988) applied the predecessor theory of reasoned action (TRA) to lithium compliance. Modification of the TRA model was necessary to best account for results. The Health Belief Model, a related theory, was applied to drug compliance in urinary tract infection treatment by Reid & Christensen (1988), the HBM predicted 10 per cent of the variance, addition of TRA variables increasing this to 29 per cent. The Health Belief Model was used by Budd *et al.* (1996) to explain

compliance with depot neuroleptic medication. They found some elements of the model useful and others not. They too experienced difficulty in developing a reliable measure of one HBM variable, 'costs'. In summary, there is little previous research to shed light on the difficulties experienced in the present study, but that which does exist begins to show evidence of similar problems.

A perusal of the item content of the unreliable variables shows that all three can be seen to be problematic, for this group of patients and potentially for other groups. Subjective norm is a collection of ratings of how much other people are perceived to want the person to engage in the behaviour. In this study, patients' perceptions of how much their psychiatrist, for example, wished them to adhere to prescription seems to have had little relationship with how much their friends desired this behaviour in them. On the perceived behavioural control (or 'willpower') variable, it is possible to see how items such as 'whether I take my drugs is entirely up to me' could be interpreted by the participant as 'disobedient' within the patient-prescriber relationship context, rather than as an expression of control and choice as it is probably intended within the context of the theory of planned behaviour. With regard to the behavioural intention variable, again the patient may feel it necessary to endorse statements such as 'I always intend to take my medication' more for reasons of the perceived unacceptability of harbouring premeditated intent to deviate from prescription than because this statement reflects the real situation. These arguments lead to the conclusion that the theory of planned behaviour may prematurely exclude relevant variables reflecting the power relationships involved in the use of neuroleptic medication, because it has not been developed for use in this context and assumes some sort of 'free choice' context for the person taking the drugs or engaging in the health behaviour. The other related models such as the health belief model may suffer from similar shortcomings in this context.

The relative simplicity of the theory of planned behaviour, while allowing ease of analysis in theory, in practice may also be a drawback because it only describes one-way interactions between variables, again possibly prematurely excluding other possible interactions as described by

Liska (1984). However, the lack of reliable measures of all but one of the TPB variables in this study meant no information is available on this point.

Another criticism which could be levelled against the theory of planned behaviour is that it represents a deliberative processing model, that is, that it assumes we humans make decisions through more or less conscious and more or less logical analytic processes. The fact that so many participants could not articulate reasons for deviation from prescription may imply that the decision processes involved were not accessible to consciousness. The powerful influences of non conscious information processing have been extensively discussed by cognitive psychologists and may be seen, for example, in phenomena such as the Stroop effect, where unconsciously perceived emotionally valent word content slows down reaction time on a colour-naming task (Williams *et al.*, 1997). Even if the question of conscious awareness of the process is set aside, whether the decision-making process is rational in the sense assumed by all subjective expected utility theory is also questionable. The distinction drawn by Evans & Over (1997) between 'logical' and 'effective and adaptive' rationalities is relevant here, the latter referring to decisions based on past experience. This brings the discussion back to the question of the theory of planned behaviour excluding potentially useful variables such as the effects of past experience.

The previous compliance literature is heavily influenced by the medical paradigm, or 'doctor knows best' approach, so that power relationship variables are not addressed within this literature, except insofar as the suggestion that the term compliance be replaced with the term adherence. A relatively value-free approach is needed to construct a useful model of neuroleptic drug use by people with a diagnosis of schizophrenia,. The Q-sort study by Day *et al.* (1996) was an attempt to do this and resulted in the production of two of the three reliable variables in the present study. Discourse analytic methods deal with the problem of the investigators' value systems by overt acknowledgement of the value base, so that the reader may take these influences into account when judging the work (Potter & Wetherell, 1987). This seems to offer promise for an area where covert value systems seem to have had longstanding and generally obscuring

effects. Perhaps starting from this kind of approach relevant variables could be identified which could be shaped into a testable model at a later stage.

4.4 Clinical implications

4.4.1 *Use of patient profiles for individual work*

The patient profiles of which examples are given in Figure 3 show typical patterns of responding. This should be most useful for prescribers and nurses monitoring medication to alert them to potentially non compliant individuals. Clinicians can use these profiles to gain a snapshot of each patient's attitudes and likelihood of compliance. This will allow individually tailored approaches to prescribing and management which can be built into care plans. For a patient high on conditional positive attitude and low on other attitudes, it may be useful to ask the person to record the advantages and disadvantages of their medication as they proceed through their day, then use this information to analyse what 'critical incidents' might make them deviate from prescription and plan preventative strategies in advance. Preventative strategies should include the possibility of the prescriber offering to change the prescription in response to specific critical incidents, or even to agree a 'flexible prescription' with the person which allows changes to the regime to be made by them in response to self-observed changes. For a patient high on negative attitude and low on others, it might be important to try to identify the different elements of the negative attitude in order to design interventions, for example dysphoric drug reactions, different perceptions of the diagnosis, toxicity, depression. Those with very negative attitudes tend to report themselves as non compliant and tend to have a dysphoric response to medication, as shown by the item content of the negative attitude subscale. It is obviously vital to try to improve the subjective response of these individuals, especially in view of the fact that past research has shown that even with enforced compliance, dysphoric responders have negative clinical outcome (Falloon, Watt & Shepherd, 1978; Hogarty *et al.* 1979; Rifkin *et al.* 1977). The literature shows that there are certain individuals for whom medication does not produce, or produces negative, results (Hogarty *et al.* 1974; Judd *et al.*, 1973;

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Women may also show higher levels of distress in response to side effects such as weight gain, sweating and hypersalivation and there are distressing effects for forty per cent of older women of hypotension increasing the risk of falling, with increased risk of painful fractures (Jefferson, 1974).

From a more political point of view, Stephenson & Walker (1981) contend that the psychiatrist-woman patient relationship is affected by a number of powerful, yet often subtle, social pressures. They review research evidence showing that three factors in particular affect treatment delivered to women by psychiatrists. Firstly, there are the medical and mental health systems and the "medicalisation of life" (p.126) that has taken place over the last century. Secondly, a woman's treatment is affected by her psychiatrist's training, attitude and theoretical background. Thirdly the woman's socialisation and world view, which is based, they argue, on perspectives formulated from a male viewpoint, will affect her treatment. As a result of these factors, women referred to a psychiatrist are more likely than men to receive a psychiatric diagnosis and treatment is likely to be aimed at helping women to meet traditional expectations. The social obstacles faced by women are likely to be ignored or minimised and problems viewed as individual and intrapsychic. In this way, the psychiatric establishment contributes to the oppression of women. From this viewpoint, neuroleptic treatment can indeed be seen as a kind of latter-day straightjacket. The more negative attitudes and lower compliance levels shown by female participants in this study would make sense in this context, as would their reluctance to report non-compliance. It is possible to apply this kind of analysis to the whole group of people taking neuroleptics. Certainly the first two factors mentioned by Stephenson & Walker (op. cit.) should apply to both men and women. Given the status differences between the participants in this study and their psychiatrists there must exist a power imbalance within the relationship which affects all patients. In this context, women could be seen as suffering 'double jeopardy', the first two factors' effects being exacerbated by their gender, the third, socialisation, applying exclusively to their disadvantage.

The findings that women are more likely to be married than men, that people with diagnoses of schizoaffective disorder show more negative attitudes and that there is a (non-significant) trend for women to be diagnosed in the schizoaffective category more often than men are not conclusive evidence of anything, but are consistent with the following speculations. Firstly, that it may be easier for a socially disadvantaged woman to marry than for a similarly disadvantaged male and this may be a reason for the differences in marital status between the sexes in the study. Secondly, that women habitually express more emotion than men, emotionality being the differentiating element between schizophrenic and schizoaffective categories, so that women may be more likely to receive a diagnosis of schizoaffective disorder. The emotions in question are usually negative, so that there may be a general bias towards negative perceptions and cognitions being expressed by women, which affects their subjective appraisal of neuroleptics along with other things.

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effects. Perhaps starting from this kind of approach relevant variables could be identified which could be shaped into a testable model at a later stage.

4.4 Clinical implications

4.4.1 *Use of patient profiles for individual work*

The patient profiles of which examples are given in Figure 3 show typical patterns of responding. It was hoped to alert those monitoring medication to potentially non compliant individuals, but the levels of validity demonstrated were insufficient to allow this. In any case, individually tailored approaches to prescribing and management should be built into care plans. It may be useful to ask the person to record the advantages and disadvantages of their medication as they proceed through their day, then use this information to analyse what 'critical incidents' might make them deviate from prescription and plan preventative strategies in advance. Preventative strategies should include the possibility of the prescriber offering to change the prescription in response to specific critical incidents, or even to agree a 'flexible prescription' with the person which allows changes to the regime to be made by them in response to self-observed changes. It is important to try to identify the different elements in any negative attitude in order to design interventions, for example dysphoric drug reactions, different perceptions of the diagnosis, toxicity, depression. Those with very negative attitudes tend to report themselves as non compliant and tend to report a dysphoric response to medication. It is obviously vital to try to improve the subjective response of these individuals, especially in view of the fact that past research has shown that even with enforced compliance, dysphoric responders have negative clinical outcome (Falloon, Watt & Shepherd, 1978; Hogarty *et al.* 1979; Rifkin *et al.* 1977). The literature shows that there are certain individuals for whom medication does not produce, or produces negative, results (Hogarty *et al.* 1974; Judd *et al.*, 1973; Rappaport *et al.,* 1978). The task would then be to manage the high levels of patient and carer distress without in any way blaming the patient. It is in

this case that the need for alternatives to medication is most pressing. The decision not to prescribe medication is likely to be seen as most 'risky' for prescribers in case the person should harm self or others, yet is the most logical and most humane approach, especially if alternative strategies for symptom and quality of life management can be developed. The most promising strategies here appear to be cognitive-behavioural in nature. There may well be within the group of people who tend to have negative attitudes those for whom more could be done in terms of changing medication and exploring the reasons for non compliance.

Prescribers may need to act as experts, giving clear instructions with repetition and jargon free language (Dencker & Liberman, 1995) and reinforcing compliant behaviour with encouragement and approval.

The components of the profiles at present have insufficient validity for clinical use. Apparently extreme profiles could occur just as the result of chance variation, the error component of the variance. Further work is needed to develop clinically useful profiles.

4.4.2 *Targeted compliance programmes*

The group who tend to report themselves as compliant but are not necessarily so according to keyworkers (those high on conditional attitude) may well be an easy group to target for group work, as they represent mixed attitudes, with positive and negative elements. Interventions which provide information about drugs and attempt to address concerns (e.g. Guimon, 1995; Kemp *et al.*, 1996) may indirectly assist with this group's compliance by facilitating the development of informed thinking on the patients' parts, but subtler interventions to explore the positive and negative aspects of the patients' perceptions may be even more effective. Combining cognitive and drug treatments for this group could mean greater patient empowerment (and hence quality of life improvement) as well as improved response to medication.

Those who tend to have positive attitudes towards the act of taking medication should not be neglected and could be gathered infrequently into supportive or self-help groups to share experiences and to reinforce

compliant drug taking behaviour, to ensure that they do not shift towards non compliance.

4.4.3 *Prescriber style*

The use of patient profiling should enable prescribers to begin to adopt different styles and approaches to suit their patients, 'encouraging expert' might match positive attitude, 'informative discussant' might match conditional attitude, 'non judgmental troubleshooter' might match negative attitude. In any case the use of profiles and feeding back results to the patient should facilitate a dialogue between doctor and patient and an active involvement for the patient in decision making about treatment, which has been shown to enhance compliance (Eisenthal *et al.*, 1979; Hertz *et al.*, 1976). In those cases where the drug is not effective (and may still carry side effects), enhancing compliance should not be the aim, rather, the prescriber should work with the person to devise a self-management program as an alternative to drug therapy.

4.5 Critical review of the present study

The strengths of the present study lie in the avoidance of the imposition of the value system implicit in much of the medical literature, namely that the prescriber should make most if not all of the decisions regarding neuroleptic medication use by the patient. This value system appears to have lead to the frustration of medical approaches to finding answers to the question of why people do not take their medication. The present study assumes that much of relevance to this question can be learned by studying the patient's perceptions and by asking the patients. Other methodological strengths include the use of multiple sources for information about compliance and the conceptualisation of compliance as a continuum of drug-taking behaviours and as something which will be perceived differently by different people. In terms of the study results, the production of a clinical tool that should be non threatening to either prescriber or patient may go some way towards beginning to change the authoritarian dynamic which can exist within the relationship. For research purposes, the ability to assess patient attitude profiles may help generate more specific information relevant to

subgroups of people within the heterogeneous group of people with a diagnosis of schizophrenia.

The main methodological weakness may be the reliance of the study on past research and existing models. It is arguable that, despite the hefty medical literature in the field of compliance, for the reasons outlined above there is little of relevance to generating a psychological model of neuroleptic drug use. The exclusive reliance on Day *et al*'s research along with the theory of planned behaviour meant that some potentially useful 'predictor' variables may have been prematurely excluded. It would have been relatively simple to include measures of other variables, in particular a measure of past experience and a measure of side-effects may have proved fruitful. Some attempt to measure the perceived power relationships would also have been useful, but it may have been difficult to obtain psychiatric co-operation with research into this area.

The difficulties with reliability could have been addressed much earlier in the study, during the pilot phase. This was not done because the focus at the time was on the intention to factor analyse results from all items on both questionnaires in order to confirm the assumed underlying factor structure of seven predictor variables. In the event, this approach to data analysis was unsuccessful, probably because of the very reliability problems revealed by the second approach of checking internal reliability of each variable. The pilot study was only used to identify practical problems such as communication difficulties and form-filling procedures and could have been of much more use in terms of data analysis.

The personal communication from Dr. Cramer concerning loss of data by selecting only a subset of items from Day *et al*'s Q-sort item set was very useful. Both factor analytic methods and internal reliability checks may have been more favourable if the whole 45-item set had been used. By selecting only those items which produced extreme ratings (-5 or -4 and +4or +5 on the Q-sort) and those which discriminated best between domains, important information relevant to people who tend to use the middle rankings may have been lost.

The ability of patients to sustain concentration during the interviews was a major issue for the interviewers, despite evidence from the pilot that

this was not a problem. With hindsight, it would have been better to administer the DAI to all the participants rather than to a subset in order to have larger numbers for the comparisons on predictive validity and concurrent validity. The DAI was given to the later participants after the interviewers had convinced themselves that the participants in general could sustain concentration for the full length of time.

Additional open-ended data could have been collected on whether and why people augmented as well as reduced their medication and on the relationship with their doctor and their keyworker.

The high number of non-participants was largely because the keyworker judged the patient to be unfit to participate. It would have been useful firstly to have some measure of severity of illness and secondly to have some possibly less structured contact with the non-participants to assess the accuracy of the keyworkers' judgements.

In order to venture even further away from the imposition of experimenter bias, it would have been most interesting to begin the study with a set of focus groups, some just for patients and others including various stakeholders in the use of neuroleptics and to carry out a discourse analysis of the major themes within the conversation, then move from there to the development of more quantitative and structured attitude measures. This would be the major change to be recommended should the study be repeated.

4.6 Recommendations for future research

4.6.1 *Developing more sophisticated concepts of compliance*

This study has shown that regarding compliance as deviation from prescribed behaviour rather than taking versus not taking drugs can produce informative results. Asking patients why they do not comply has produced informative responses showing that patients are often active manipulators of their drugs rather than passively forgetful. More research into the complexities of this behaviour would be useful. The large number of patients who could not provide reasons for non compliance is concerning and research is required into whether this represents unwillingness or

inability to introspect on these patients' parts. Greater understanding of the motivations for deviation from prescription is the most likely resource for future interventions to improve compliance and to develop alternative treatments.

4.6.2 *Investigating targeted programme effectiveness*

Very few of the existing programmes to improve compliance have been investigated for effectiveness, with the exception of Kemp *et al's* (1996) study which showed improved compliance and reduced negative attitudes. It would be fruitful to investigate the effectiveness of the individually tailored and group approaches discussed above using patient profiles, in comparison with more blanket approaches, not just in terms of compliance but in terms of subjective appraisal and quality of life..

4.6.3 *Increasing prescriber repertoire*

Many prescribers already use different approaches for different patients as part of their 'bedside manner'. The use of profiles would allow them to more consciously tailor themselves to their patients and an investigation of outcome in relation to consciously changed techniques. Profiles may also assist prescribers to feel less responsible for the behaviour of their patients, so making their jobs in dealing with non-compliant people less stressful and avoiding patient-prescriber conflict. These prescriber factors could also be measured, as could the sophistication of prescribers' understandings of non-compliance and their willingness to consider the 'rationality' of such responses.

4.6.4 *Health behaviour models*

The least successful part of this study has been the application of the theory of planned behaviour to compliance behaviours, with the exception of the attitude to taking medication variable which was renamed positive attitude. Yet other studies have applied versions of the model to lithium compliance with some success (Cochran & Gitlin, 1988). Conner & Sherlock (1993) found the model useful for predicting intention to use ecstasy, but recreational drug use is not very similar to the use of long term prescribed medication. As the majority of applications of this model have been to relatively simple, easy to define behaviours and have not measured compliance directly (Conner & Sparks, 1996), it may be that this attempt to

apply the theory stretched the model too far. Since the development of reliable measures for three of the four variables was unsuccessful, it is too early to reach such a conclusion. Future research should concentrate on the development of more reliable measures, perhaps by checking this more carefully at the outset. Finally, the cross-sectional nature of this study has been noted. Replications including longitudinal data would increase confidence in the results.

4.6.5 *Women and neuroleptics*

The findings concerning women's attitudes to neuroleptics need replicating and exploring. Because they do not report themselves as non-compliant, multiple measures are necessary to detect non compliance and the reasons for this. One could speculate that women in this group, with their restricted access to further education and the world of work, may be relatively conservative in their values and passive in their dealings with authority figures such as doctors. These characteristics may mean a tendency to outwardly conform, while privately altering adherence behaviour. This would make it particularly difficult for the prescriber to establish a collaborative relationship, but most important that it be established. Clinical case studies addressing these speculations would be useful, as would studies aimed specifically at women's concerns around the effects of medication upon their quality of life and their behavioural responses to these.

4.6.6 *New versus old neuroleptics*

The finding of no difference in compliance levels with new and old drugs needs replicating urgently. Differentiating between the new drugs rather than treating them all together is important, as anecdotal evidence suggests different side effect profiles for each. It is also important that patients are randomly allocated to groups, or that compliance differences before changing medication are somehow controlled, as the tendency is to move non-compliant or dysphoric patients onto new neuroleptics. Some of the new neuroleptics are extremely expensive when compared with older drugs, so that prescribers need advice as to patients' willingness to take them along with the effectiveness and side-effect data which is emerging.

4.7 Conclusion

This study aimed to investigate the prediction of and reasons for patient non- compliance with neuroleptic prescriptions. Several key findings were worthy of consideration. First, the new scale (the Drug Compliance Attitude Scale) has reasonable reliability and validity and has greater predictive power than the most popular scale in use at present. Secondly, the idea of operationalising non-compliance as deviation from prescribed drug taking behaviour has begun to cast light on the complexities of drug -taking behaviour. Thirdly, it has been shown, in line with past research, that some patients tend to exaggerate their compliance compared with observer ratings. These patients tend to score highly on conditional positive attitude. Fourth, asking patients why they do not comply has shown reasons are often very basic and practical and include active manipulation of subjective state. Fifth, no improvement in compliance rates was found for patients taking new or atypical neuroleptics as compared with those taking old neuroleptics, despite optimism among the medical community that this would be the case. Sixth, women appear to have specific issues concerning taking neuroleptic medication.

The scale developed allows profiling of individual patients' attitudes to allow clinicians to predict whether and why patients will comply with their prescriptions. This has utility for individual and group interventions to increase the collaboration within the clinician-patient relationship and enhance therapeutic outcome and quality of life. The scale offers new possibilities for future research which takes into account psychological differences between individuals who constitute the heterogeneous group of people taking neuroleptics.

The study has highlighted the need for research into women's experiences of neuroleptic treatment and has challenged pervasive predictions about superior adherence to prescriptions of atypical neuroleptics.

The progress from treating syndromes to treating symptoms and thence to treating the whole person which has taken place within the cognitive-behavioural field, should be mirrored within the work on

neuroleptic compliance, along with finding alternatives and adjuncts to drug treatment for patients living with neuroleptic medication. An understanding of the person and the social environment is needed for the development of satisfactory models of the complex behaviours and responses surrounding neuroleptic medication.

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APPENDIX A: DSM IV diagnostic criteria for schizophrenia and schizoaffective disorder

Schizophrenia

A. Characteristic symptoms: Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):

(1) delusions
(2) hallucinations
(3) disorganised speech (e.g., frequent derailment or incoherence)
(4) grossly disorganised or catatonic behaviour
(5) negative symptoms, i.e., affective flattening, alogia, or avolition

Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.

B. Social/occupational dysfunction: For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. Duration: Continuous signs of the disturbance persist for at least 6 months. This 6 month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criteria A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criteria A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Schizoaffective and Mood Disorder exclusion: Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. Substance/general medical condition exclusion: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

F. Relationship to a Pervasive Developmental Disorder: If there is a history a Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Classification of longitudinal course (can be applied only after at least 1 year has elapsed since the initial onset of active-phase symptoms):

Episodic With Interepisode Residual Symptoms (episodes are defined by the re-emergence of prominent psychotic symptoms); also specify if:

With Prominent Negative Symptoms

Episodic With No Interepisode Residual Symptoms

Continuous (prominent psychotic symptoms are present throughout the period of observation); also specify if: With Prominent Negative Symptoms.

Single Episode In Partial Remission: also specify if: With Prominent Negative Symptoms

Single Episode In Full Remission

Other or Unspecified Pattern

schizoaffective disorder

A. An uninterrupted period of illness during which, at some time, there is either a Major Depressive Episode, a Manic Episode, or a Mixed Episode concurrent with symptoms that meet Criterion A for Schizophrenia.

Note: The Major Depressive Episode must include Criterion A1: depressed mood.

B. During the same period of illness, there have been delusions or hallucinations for at least 2 weeks in the absence of prominent mood symptoms.

C. Symptoms that meet criteria for a mood episode are present for a substantial portion of the total duration of the active and residual periods of the illness.

D. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Specify type:
Bipolar Type: if the disturbance includes a Manic or a Mixed Episode (or a Manic or a Mixed Episode and Major Depressive Episodes)
Depressive Type: if the disturbance only includes Major Depressive Episodes.

APPENDIX B: Participant information sheet

PARTICIPANT INFORMATION SHEET

Re: STUDY TO UNDERSTAND HOW PEOPLE FEEL ABOUT THEIR MEDICATION AND HOW THEY TAKE THEIR MEDICATION.

Those who prescribe medication and those who take it are interested in producing the best care possible. It is important that people feel happy with their medication. The drugs control symptoms like mood swings and hearing voices and should also produce few side effects.

We are carrying out a study about the drugs that you take. We are interested in how you feel about your drugs and how and when you take them. This study does not in any way alter your treatment. It is simply to look at how you feel about your medication, and how you take it.

What people think of their drugs may be important in predicting their response to the drugs. We are interested in seeing if there is a connection between people's thoughts about medication and their behaviour in taking the medication.

This study may help us be more aware of patients' attitudes and behaviour towards their drugs. It may help doctors to prescribe even more effectively. The medication may then work better and the patient may feel happier with their drugs.

The study involves a short meeting (about half an hour) when you will be asked some questions about your drugs. The interviewer and your psychiatrist will be able to answer any questions you might have.

Everything will be confidential. You can pull out of the study at any time. You can also ask for all the information collected to be destroyed. Your name will be coded and locked in a drawer at Psychology. No one involved in your treatment will know your name. Only one person involved in the study will know your name.

The study does not in any way alter your treatment. It is simply to look at how you feel about your medication, and how you take it.

Please fill in the form overleaf if you agree to take part and return it in the stamped addressed envelope. You can ask us any questions you like if you are unsure.

Soon after you receive this letter we will ring you to see if you agree to take part. Please feel free to ask any questions when we call.

APPENDIX C: Consent form

CONSENT FORM

Name:

Please circle **Y** if you agree with the following statements, and **N** if you do not.

I have been given and read the information sheet. **Y** **N**

I have been able to ask questions about this and had satisfactory answers. **Y** **N**

I agree to answering questions about drugs prescribed to me. **Y** **N**

Please sign here:

Signed..... **Dated.....**

Remember all information is confidential. No information about you will be disclosed to other agencies.

Please keep this form and bring it with you to your meeting.

Thank you very much.

Fiona Kennedy
Consultant Clinical Psychologist

Dr R V Seth
Consultant Psychiatrist

APPENDIX D: The Drug Attitude Scale

THE DRUG ATTITUDE SCALE (DAS)

DAS patient code ☐☐☐☐

1.	It is hell taking this medication	☐
2.	I should have the minimum dose needed to keep my symptoms under control	☐
3.	Neuroleptics aren't good for me	☐
4.	I don't know why I take my medication	☐
5.	If I didn't take my medication I'd end up back in hospital	☐
6.	Neuroleptics give me control over my life	☐
7.	Neuroleptics are just chemical straight jackets	☐
8.	Neuroleptics make my brain work better	☐
9.	Neuroleptics make me think clearer	☐
10.	My symptoms are still there but they just don't bother me as much when I've taken my medication	☐
11.	This medication drains my energy	☐
12.	I don't think my medication is totally suited to me	☐
13.	My neuroleptics aren't as good as they're made out to be	☐
14.	I'm worried about what will happen if they stop my medication	☐
15.	I think all neuroleptics are the same so it doesn't matter which one I'm on	☐
16.	If I started getting any serious side-effects I'd stop taking my medication	☐
17.	I'm frightened of my medication controlling me	☐
18.	People wouldn't like me if they saw what I was like without my medication	☐
19.	I don't have any side-effects from my medication	☐
20.	Neuroleptics make me happier	☐
21.	I would never change my medication of my own accord	☐
22.	I come to get my medication to meet people	☐
23.	If a doctor prescribes something I think I should stick to it	☐
24.	I've lost interest in things since I've been on the neuroleptics	☐
25.	Neuroleptics make me see reality better	☐
26.	I can't do without my medication	☐
27.	The medication doesn't cure my illness it just controls the symptoms	☐
28.	Neuroleptics make me less tense	☐
29.	I don't like taking my medication	☐
30.	This medication is harmless to me	☐

APPENDIX E: The Theory of Planned Behaviour Scale

THE THEORY OF PLANNED BEHAVIOUR SCALE (TBS)

TPB patient code [ ][ ][ ][ ]

1.	I always intend to take my medication	☐
2.	Taking my drugs is unpleasant	☐
3.	My friends think I should not take my medication	☐
4.	I know I can take my medication if I want to	☐
5.	I always expect that I will take my drugs	☐
6.	Taking my medication is enjoyable	☐
7.	I feel under social pressure not to take my drugs	☐
8.	Taking my medication is foolish	☐
9.	Whether I take my drugs or not is entirely up to me	☐
10.	My psychiatrist would approve of me taking my drugs	☐
11.	Taking my drugs is harmful	☐
12.	I always plan not to take my drugs	☐
13.	People who are important to me think I should not take my drugs	☐
14.	I want to take my drugs but don't always manage to	☐
15.	Taking my medication is good	☐
16.	I have no control over taking my medication	☐
17.	My family/carers want me to take my drugs	☐
18.	It is easy for me to take my medication	☐
19.	I never want to take my drugs	☐

APPENDIX F: The Drug Attitude Inventory 30 item version (DAI-30)

THE DRUG ATTITUDE INVENTORY (30 item version) (DAI 30)

To be answered "T" = True or "F" = False

DAI (30) patient code | | | | | |

1.	I don't need to take medication once I feel better	☐
2.	For me, the good things about medication outweigh the bad	☐
3.	I feel weird, like a 'zombie' on medication	☐
4.	Even when I'm not in hospital I need medication regularly	☐
5.	If I take medication it's only because of pressure from other people	☐
6.	I am more aware of what I am doing, of what is going on around me when I am on medication	☐
7.	Taking medications will do me no harm	☐
8.	I take medications of my own choice	☐
9.	Medications make me feel more relaxed	☐
10.	I am no different on or off medication	☐
11.	The unpleasant effects of medication are always present	☐
12.	Medication makes me feel tired and sluggish	☐
13.	I take medication only when I am sick	☐
14.	Medication is slow-acting poison	☐
15.	I get along better with people when I am taking medication	☐
16.	I can't concentrate on anything when I am taking medication	☐
17.	I know better than the doctor when to go off medication	☐
18.	I feel more normal on medication	☐
19.	I would rather be sick than taking medications	☐
20.	It is unnatural for my mind and body to be controlled by medication	☐
21.	My thoughts are clearer on medication	☐
22.	I should stay on medication even if I feel all right	☐
23.	Taking medication will prevent me from having a breakdown	☐
24.	It is up to the doctor when I go off medication	☐
25.	Things that I could do easily are much more difficult when I am on medication	☐
26.	I am happier, feel better, when taking medication	☐
27.	I am given medication to control behaviour that <u>other</u> people (not myself) don't like	☐
28.	I can't relax on medication	☐
29.	I am in better control of myself when taking medications	☐
30.	By staying on medications I can prevent getting sick	☐

APPENDIX G The Drug Attitude Inventory 10 item version (DAI 10)

THE DRUG ATTITUDE INVENTORY 10 ITEM VERSION (DAI 10)

To be answered "T" = True or "F" = False

DAI 10 patient code [ ][ ][ ][ ]

1. For .me, the good things about medication outweigh the bad ☐
2. I feel weird like a "zombie" on medication ☐
3. I take medication of own free choice ☐
4. Medication makes me feel more relaxed ☐
5. Medication makes me feel tired and sluggish ☐
6. I take medication only when I am sick ☐
7. I feel more normal on medication ☐
8. It is unnatural for my mind and body to be controlled by medication ☐
9. My thoughts are clearer on medication ☐
10. By staying on medication I can prevent getting sick. ☐

APPENDIX H: The Drug behaviour Scale

THE DRUG BEHAVIOUR SCALE (DBS)

DBS patient code [ ][ ][ ][ ]

1. Method of administration of drug

TABLET/SYRUP/DEPOT INJECTION/OTHER

	From Case notes/carer			Patient report		
2.	Neuroleptics	Dose	Times daily	Neuroleptics	Dose	Times Daily
	.....			.....		
	.....			.....		
	.....			.....		
	.....			.....		...

3. I change the TIME I'm supposed to take my (drugs)? Never always

   If rating >-3 ask:
   Why do you change the time?.....
   .....

4. I change the DOSE of (drugs) I'm supposed to take Never always

   If rating >-3 ask:
   Why do you change the dose?.....
   .....

5. I miss out taking my (drug) altogether Never always

   If rating >-3 ask:
   Why don't you take your drugs?.....
   .....

6. I add over-the counter medicines to my (drugs) Never always

   If rating >-3 ask:
   Why do you do that?.....
   .....

7. I add street drugs to my (drug/s) Never always

   If rating >-3 ask:
   Why do you do that?.....

DBS patient code □□□□

8. Do you hold your own (drugs)? ☐ Yes ☐ Some Help ☐ No

9. Tell me your understanding of why you take (the drug/s)
.....
.....

10. Tell me about any side-effects you have from (the drug/s)?
.....
.....

11. Do you think you could do anything to improve the effect of (the drug/s) for yourself?
.....
.....

12. Do you think the person who prescribed your (drug/s) could improve the effects of (the drugs)? for you?
.....
.....

13. What makes it easier to take (the drug/s)?
.....
.....

14. What makes it harder to take (the drug/s)?
.....
.....

THANK YOU VERY MUCH

APPENDIX I: The Kemp Scale

KEMP COMPLIANCE RATING (from Primary Nurse)

Please circle **one** number you feel best represents your patient's compliance

KEY:

1 2 3 4 5 6 7

1 - Complete refusal

2 - Partial refusal e.g. only accepting minimum dose, refusing depot drugs

3 - Reluctant acceptance e.g. patient questions need for treatment frequently (i.e. every 2 days), only accepts medication because it is compulsory

4 - Occasional reluctance e.g. patient questions need for treatment on regular basis (i.e. every week)

5 - Passive acceptance

6 - Moderate participation e.g. patient has some interest in their treatment and needs no prompting to take their medication

7 - Active participation e.g. patient readily accepts medication and takes responsibility for their treatment

---

Patient's Name.....

Address.....

.....

.....

Keyworker.....

Date scale completed

APPENDIX J: Instructions to interviewers

Instructions for the Interviewer.

To administer this questionnaire, it is important to **minimise distractions** and **interruptions**. The questionnaire should be carried out in a **quiet room** on a **one** to **one** basis, allowing the participant to fully concentrate. There is a short explanation of what the questionnaire is about and how to carry it out.

The interviewer should put the 7 point scale marked on card in front of the participant.

A copy of the questionnaire should be given to the participant.

A copy of the explanation should be given to the participant, the interviewer should also read the explanation aloud to the participant.

To make sure everything is understood before continuing, the interviewer should then ask "Do you understand?.".

If the participant is unsure then the instructions should be read to them again, if still unsure a further explanation and rehearsal of what they need to do should be provided until the person feels that they fully understand.

The interviewer should then say: **"I will read you a statement, and you then have to decide how much you agree or disagree with it. To answer just point to one of the 7 points on the scale which is in front of you. The points range from strongly agree (+3) to strongly disagree (-3). Please tell me your choice at the same time as pointing. Here is the first statement..."**.

Each statement should be read aloud to the subject. To respond the subject has to point to that one of the 7 numbers which most appropriately reflects their view and to say the number aloud. Their response needs to be recorded on the questionnaire score sheet **by the interviewer.**

INSTRUCTIONS TO PARTICIPANTS

THOUGHTS AND FEELINGS ABOUT YOUR DRUGS.

The questionnaires will help us understand people's thoughts and feelings about taking their medication. The drugs are known as neuroleptics. These drugs are prescribed to help control symptoms such as hearing voices, seeing things, mood problems, and distressing thoughts.

You will be read some statements about neuroleptics. Then you will be asked to point to the number (3 to -3) which shows best your own opinion. Pointing to 3 would mean "I strongly agree" whereas -3 would mean "I strongly disagree" and numbers in between mean opinions in between.

The interviewer will make a note of your opinions. Your name will not appear on the note, only a code number. All answers will be confidential and will not be shared with your consultant psychiatrist or with any other professional involved with you.

APPENDIX L: Demographic data sheet

DEMOGRAPHIC DATA SHEET (DDS).

PATIENT'S NAME _____CODE_____

KEYWORKER _____

PSYCHIATRIST'S NAME _____

INTERVIEWER'S NAME_____DATE_____

SEX (Please circle one) Male Female

AGE _____ years

MARITAL STATUS (Please circle one)

Single Married Divorced Widow/er

NUMBER OF YEARS IN FULL TIME EDUCATION
(POST 5) _____ years

WHERE DO YOU CURRENTLY LIVE? (Please circle one)

Residential Home Supportive Lodgings Own Home Other

DSM IV DIAGNOSIS Schizophrenia/Schizoaffective

NEGATIVE SYMPTOMS Y N

DURATION OF ILLNESS FROM 1st ONSET _____ years _____mths

Neuroleptic	**Dose**	**How Often**
.....		
.....		
.....		
.....		
.....		

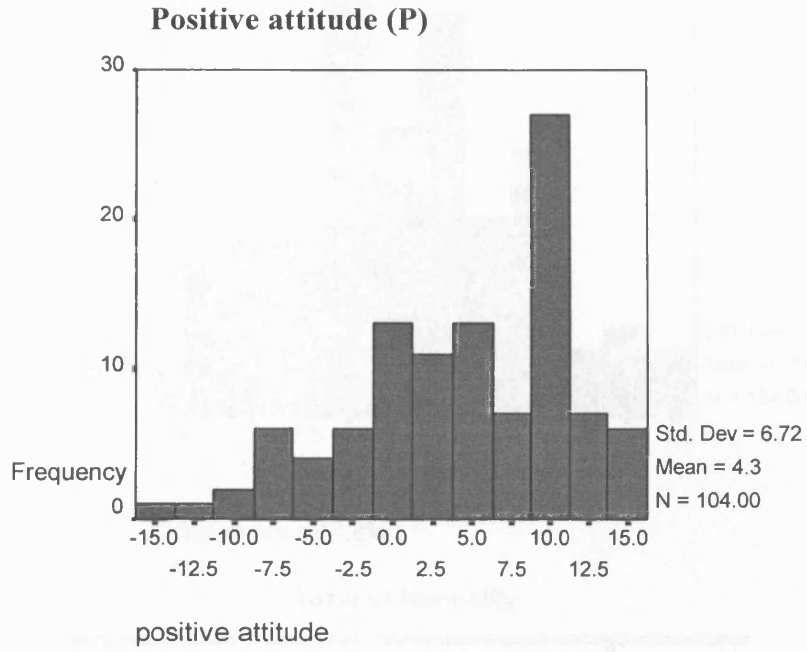
IP OP New Neuroleptic/Old Neuroleptic DEPOT <3 months? Y N

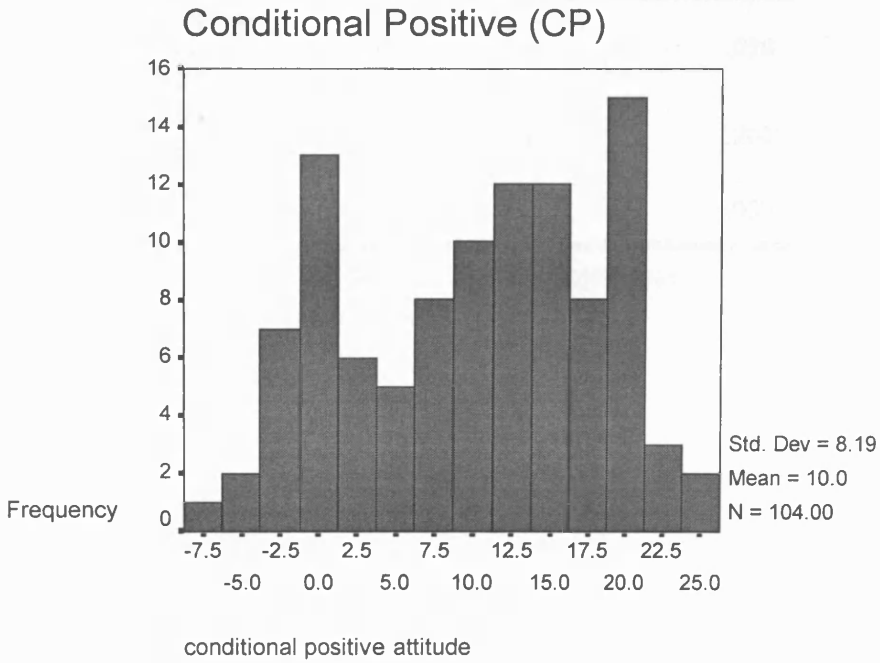
APPENDIX M: Drug compliance and Attitude Scale (DCAS)

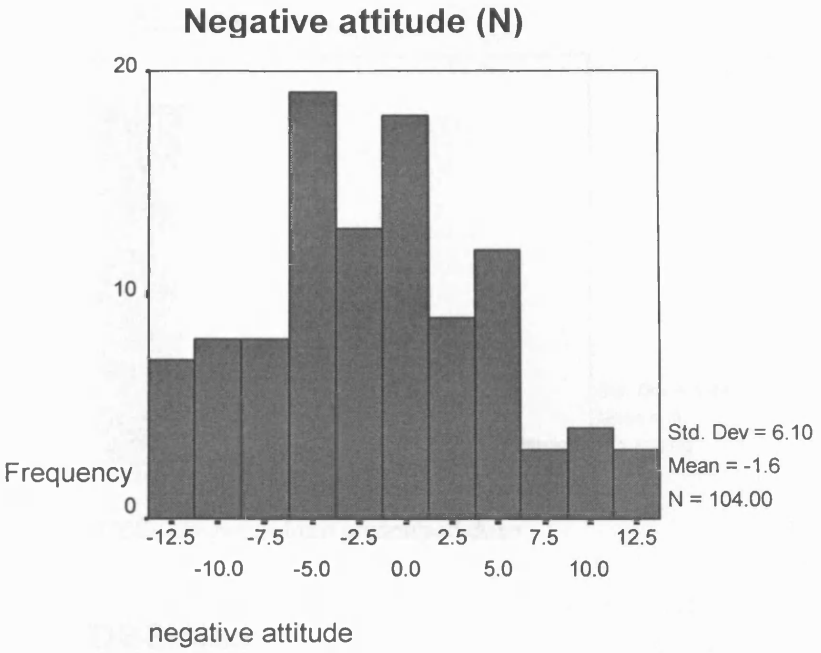
DRUG COMPLIANCE & ATTITUDE SCALE (DCAS)

		Strongly disagree	Strongly agree
1.	Neuroleptics make me happier	☐☐☐☐☐☐☐	
2.	This medication drains my energy	☐☐☐☐☐☐☐	
3.	Taking my drugs is unpleasant	☐☐☐☐☐☐☐	
4.	Its hell taking this medication	☐☐☐☐☐☐☐	
5.	Neuroleptics make me think clearer	☐☐☐☐☐☐☐	
6.	Neuroleptics make me less tense	☐☐☐☐☐☐☐	
7.	Taking my drugs is harmful	☐☐☐☐☐☐☐	
8.	I'm frightened of my medication controlling me	☐☐☐☐☐☐☐	
9.	Neuroleptics aren't good for me	☐☐☐☐☐☐☐	
10.	Taking my medication is foolish	☐☐☐☐☐☐☐	
11.	I should have the minimum dose needed to keep my symptoms under control	☐☐☐☐☐☐☐	
12.	Taking my medication is enjoyable	☐☐☐☐☐☐☐	
13.	I've lost interest in things since I've been on the neuroleptics	☐☐☐☐☐☐☐	
14.	Neuroleptics make my brain work better	☐☐☐☐☐☐☐	
15.	Taking my medication is good	☐☐☐☐☐☐☐	
16.	Neuroleptics make me see reality better	☐☐☐☐☐☐☐	
17.	I don't have any side effects from my medication	☐☐☐☐☐☐☐	

APPENDIX N: Distributions of independent and dependent variables: Histograms and normality tests





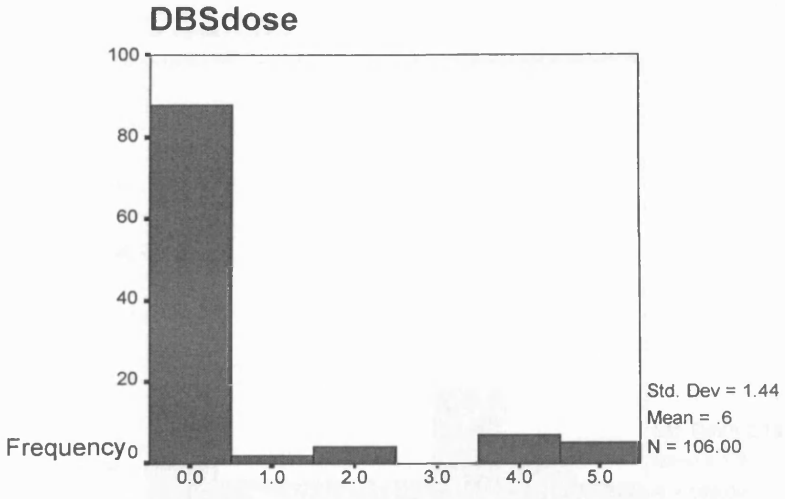


Tests of Normality

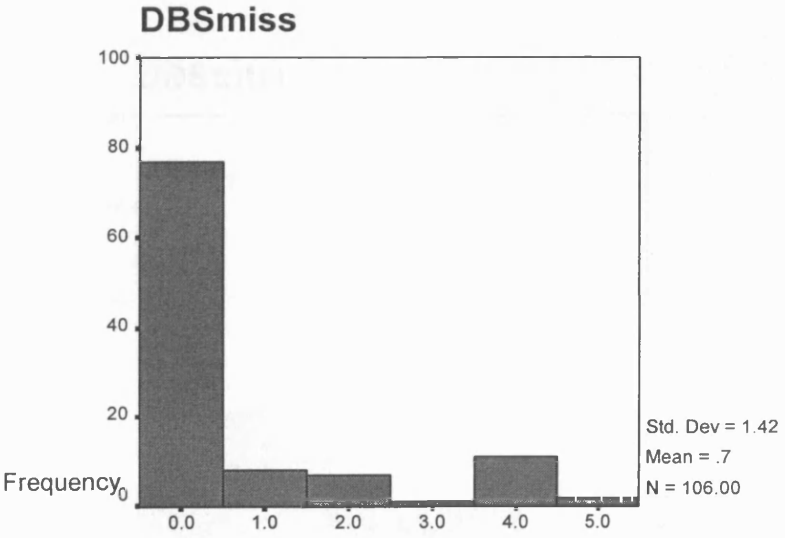
	Kolmogorov-Smirnov[a]		
	Statistic	df	Sig.
conditional positive attitude	.096	104	.019
negative attitude	.069	104	.200*
positive attitude	.144	104	.000

*. This is a lower bound of the true significance.

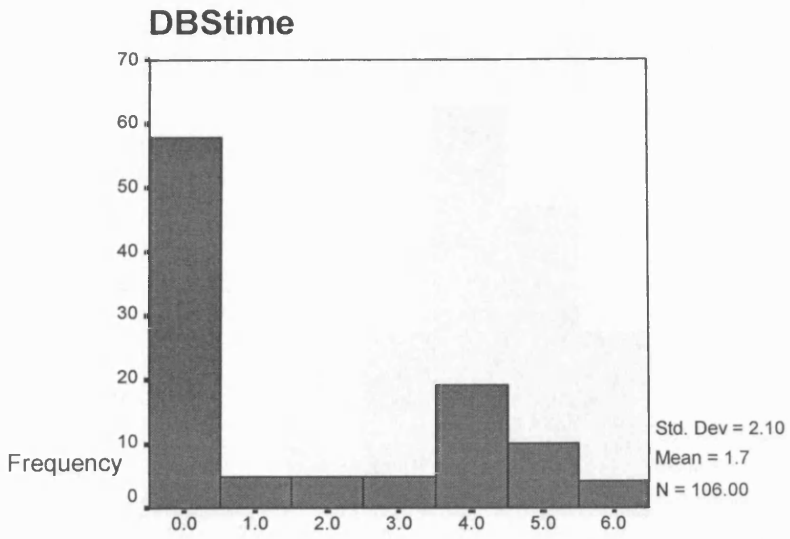
a. Lilliefors Significance Correction



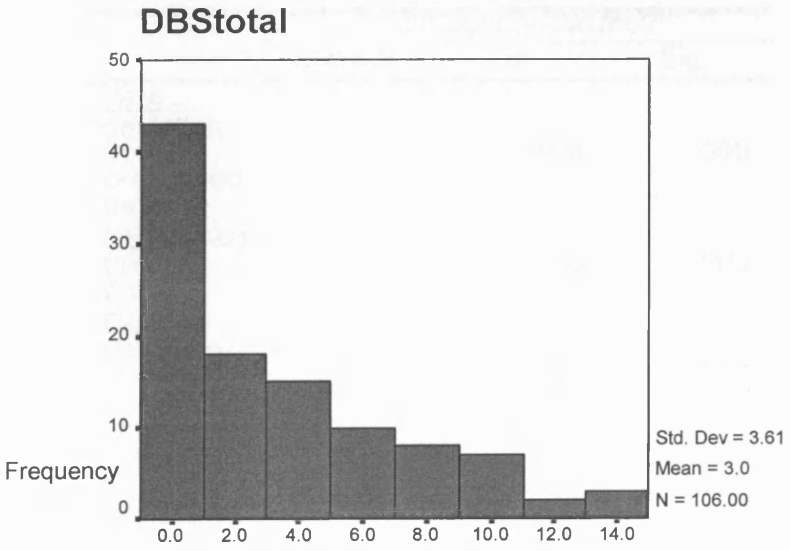
DBS - deviation from prescribed dose



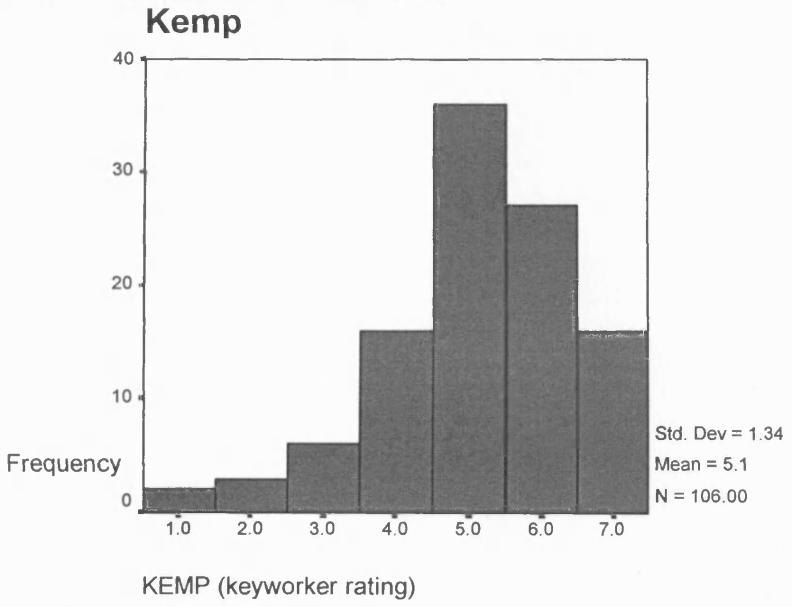
DBS - miss taking drugs



DBS - deviation from prescribed time



DBS - total deviation

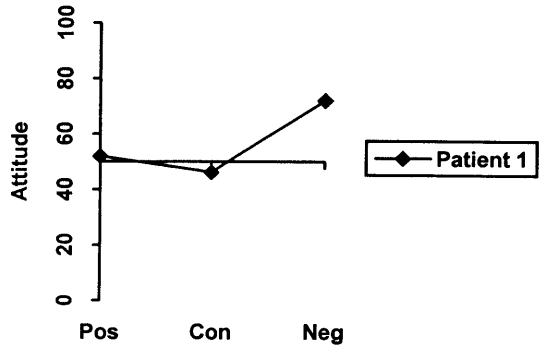


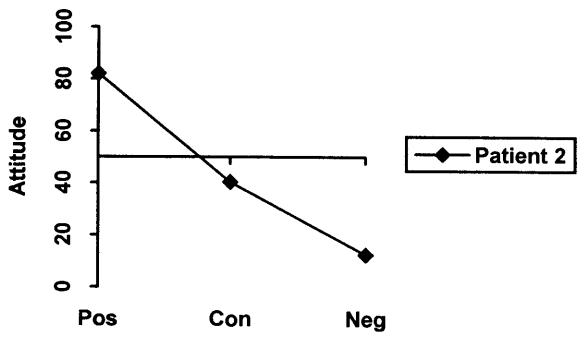
Tests of Normality

	Kolmogorov-Smirnov[a]		
	Statistic	df	Sig.
DBS - deviation from prescribed dose	.490	106	.000
DBS - miss taking drugs	.426	106	.000
DBS - deviation from prescribed time	.338	106	.000
DBS - total deviation	.223	106	.000
KEMP	.206	106	.000

a. Lilliefors Significance Correction

APPENDIX O: DCAS profiles for each participant


Attitude
0
20
40
60
80
100
Pos
Con
Neg
Patient 1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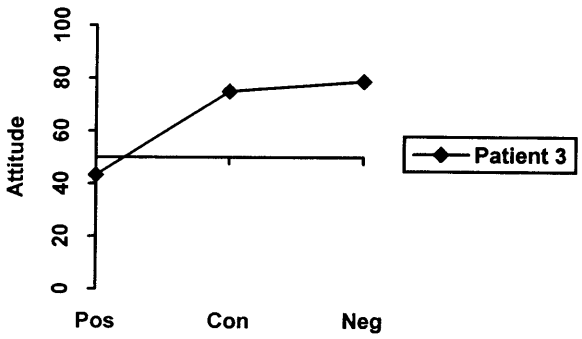
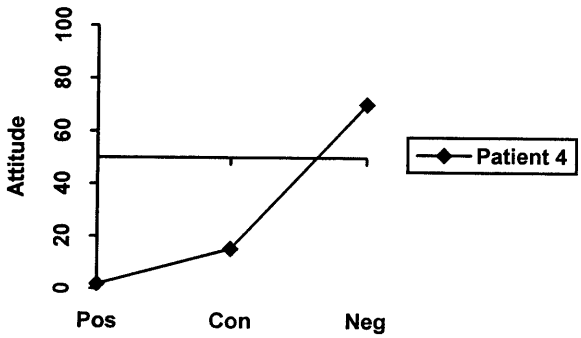
20
40
60
80
100
Pos
Con
Neg
Patient 2


Attitude
0
20
40
60
80
100
Pos
Con
Neg
Patient 3


Attitude
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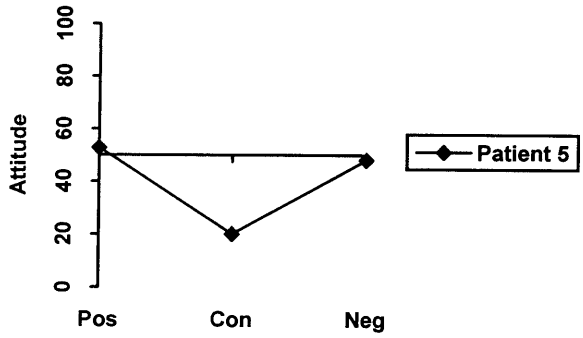
20
40
60
80
100
Pos
Con
Neg
Patient 4


Attitude
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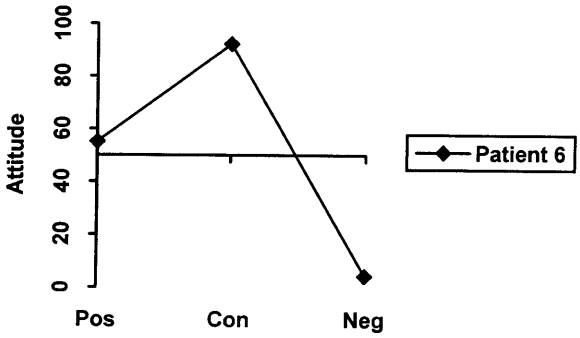
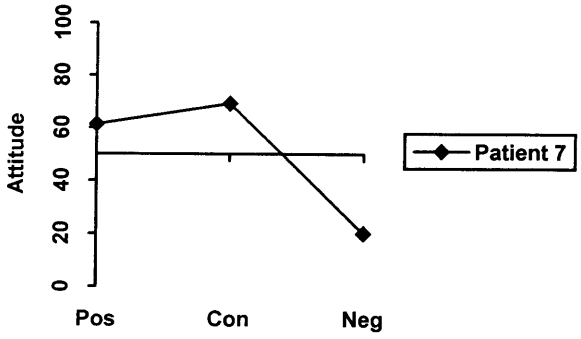
20
40
60
80
100
Pos
Con
Neg
Patient 5


Attitude
0
20
40
60
80
100
Pos
Con
Neg
Patient 6


Attitude
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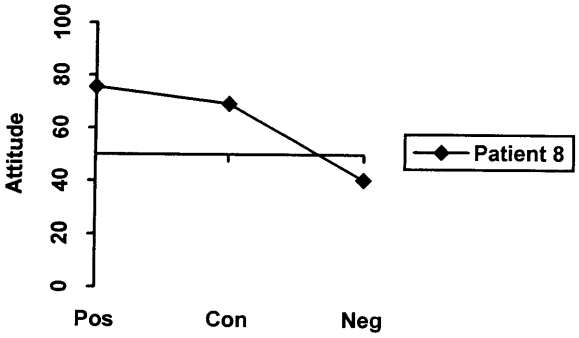
20
40
60
80
100
Pos
Con
Neg
Patient 7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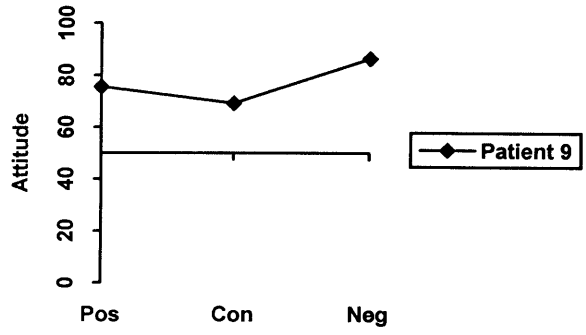
Patient 8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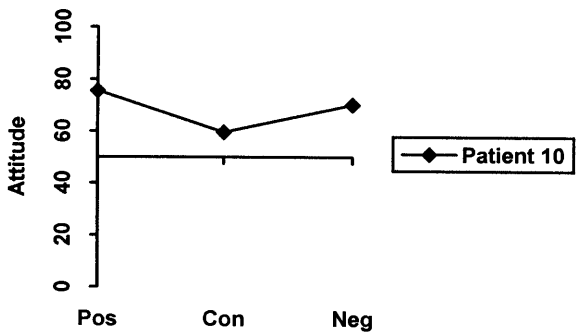
Patient 9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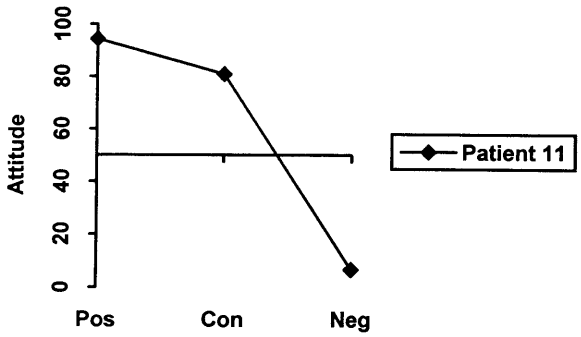
Patient 10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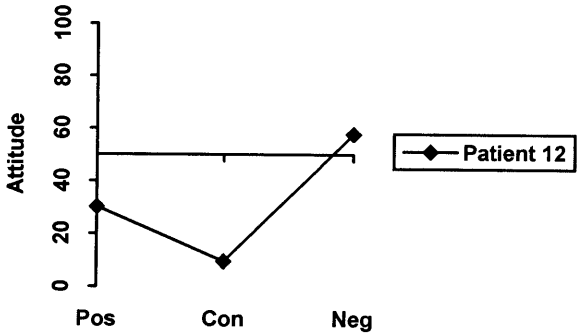
Patient 11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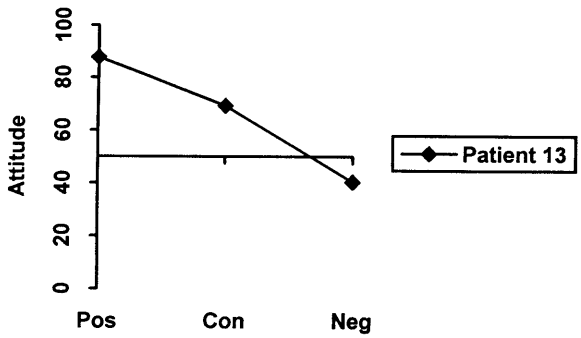
Patient 12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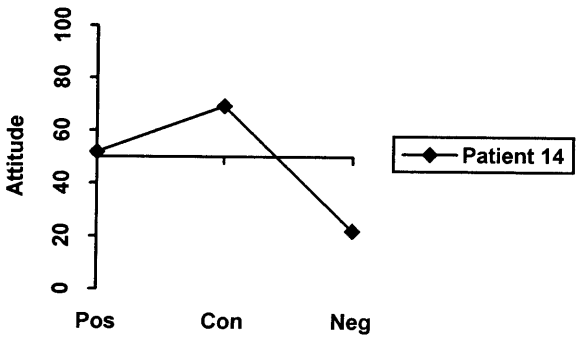
Patient 13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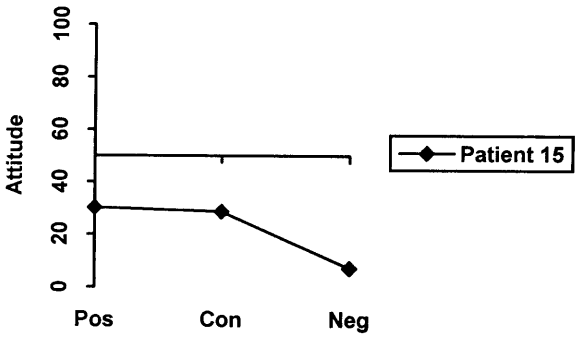
Patient 14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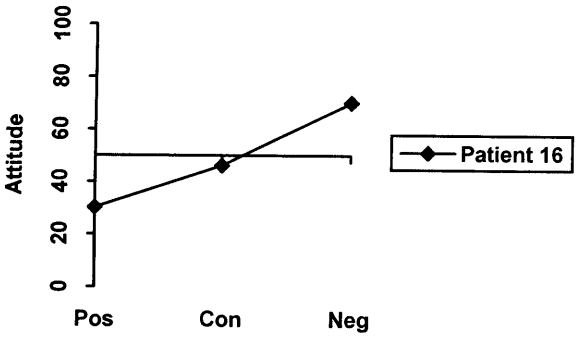
Patient 15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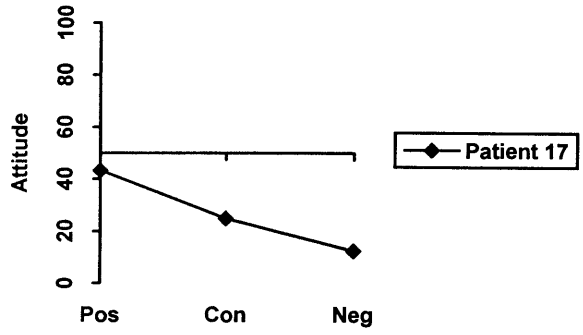
Patient 16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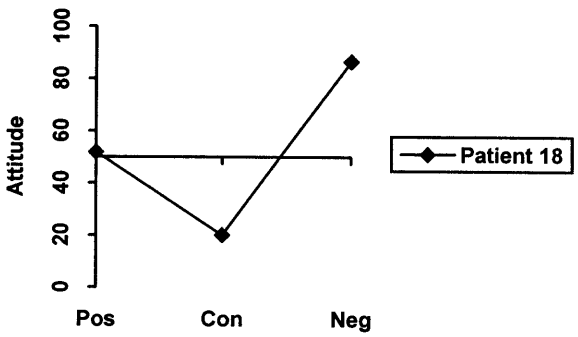
Patient 17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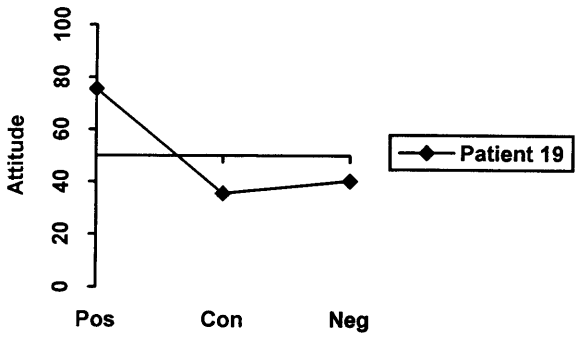
Patient 18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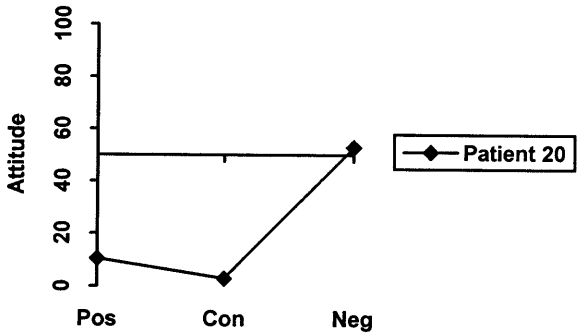
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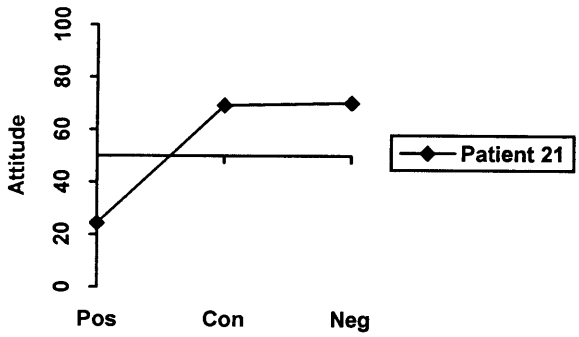
Patient 20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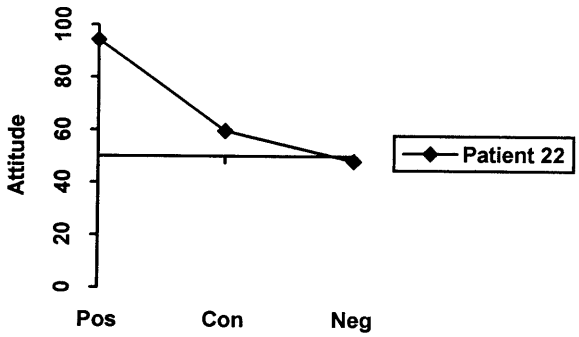
Patient 21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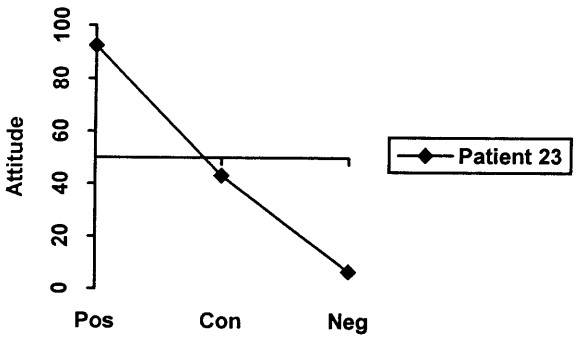
Patient 22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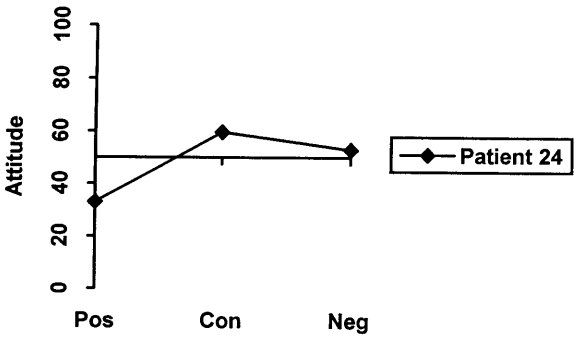
Patient 23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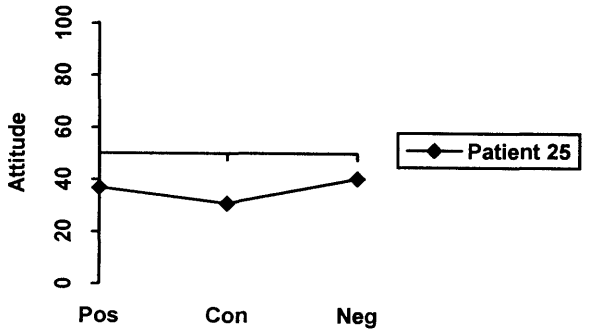
Patient 24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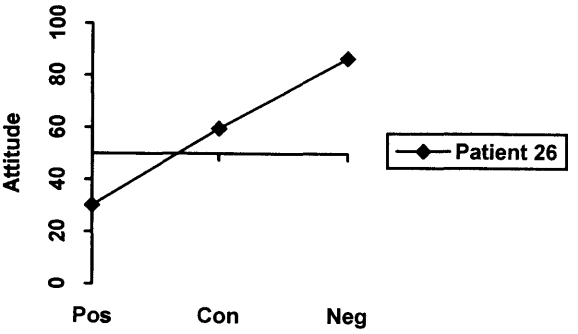
Patient 25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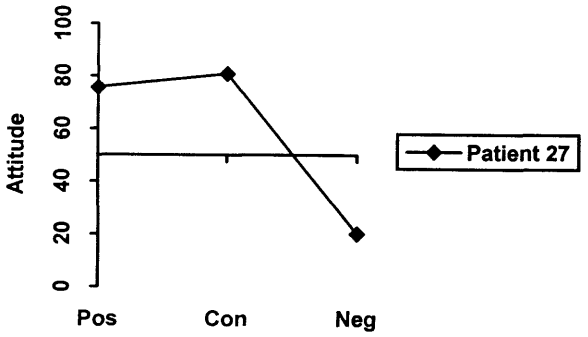
Patient 26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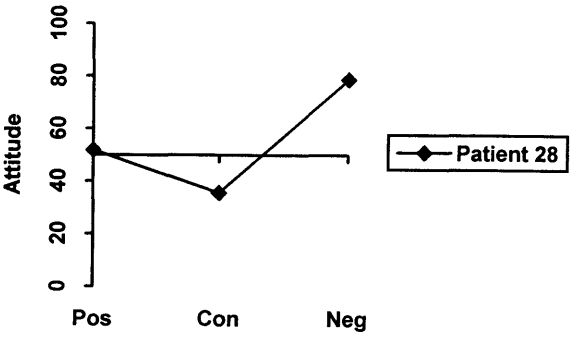
Patient 27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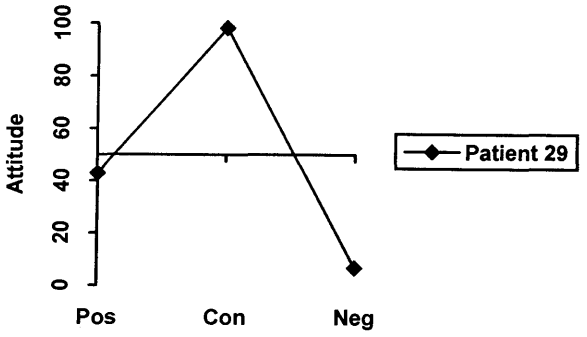
Patient 28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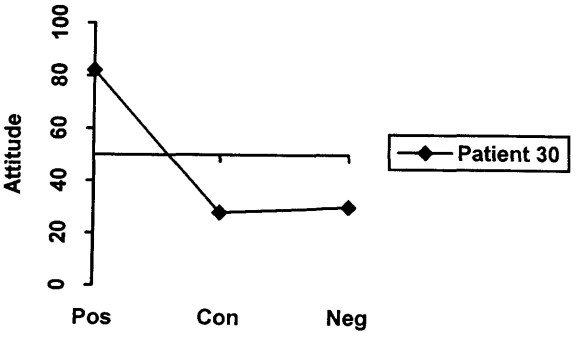
Patient 29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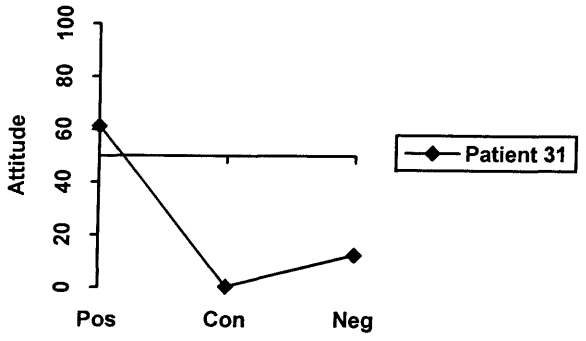
Patient 30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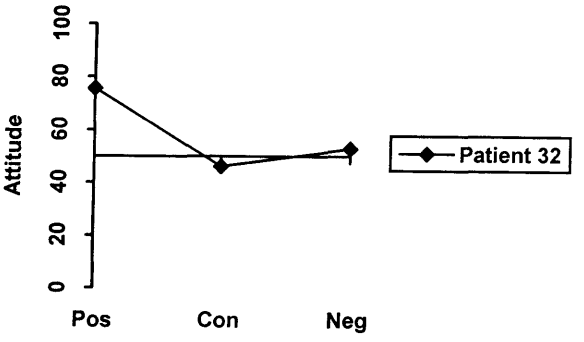
Patient 31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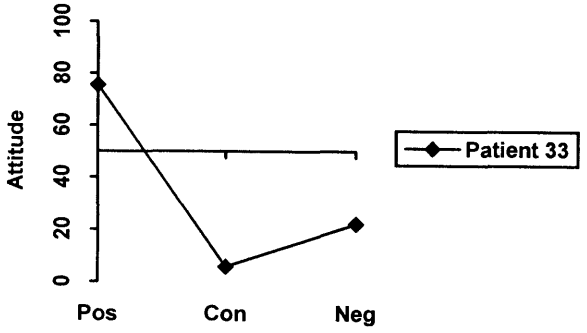
Patient 32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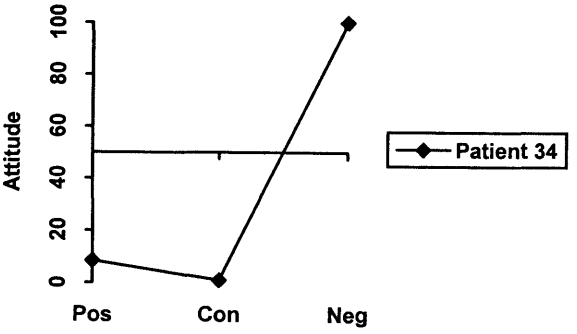
Patient 33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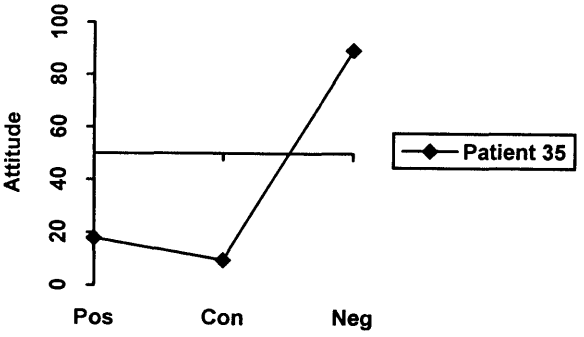
Patient 34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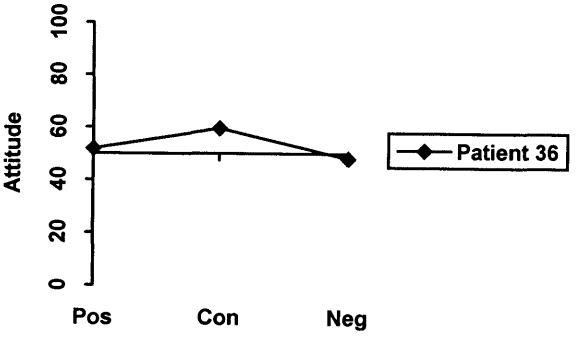
Patient 35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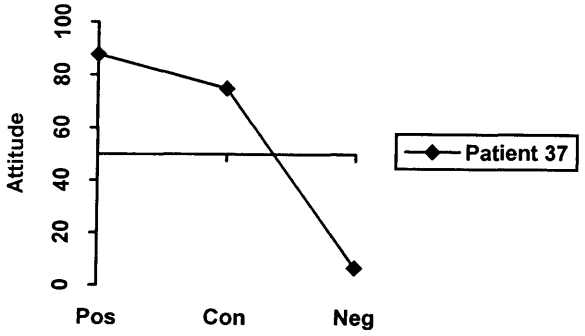
Patient 36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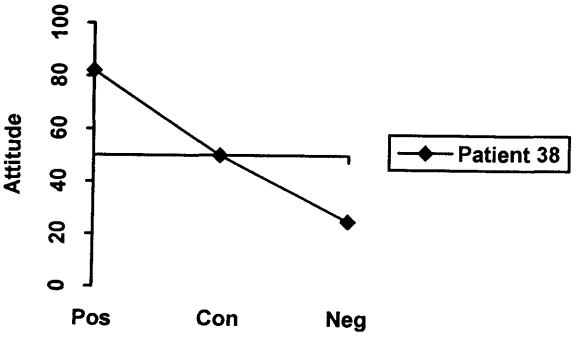
Patient 37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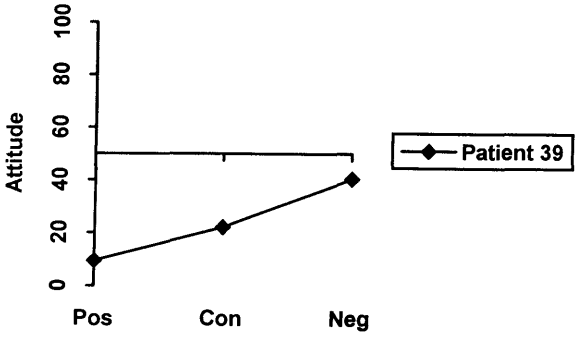
Patient 38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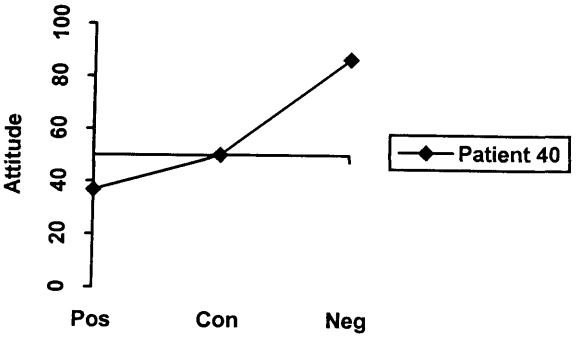
Patient 39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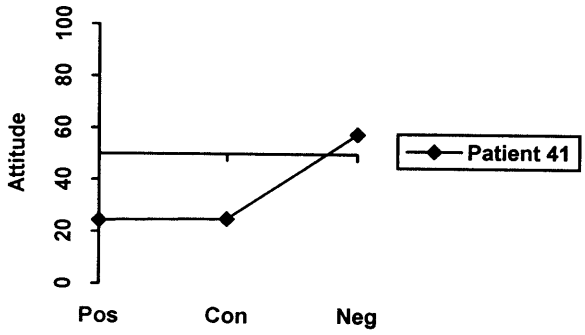
Patient 40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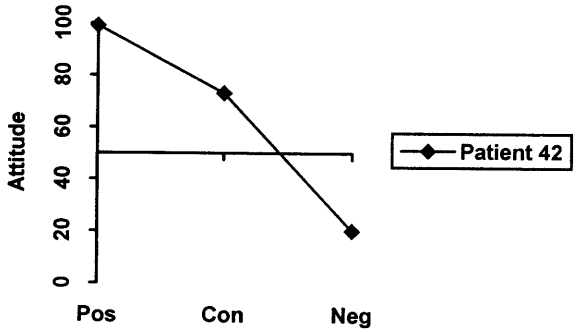
Patient 41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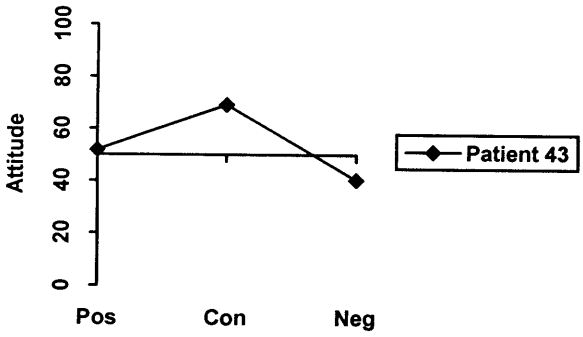
Patient 42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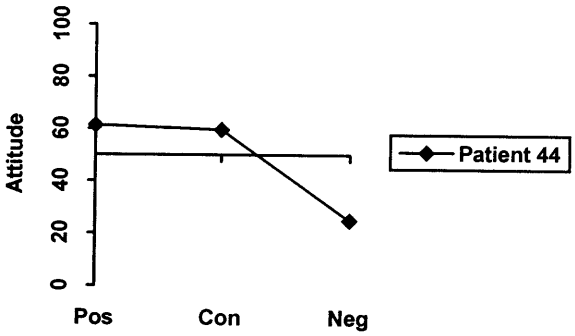
Patient 43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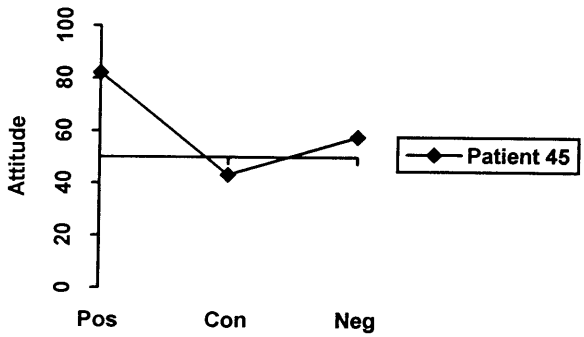
Patient 44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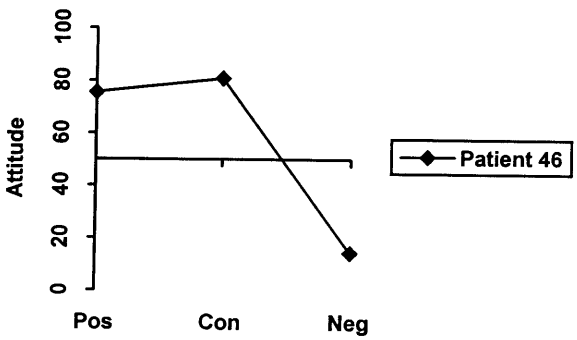
Patient 45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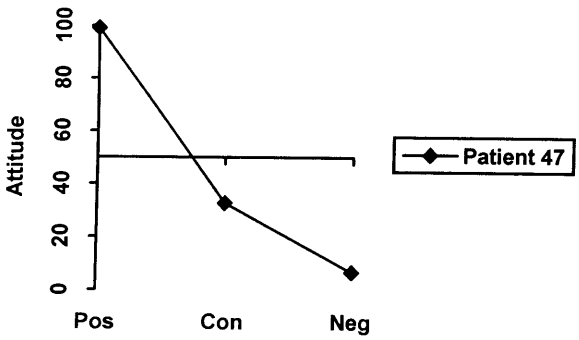
Patient 46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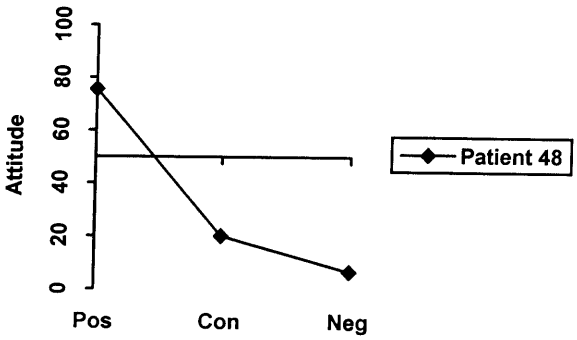
Patient 47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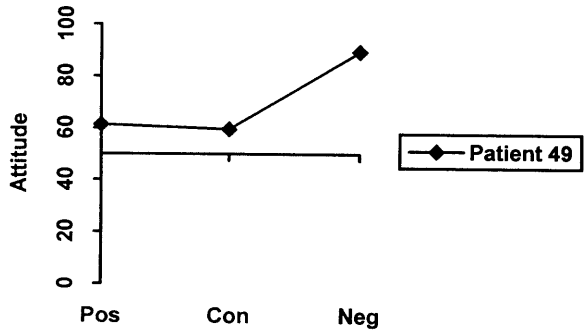
Patient 48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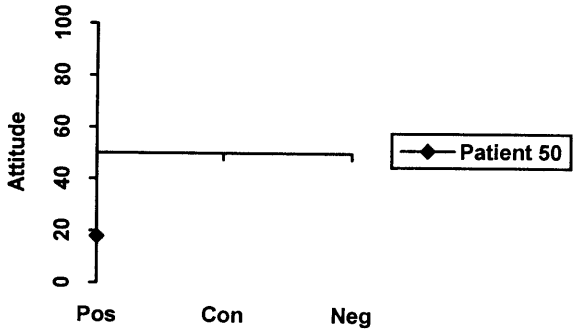
Neg
Patient 49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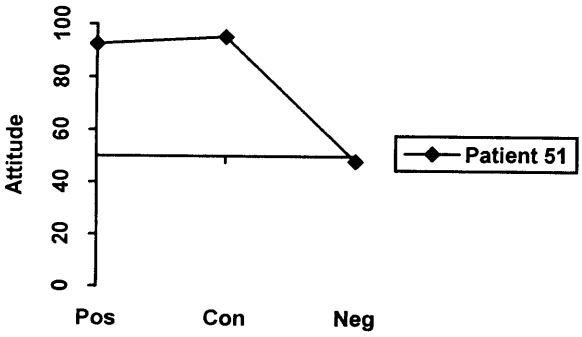
Patient 50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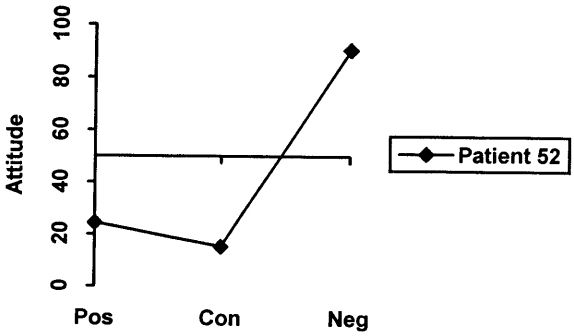
Patient 51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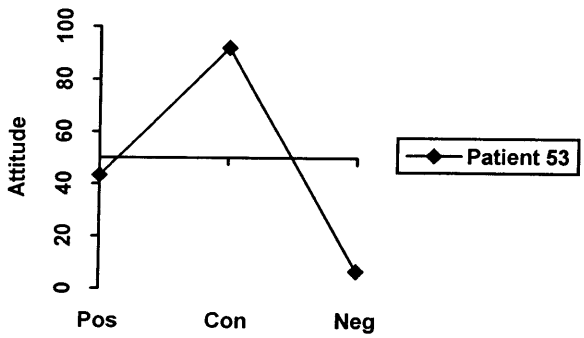
Patient 52


Attitude
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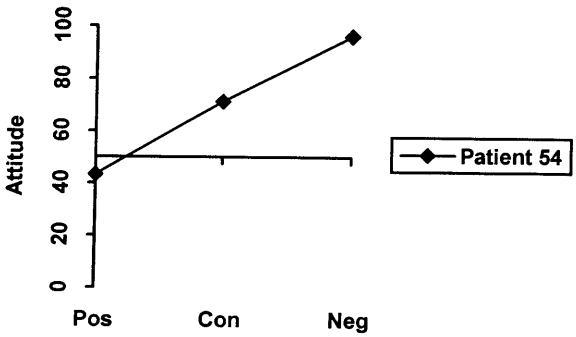
Neg
Patient 53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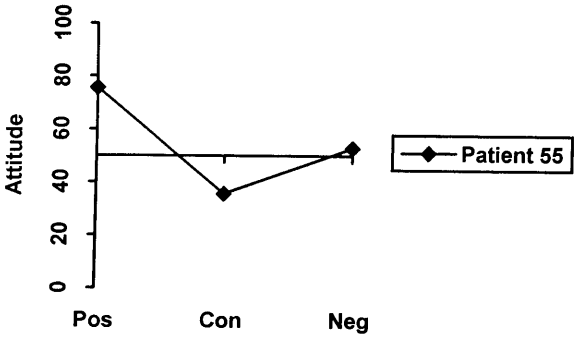
Patient 54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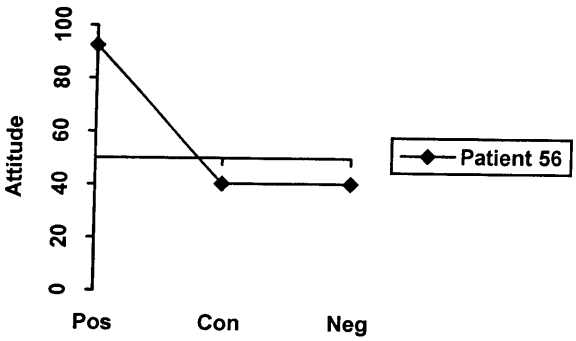
Patient 55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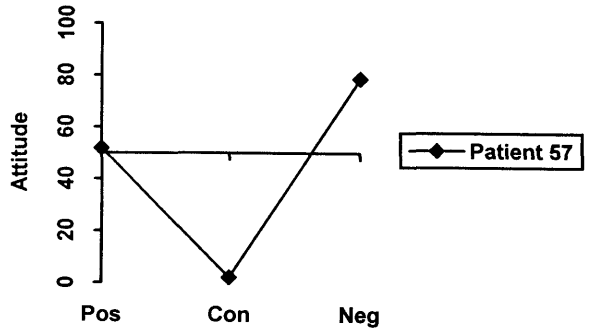
Patient 56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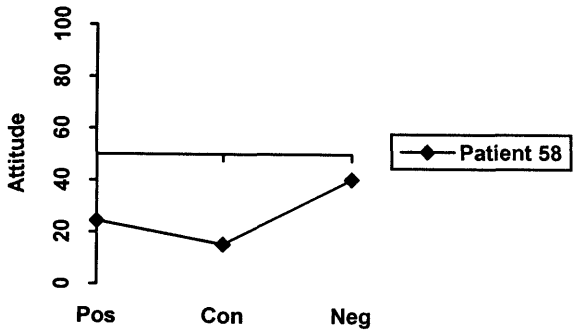
Patient 57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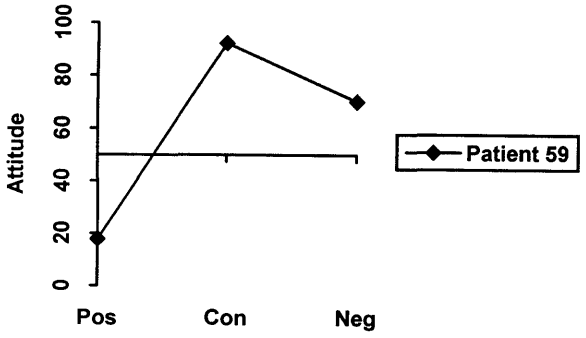
Patient 58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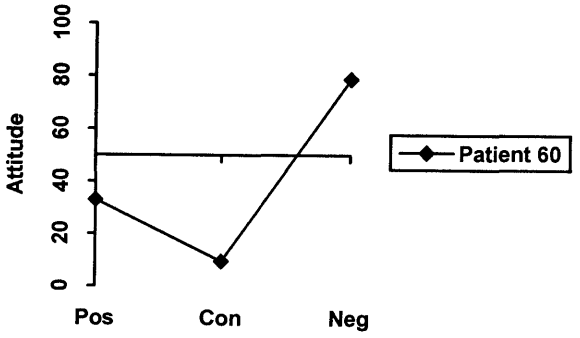
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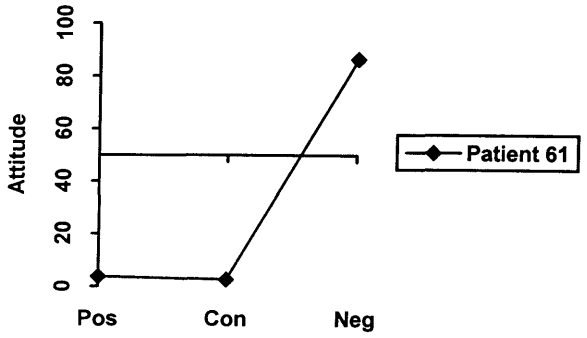
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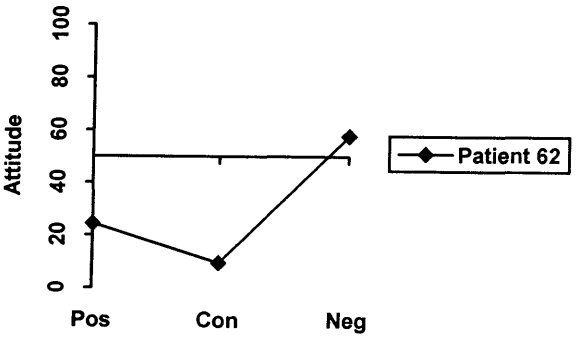
Patient 61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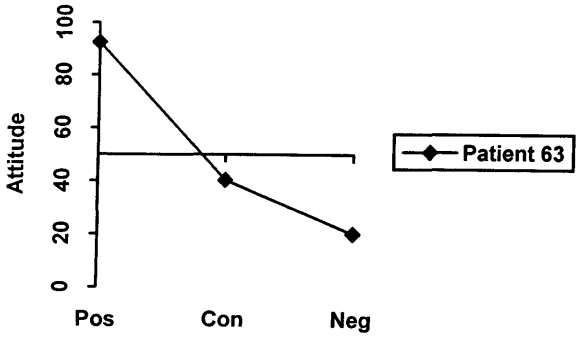
Patient 62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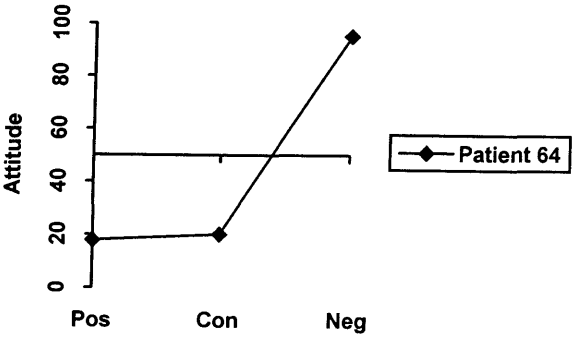
Patient 63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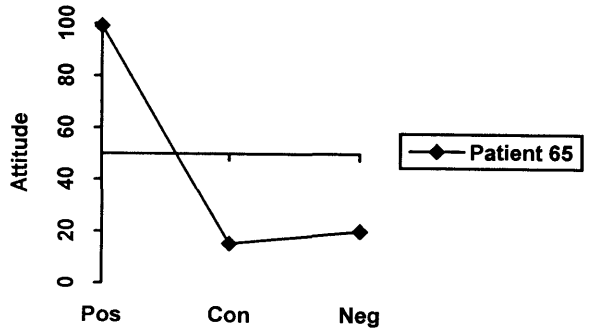
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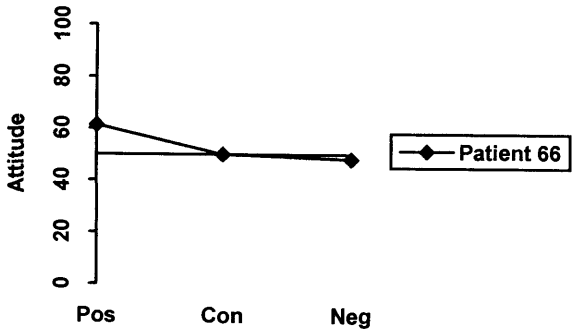
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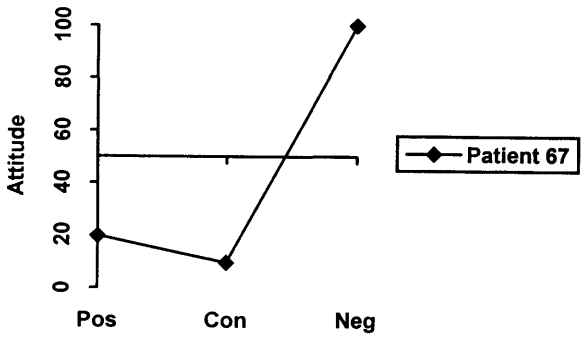
Patient 66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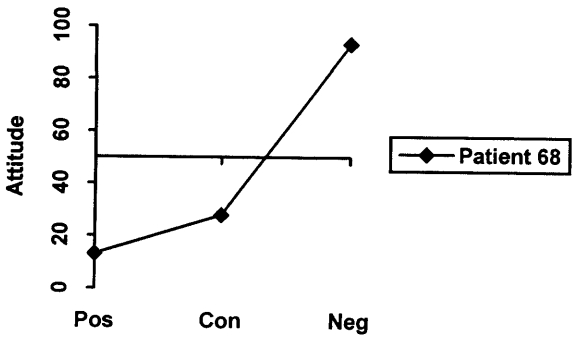
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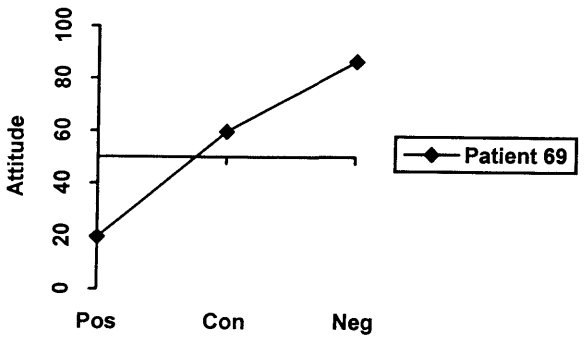
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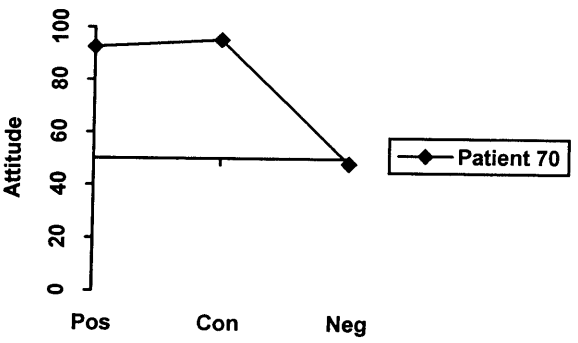
Patient 69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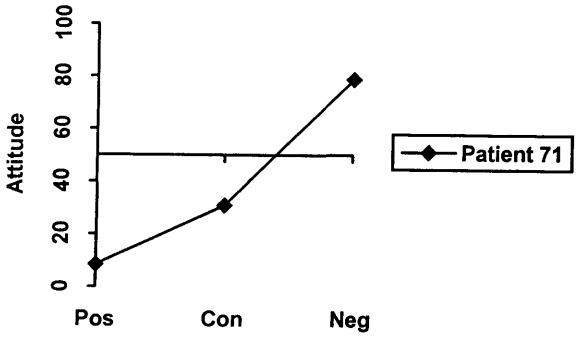
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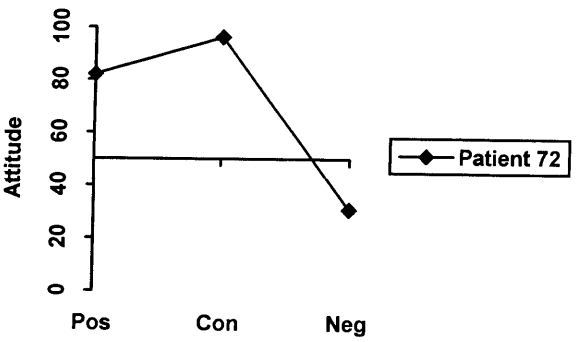
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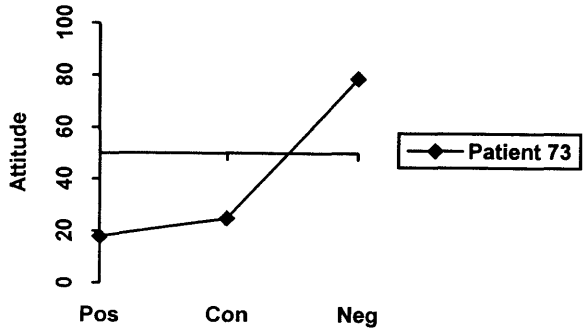
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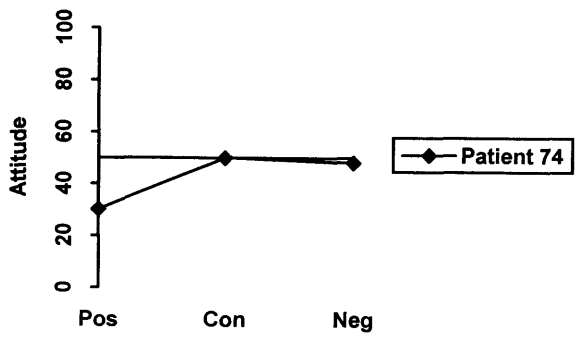
Patient 73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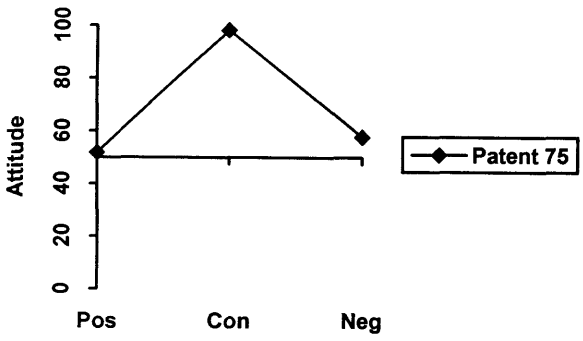
Patient 74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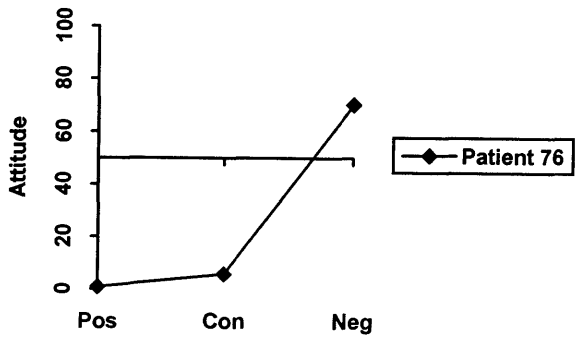
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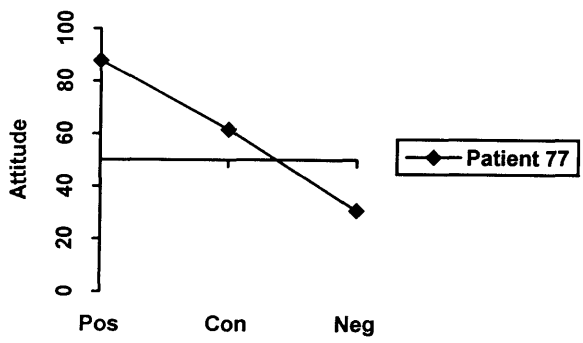
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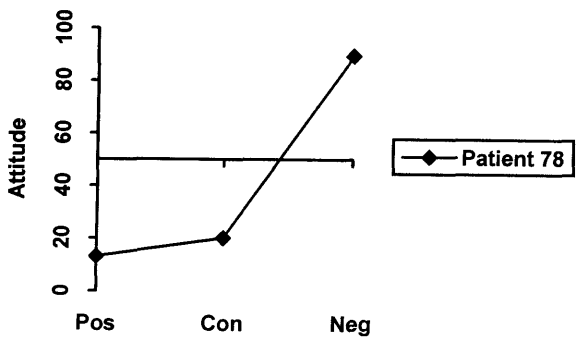
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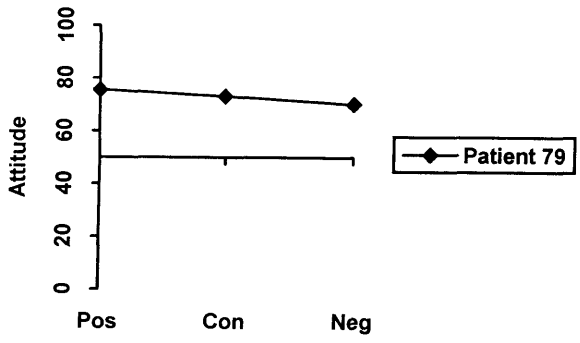
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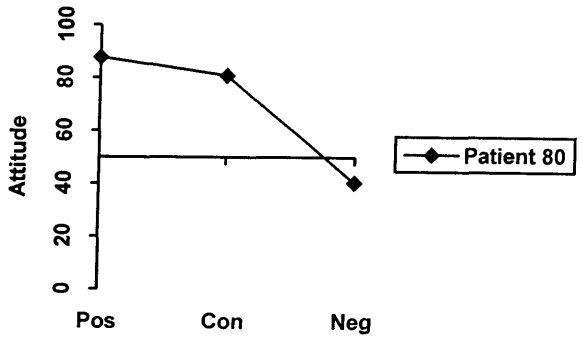
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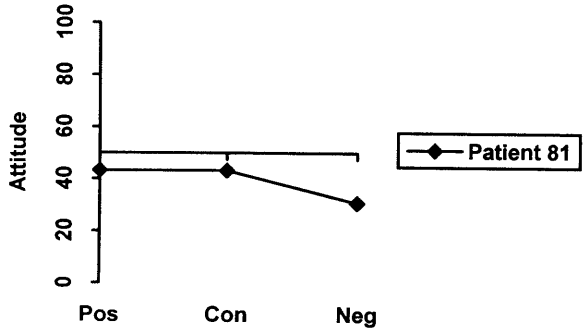
Patient 80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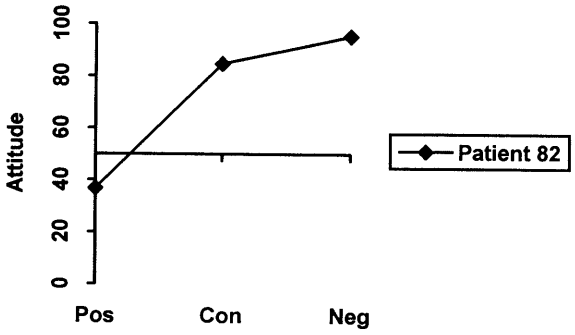
Patient 81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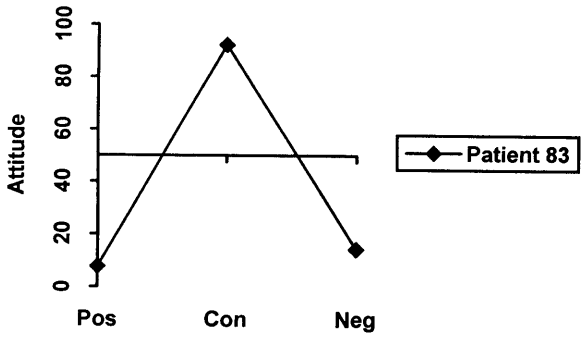
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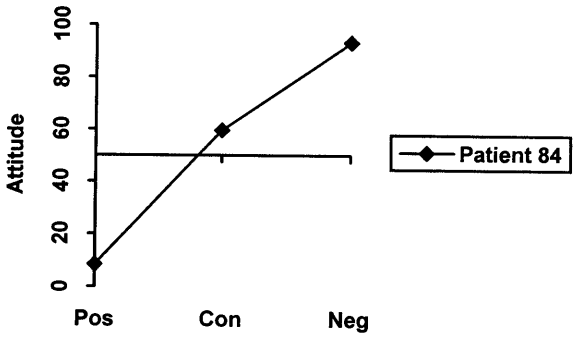
Patient 83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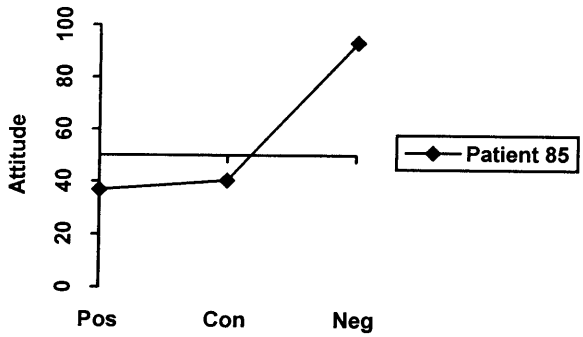
Patient 84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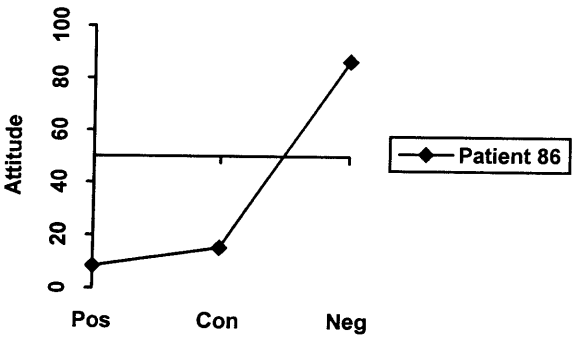
Patient 85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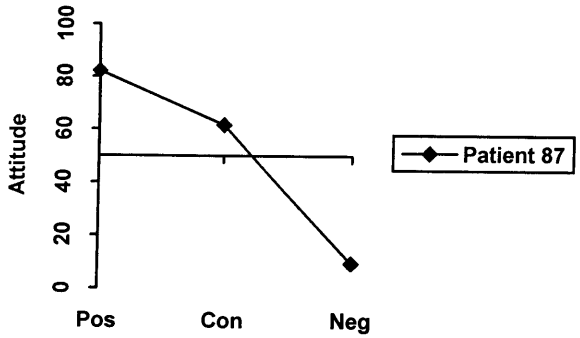
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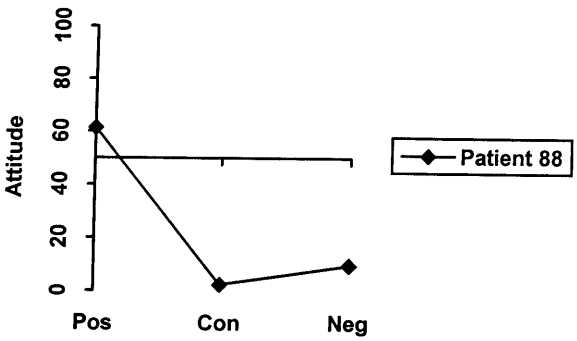
Patient 87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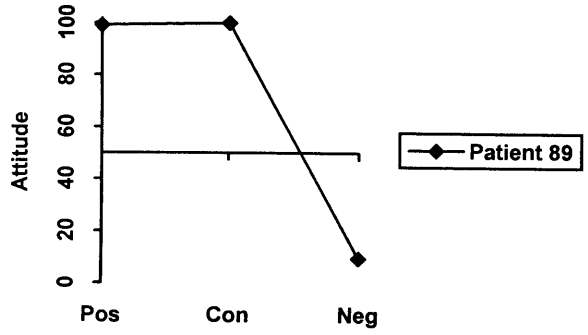
Patient 88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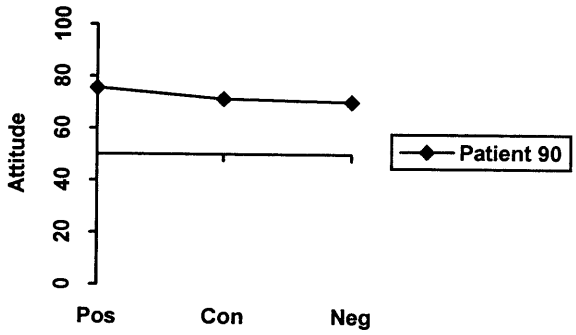
Patient 89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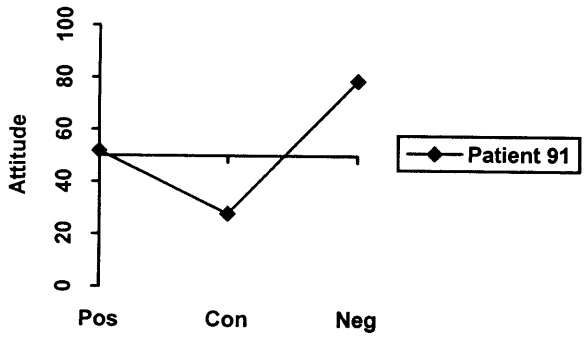
Patient 90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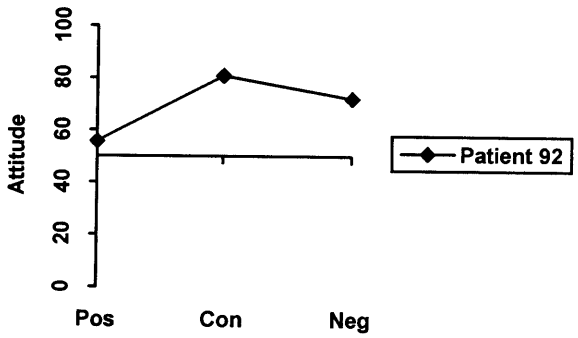
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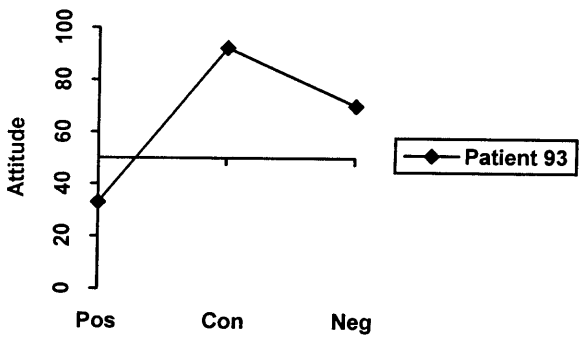
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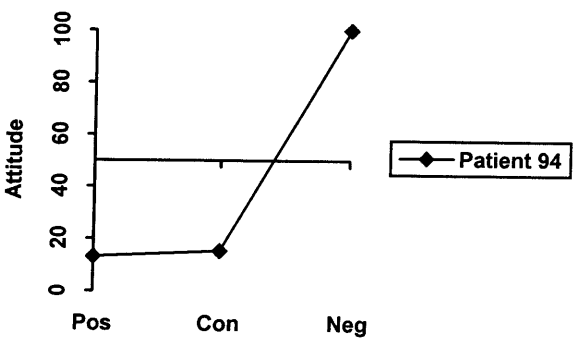
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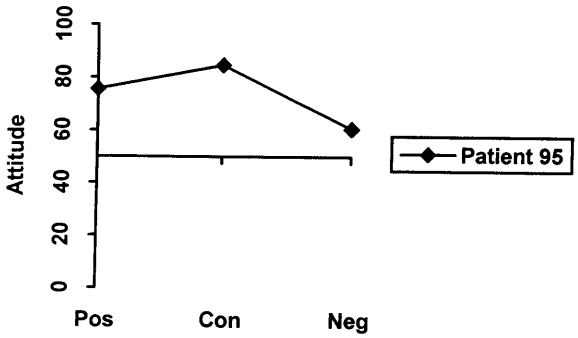
Patient 94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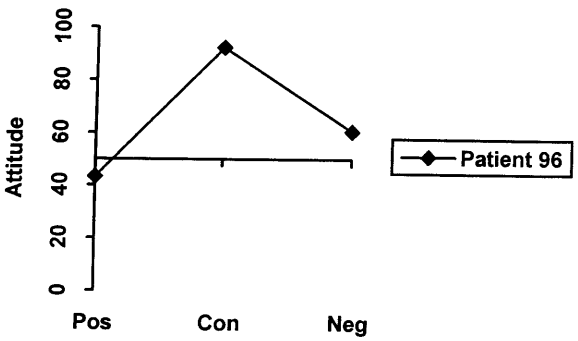
Patient 95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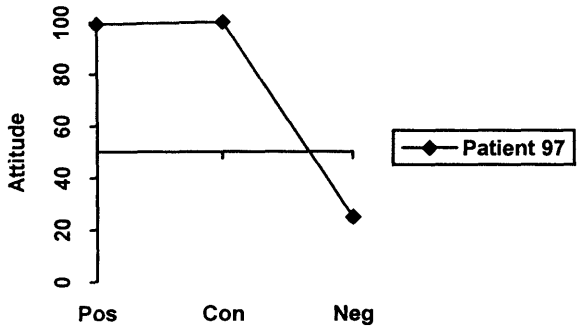
Patient 96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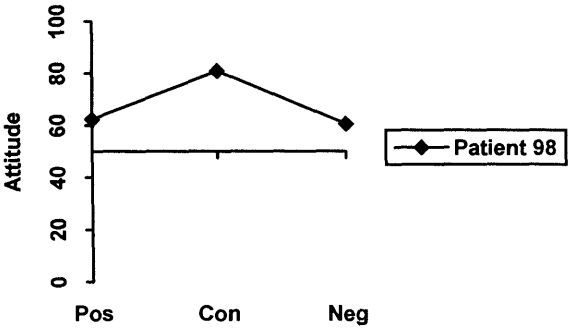
Patient 97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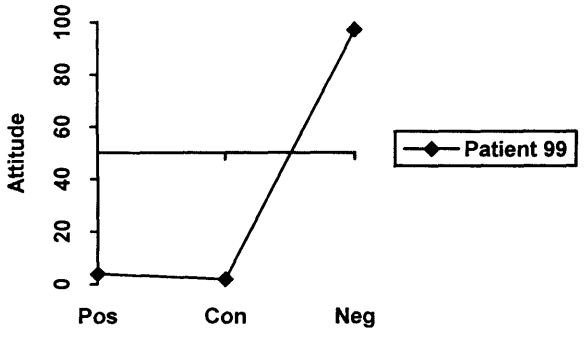
Patient 98


Attitude
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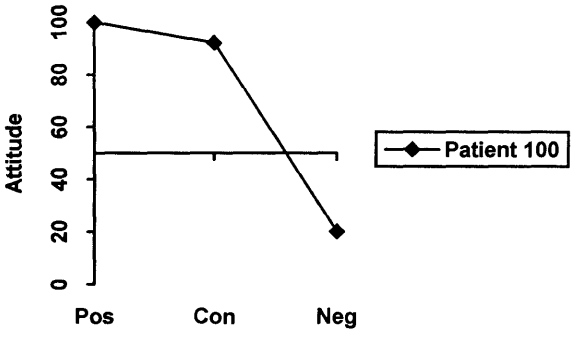
Neg
Patient 99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100
Pos
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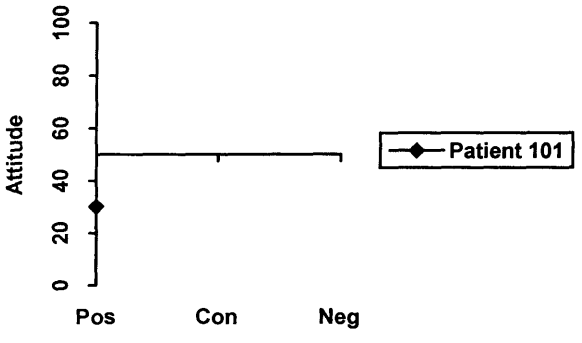
Neg
Patient 100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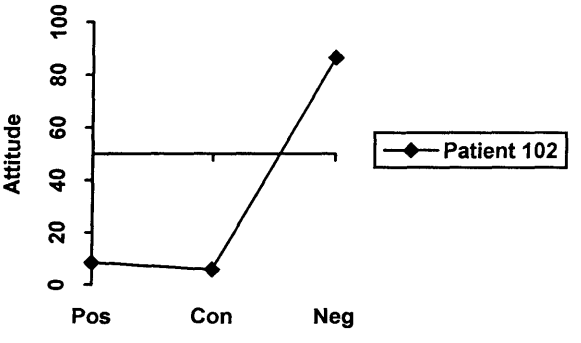
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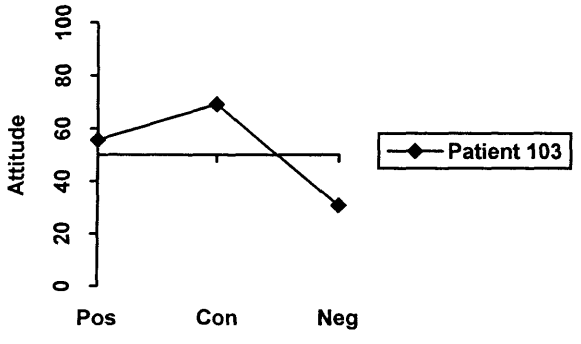
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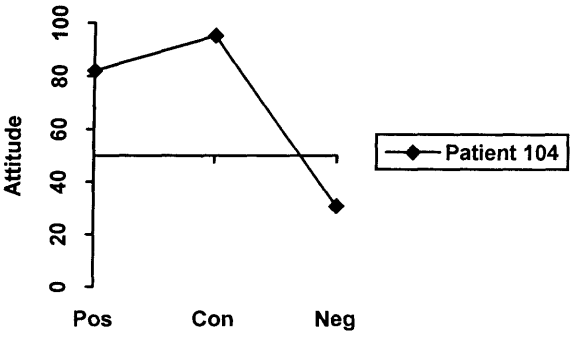
Patient 103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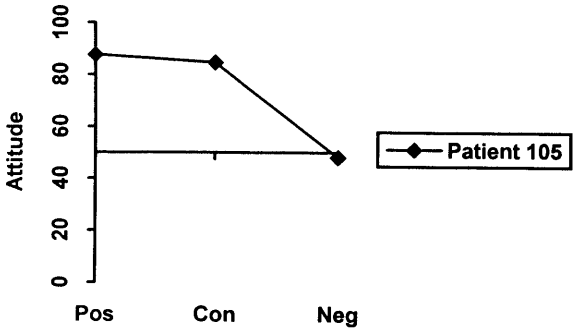
Patient 104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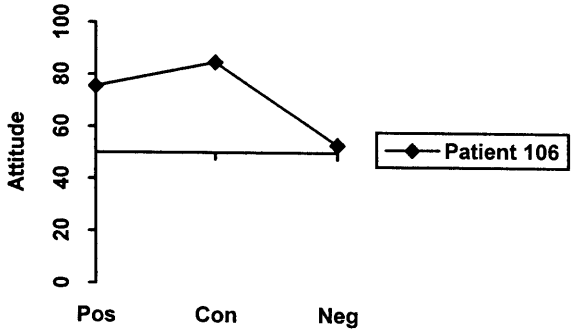
Patient 105


Attitude
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80
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Pos
Con
Neg
Patient 106

APPENDIX P: Non-participants' characteristics

No significant differences were found for any variable between the group of participants (N = 106) and the group of non-participants (N = 56). Variation in the numbers for some comparisons is a result of the information being unobtainable, mostly for the non-participants.

	Sex		
	male	female	total
participant	53	53	106
non-participant	28	28	56
total	81	81	162

	group	N	X	s. d.	F [a]	t [b]
age	participants	106	42.92	14.17	.00	.95
	non-participants	56	42.76	13.27		
years in education	participants	106	11.11	.80	6.47*	.87
	non-participants	32	11.15	1.35		
illness duration	participants	82	13.80	10.27	1.11	.28
	non-participants	42	16.07	12.33		
Kemp ratings	participants	106	5.13	1.34	.76	.20
	non-participants	39	4.79	1.56		

a Levene's test for equality of variances * p = < .05
b t-test for equality of means

between group comparisons	N	χ^2	d. f.	p
marital status [a]	136	.33 [b]	1	.57
living circumstances	147	3.92	3	.27
diagnosis	158	1.65 [b]	1	.20
psychiatrist	161	3.62	4	.46
drug type (old/new/both)	128	1.57	2	.46

a excluding divorced and widowed people
b computed only for 2 x 2 table